

**PORTUGUESE INDIVIDUALS`
EXPERIENCES AND PERCEPTIONS
OF NON-SPECIFIC CHRONIC LOW
BACK PAIN**

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Abstract

Low back pain (LBP) is the most common form of chronic pain. Approximately 85% to 90% of chronic low back pain (CLBP) episodes in primary care cannot be related to serious pathology or neurocompression, being described as non-specific chronic low back pain (NSCLBP). This disorder involves continuous pain or recurrent flare-ups that are responsible for high levels of distress, functional disability and work absenteeism. It has also a significant impact on health care systems and society in general.

Considering the complexity inherent in the experience of NSCLBP, where personal and cultural contexts play a major role, research has highlighted the need to study this phenomenon in contexts that have not yet been investigated. This study aimed to explore the Portuguese individuals' experiences and perceptions of NSCLBP. An interpretative phenomenological analysis (IPA) was employed to explore the experiences of eight participants, who were recruited purposefully from three Portuguese health sites. Semi-structured one-to-one interviews were carried out in order to collect data. The interviews were audio-recorded and transcribed verbatim. Following an inductive process of data analysis, five themes emerged as interrelated parts of an extended account that explored the Portuguese individuals' experiences and perceptions of NSCLBP. In the first theme the disruptive nature of the NSCLBP experience was emphasised. In the second, the participants' meaning making of NSCLBP and their need to understand it were highlighted. In the third, the clinical encounters and their contribution to maintaining the lack of participants' understanding about NSCLBP were emphasised. In the fourth, the meaning making of NSCLBP contribution to reshaping the participants' social interactions was explored. In the fifth, the participants' definition of their sense of self through the meaning making of NSCLBP was highlighted. In order to promote the transparency of data analysis, an audit trail was developed to document all relevant steps of this process. This study has offered the first insights into the Portuguese individuals' experiences of NSCLBP disorder, which may help clinicians in transferring this knowledge to the therapeutic approach to patients with similar experiences. The knowledge produced may be used to inform recommendations for NSCLBP management.

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Candidate`s Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

A handwritten signature in black ink on a light gray rectangular background. The signature is cursive and appears to be 'C. G. S.' with a long horizontal stroke extending to the right.

Dated 31 May 2016

Abbreviations

ACES – Agrupamento de Centros de Saúde [Group of Primary Care Centres]

CB – Cognitive-behavioural

CBP – Chronic Benign Pain

CI – Confidence Interval

CLBP – Chronic Low Back Pain

EU – European Union

FREGC – Faculty of Health and Social Science Research Ethics & Governance
Committee

GP – General Practitioner

GT – Grounded Theory

IASP – International Association for the Study of Pain

ICD – International Classification of Diseases

INE – Instituto Nacional de Estatística [Statistics Portugal]

IPA – Interpretative Phenomenological Analysis

LBP – Low Back Pain

MSK – Musculoskeletal

NA – Narrative Analysis

NHS – National Health Services

NHP 2004-2010 – National Health Plan 2004-2010

NHP 2011-2016 - National Health Plan 2011-2016

NSCLBP – Non-Specific Chronic Low Back Pain

OPSS – Observatório Português dos Sistemas de Saúde Portuguese
[Portuguese Observatory on Health Systems and Policies]

PT – Physiotherapist

SD – Standard Deviation

TA – Thematic Analysis

WHO – World Health Organisation

Chapter 1: Introduction

In this chapter, an overview of the background for this study is introduced. More specifically, in the first section an overall perspective about the rationale for undertaking this study in the Portuguese context is provided. In the second, the researcher and the personal and professional motivations for this study are introduced. Finally, the chapters that constitute this thesis are briefly outlined in the last section.

1.1. Rationale for the study

Research has highlighted the growing impact of non-specific chronic low back pain (NSCLBP) disorder in western societies. Since the second half of the 20th century, it has dramatically affected individuals, families, work contexts, economy and society in general (Andersson, 1999; Goubert et al., 2004; Breivik et al., 2006; Deyo et al., 2006; Castro-Lopes et al., 2010; Baker et al., 2010; Hoy et al., 2010; 2012; Azevedo et al., 2012; Breivik et al., 2013).

The significant impact of NSCLBP internationally has precipitated the development of research in this area in order to develop better responses to address this problem. In the 1980s, pain research increased dramatically under the influence of the positivist and the subsequent post-positivist paradigm (Smith, 2004). The contribution of the research carried out under the scope of these paradigms to the development of knowledge about pain is unquestionable. However, as pain research has progressed, the views about the pain phenomenon have changed. In consequence, the positivist and the post-positivist paradigms have become insufficient to explain all dimensions of the pain phenomenon (Mitchell & MacDonald, 2009).

The positivist paradigm is conceptualised as a research paradigm that asserts human knowledge is only possible through the use of scientific and objective methods in well-controlled contexts (Willis, 2007e). According to this paradigm, if one does enough research and it verifies one's theory, then one can be confident that this theory reflects the true nature of the world (Willis, 2007e). On the other hand, post-positivist is viewed as a modified version of positivism that resulted from a range of critiques faced by the latter. Post-positivism adopts a

different position regarding the meaning of data collected and states that there is never enough research to permit one to eliminate all doubt about a theory. Studies underpinned by this paradigm have adopted a modified falsification approach, in which failure (to prove a theory) may result from a range of aspects such as instrumentation and poor sampling, amongst others (Willis, 2007e).

Considering the multidimensional view about pain that has been developed over the last four decades, these paradigms have failed to explore the complexity in which pain is experienced (Mitchell & MacDonald, 2009; Osborn & Rodham, 2010). Consequently, as a reaction to the need to develop a better and deeper understanding about the complexity inherent in the experience of pain, the interpretive paradigm has become increasingly recognised within pain research (Mitchell & MacDonald, 2009). The interpretive paradigm asserts that there is no truly objective form of research (Willis, 2007e) and that meaning is socially constructed, as individuals engage with the world they are interpreting (Crotty, 1998b; Finlay, 2006; Willis, 2007d). The epistemological (refers to what and how one can know reality) and ontological position (refers to the nature of reality) underpinned by this paradigm (Crotty, 1998b; Willis, 2007e) has allowed researchers to explore the multiple meanings of the pain phenomenon.

Despite the efforts to recognise the complimentary relationship between these paradigms in developing a deeper understanding about the pain phenomenon, the positivist and post-positivist paradigm are still dominating the research in this area (Newton et al., 2012). Thus, research has drawn attention to the need to undertake studies through the “lens” of the interpretive paradigm in order to better understand how individuals with NSCLBP disorder experience it, which could facilitate the design of therapeutic approaches centred on patients` needs. The few existing studies, which have focused on the experience of living with NSCLBP and seeking health care, have demonstrated that patients express the need to be listened to and to be understood by health professionals (Rhodes et al., 1999; Werner & Malterud, 2003; Cooper et al., 2008; Dow et al., 2012; Howarth et al., 2014).

Additionally, research has established different reactions to pain depending on culture (which is defined as a framework for individuals' beliefs and practices as a society that includes health beliefs and behaviours) (Yaphe, 2014; Khan et al., 2015). Research in this area has supported that chronic pain is a dynamic process of mutual influence involving pathophysiology, individual neuroregulation and cultural factors that influence the individual (Riley et al., 2002; Ruhlman et al., 2005; Pillay et al., 2014). Thus, the perception and behaviours associated with chronic pain are significantly influenced by the cultural context (Helman, 2007; Pillay et al., 2014).

Specifically, in the scope of NSCLBP, the vast majority of research undertaken through the "lens" of the interpretive paradigm has been predominantly developed in a select few countries, such as the United Kingdom (UK) and Australia, with the vast majority of studies being carried out in the UK (Toye et al., 2013; Froud et al., 2014; MacNeela et al., 2015). To the researcher's knowledge, there are no published studies regarding how Portuguese individuals experience and make sense of NSCLBP.

Considering the complexity inherent in the experience of having NSCLBP, where personal and cultural contexts play a major role and taking into account the limited knowledge about NSCLBP experiences in countries other than the UK, it becomes particularly relevant to study this phenomenon in contexts where this disorder has a significant impact.

Based on the assumption that understanding the individuals' experiences and perceptions about pain may facilitate the design of therapeutic approaches closer to their needs, and considering the lack of research produced in Portugal within this area, this study aimed to explore the overall concept of NSCLBP in a Portuguese setting. Specifically, it aimed to explore the experiences and perceptions of Portuguese individuals with NSCLBP disorder.

It is important to clarify that this study's focus was not on the cultural aspects *per se*, rather its attention was dedicated to exploring the individuals' experiences of having NSCLBP. The cultural aspects were taken into account, since literature (for instance, Yaphe, 2014; Khan et al., 2015) has emphasised their impact on the individuals' experiences of pain.

1.2. Personal and professional motivations for this study

This study was stimulated by the researcher's reflection within three different contexts: clinical practice, undergraduate and postgraduate education as well as collaborative work with health professionals from the National Health Services (NHS). The analysis of these influences requires the use of a more personal tone in the next few paragraphs.

After graduation as a physiotherapist, I worked in private practice. During the years I worked in this context, the vast majority of patients I had the opportunity to follow had musculoskeletal conditions. I got used to the process of finding the body structure responsible for symptoms, mainly pain, and then formulating a treatment plan that would eliminate the cause of pain. The dilemmas started on the day that I could not find the origin of symptoms, or in other words the expected cause for chronic low back pain (CLBP). On that day, all my objective tests were negative, despite the patient's words "*I swear I really have pain*". At that time, I realized that I was not able to tell the patient what his/her problem was.

As a freshly graduated physiotherapist facing the dilemmas and the uncertainty of the approach to these patients, I tried to obtain some guidance from national conferences and professional meetings. However, what I obtained was focused on diagnosing and identifying the cause of pain. Thus, my experience in private practice and my contact with other health professionals in professional events drew my attention to how problematic patients' experiences of having NSCLBP in Portugal were. Stories of unsuccessful visits to diverse health professionals were, and I am afraid still are, very common in NSCLBP Portuguese individuals. Thus, my clinical practice with NSCLBP patients has had a significant role in my professional and personal development. The successively unanswered questions prompted by these patients have been the basis of a shift in the way I conceptualised both health care and my role as a health professional. These patients made me question my model of practice. They drew my attention to the relevance of psychosocial factors in the experience of chronic musculoskeletal pain. They also focused my attention on how important it is to listen to patients'

stories, to pay attention to their non-verbal communication, to establish rapport, to understand their needs and to share decisions concerning health care.

A few years later, I combined my work as a physiotherapist with teaching undergraduate and postgraduate physiotherapy courses. As an educator, working at undergraduate and latterly at post-graduate level, a significant part of my work has been focused on chronic musculoskeletal pain. In this context, I have observed the most varied responses from students and health professionals to the idea that *“sometimes we cannot find a cause for pain”*. These responses have ranged from total refusal, to a questioning attitude and occasionally to a reflective analysis of clinical practice. I have frequently heard that chronic musculoskeletal pain patients are *“difficult patients”* or *“have psychiatric disorders”*, where *“only a psychologist or a psychiatrist can help”*. The reasons for these discourses have been the most intriguing to me: *“Are they related to the use of a model of acute pain to explain chronic pain, as happened to me a few years ago? Is it about a deeply rooted model of clinical reasoning and practice? To what extent do health professionals understand and attribute meaning to their patients` accounts? To what extent do health professionals use patients` accounts as a guide for the approach to patients? And, what is like to be a patient with NSCLBP living in Portugal?”*

Indeed, these questions emerged from my professional journey and motivated me to explore the phenomenon of NSCLBP in the Portuguese context.

For the last few years, part of my work as a lecturer in physiotherapy has included a collaborative project with health professionals from the NHS. More specifically, I have been involved in the design of pain management programmes for individuals with musculoskeletal chronic pain and in the training of physiotherapy students and physiotherapists to implement these programmes in the NHS in different regions of Portugal. This project with health professionals from different backgrounds and with different levels of experience has drawn my attention to their needs in clinical practice. I have been challenged by questions like: *“How can I get patients to speak about their pain?”*

How can I have time to do this? What kind of questions should I ask? How can I explain pain to patients?"

On the other hand, this experience has also given me the opportunity to observe patients during the treatment sessions. This work as an external observer has drawn my attention to the individuality of patients' accounts and responses to pain. It has been quite motivating to observe the patients' surprise in being prompted by the physiotherapist to talk about their pain in the first session. Listening to these patients talking to each other and with physiotherapists during these sessions has drawn my attention to their need to be listened to and has made me realise that they really have important information to tell health professionals. Indeed, this experience has consolidated my view on the importance of looking at patients' accounts as powerful guides for intervention. Thus, it was crucial to start carrying out research regarding this topic in Portugal.

It is important to take into account the role of the aforementioned experiences in the approach to this study. The reflection on my own preconceptions and expectations played an important role on the investigative process. Indeed, my previous contact with individuals having NSCLBP led me to consider that these individuals needed a precise explanation for their pain. Thus, I expected to hear the participants exploring this idea. I was also keen to understand which role (if any) they attributed to health professionals in what concerns to the provision of this explanation. My initial focus on the explanation for NSCLBP and the possible role of health professionals may reveal a deeply rooted biomedical background. On the other hand, the motivation to explore the NSCLBP individuals' accounts may be indicative of the need to challenge this background and develop a biopsychosocial understanding of this phenomenon.

1.3. Outline of the structure of this thesis

This thesis consists of eight chapters, in which the research that has been undertaken with the purpose of understanding the experience of having NSCLBP disorder in a Portuguese setting is presented.

In the first chapter, the study's background is introduced, while providing the rationale for undertaking research in this area in the Portuguese context. Moreover, the researcher's personal and professional motivations for this study are introduced. Finally, the chapters that constitute this thesis are outlined.

In the second chapter, a broader perspective of the background for this study is provided. The impact of NSCLBP in western societies is examined and the view of NSCLBP adopted in this study is provided. Historical perspectives about the pain phenomenon are outlined as well as their impact on research and health care throughout the last five decades. Additionally, research carried out on the patients' experiences of NSCLBP is explored and the impact of the cultural context on these experiences is addressed. In particular, the lack of research on the Portuguese individuals' experiences of NSCLBP is emphasised.

The background provided in the previous chapter is further explored in the third chapter, through the presentation of specific information about the Portuguese context. An overview of Portuguese cultural, political and economic developments over the last five decades provides a broad perspective about the context associated to this study. The Portuguese NHS is presented and an overview of the impact of NSCLBP in the Portuguese context is provided. Despite the limited knowledge about NSCLBP and its management in Portugal, a combination between the few existing studies and some anecdotal information is used to outline Portuguese health professionals approach to NSCLBP as well as the typical journeys of patients with this disorder in Portugal.

In the fourth chapter, the research approach to this study is addressed. Philosophical considerations for this study are explored, highlighting the use of the interpretive paradigm as well as the epistemological and ontological position adopted. Furthermore, Interpretative Phenomenological Analysis (IPA) is presented as the methodological framework for this study and its philosophical roots from phenomenology and hermeneutics are outlined. Additionally, the importance of reflexivity in this study is addressed as well as the researcher's interpretative framework.

Detailed information about research methods is presented in the fifth chapter. Specifically, information about sampling is discussed, including the definition of inclusion and exclusion criteria and recruitment strategies. Ethical considerations are also addressed in this chapter with particular emphasis on participants' information and consent procedures. Additionally, the interview is presented as the method of data collection and its characteristics are analysed in what concerns the adequacy to this study. Moreover, detailed information about the approach to data analysis is provided. Finally, the procedures to ensure quality and rigour are presented.

In the sixth chapter, the findings of this study are explored. To begin with, small vignettes are used to contextualise participants, including details about age, gender, living context, family, profession, current employment status and perceived total length of time with NSCLBP disorder. Following the approach of IPA, the themes, sub-themes and concepts that have emerged from data analysis are explored and excerpts from interviews are presented to support this analysis.

In the seventh chapter, this study's findings are discussed in the context of the existing research. In order to integrate the emerged findings in the context of the methodological approach adopted in this study a critique of the method is also presented. Additionally, the study's contribution to knowledge is addressed, as well as the implications for patients, clinical practice, health services and health professionals' education. Furthermore, suggestions for future research developing from this study are outlined.

In the eighth chapter the key aspects of this study are outlined. An overview of the study is presented, and its main contribution to knowledge is briefly reviewed. This is followed by an outline of the main implication for patients, clinical practice, health services and health professionals' education. Finally, suggestions for future research are concisely appraised.

It is important to emphasise that considering the central role of reflexivity in IPA research, the aforementioned chapters include a section dedicated to this. More specifically, a reflexive account is presented throughout the thesis. It is divided into six parts that are presented as an individual section at the end of each chapter (from the second until the seventh). This reflexive account is centred on the researcher`s reflections throughout the study and aims to enhance its rigour and transparency. Considering the nature of their content, a more personal tone is used in these sections. Further information about the rationale for this reflexive account is presented in the fourth chapter.

Chapter 2: Background

This chapter consists of six sections in which the background for this study is introduced. In the first section, the definition of NSCLBP adopted in this study is presented and the challenges in defining NSCLBP are addressed. In the second, the impact of NSCLBP is examined, with particular emphasis on the growing impact of NSCLBP in western societies. In the third, historical perspectives about the pain phenomenon are outlined, with the purpose of clarifying the view of pain adopted in this study. The impact of the developments of these perspectives on research and health care is also addressed. In the fourth and fifth sections, research carried out on the patients' experiences of NSCLBP is thoroughly examined and the impact of the cultural context on these experiences is considered. Finally, a reflexive account focused on the topics covered in this chapter is presented.

2.1. Challenges in defining NSCLBP

Current definitions of pain and chronic pain are inconsistent (Kent et al., 2009). The most extensively adopted definition was provided by the International Association for the Study of Pain (IASP) in 1986. Chronic pain was defined as:

“a pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be three months)” (Harstall & Ospina, 2003, p.1)

Given that the aetiology is unknown for many forms of chronic pain, a phenomenological definition was presented by the International Classification of Diseases (ICD) of the World Health Organisation (WHO) (Treede et al., 2015). According to definition of the ICD, chronic pain was defined as a:

“pain in one or more anatomic regions that persists or recurs for longer than three months and is associated with significant emotional distress or significant functional disability (interference with activities of daily life and participation in social roles) and cannot be better explained by another chronic pain condition” (Treede et al., 2015, p.1004)

CLBP constitutes one of the variants of chronic pain and it is estimated that in 85% to 90% of the cases it cannot be associated with a specific cause (van

Tulder et al., 2002; O'Sullivan, 2005; Balagué et al., 2012). In this context, the term NSCLBP has been frequently used to describe low back pain that:

“is not attributable to a recognisable, known specific pathology (e.g. infection, tumour, osteoporosis, fracture, structural deformity, inflammatory disorder (e.g. ankylosing spondylitis), radicular syndrome or cauda equine syndrome)” (Airaksinen et al., 2006; National Collaborating Centre for Primary Care, 2009; Savigny et al., 2009; Balagué et al., 2012).

This term is not intended to be a diagnosis but rather a description of back pain for which a cause cannot be identified and a precise diagnosis cannot be established (Kent et al., 2009).

The absence of a specific diagnosis associated with NSCLBP is responsible for conflicting views about this disorder among clinicians and researchers (Kent et al., 2009). The considerable diversity of perspectives is possibly the result of different historical views about this disorder as well as the limited knowledge about its aetiology (Kent et al., 2009). The study carried out by Kent et al. (2009) aimed to develop a conceptual framework for NSCLBP, based on the expressed beliefs of individuals who treat and/ or investigate this disorder. It has demonstrated that there does not appear to be any common framework that explains the diversity of views about this disorder.

The impossibility of indicating the source of pain and the associated uncertainty about a specific diagnosis are also responsible for the dilemmas faced by health professionals in the approach to individuals with this disorder. For example, the physiotherapists that participated in a qualitative study carried out by Slade et al. (2011) about the dilemma of diagnostic uncertainty associated with the approach to individuals with NSCLBP, reported difficulties in communicating with patients due to the pressure to provide a diagnosis and considered themselves to be under-prepared by traditional education models (Slade et al., 2011). Previous research has also reported the challenges faced by primary care clinicians in diagnosing individuals with NSCLBP (Deyo & Phillips, 1996; Daykin & Richardson, 2004; Synnott et al., 2015).

2.2. Overall perspective of the impact of NSCLBP

The aforesaid conflicting views about NSCLBP have also influenced the epidemiological literature. More specifically, the epidemiological data in this area frequently refer to chronic pain or CLBP in general. Few studies have specifically explored information about NSCLBP and it has been assumed that it is included in the data provided, since in a significant proportion of patients with CLBP a cause cannot be identified (van Tulder et al., 2002; O’Sullivan, 2005; Balagué et al., 2012). Additionally, the diversity of definitions in the existing literature has also been responsible for significant variations in data. Despite the considerable variations in definition and methodology, the impact of NSCLBP has been systematically reported as significant (for instance, Baker et al., 2010; Azevedo et al., 2012). Accordingly, in order to preserve the original information from the quoted authors, the following paragraphs include information about chronic pain and CLBP, with a few references to NSCLBP.

The epidemiological literature has highlighted the growing impact of CLBP on public health worldwide since the second half of the 20th century (Andersson, 1999; van Tulder et al., 2002; Goubert et al., 2004; Deyo et al., 2006; Parthan et al., 2006; Louw et al., 2007; Freburger et al., 2009; Baker et al., 2010; Hoy et al., 2010; Balagué et al., 2012; Hoy et al., 2012; Kleijnen Systematic Reviews Ltd, 2012; Gouveia et al., 2016).

The prevalence of individuals experiencing moderate to severe chronic pain in Europe was estimated to be 19% (Breivik et al., 2006). A large scale telephone survey of 46.394 respondents carried out by Breivik et al. (2006) included individuals from fifteen European countries (Portugal was not included) and Israel. Nearly half of the respondents had back pain (18% in the lower back and 24% in the back – unspecified) (Breivik et al., 2006). CLBP has been reported as one of the most prevalent forms of chronic pain in several studies (Breivik et al., 2006; Baker et al., 2010; Castro-Lopes et al., 2010; Azevedo et al., 2012).

According to a report developed under the scientific responsibility of the European Federation of IASP Chapters, the prevalence of chronic pain has ranged from 16.61% to 46%, depending on the studies (Kleijnen Systematic

Reviews Ltd, 2012). Thus, comparing the prevalence of chronic pain in populations and over time seems to be challenging given the considerable methodological heterogeneity across studies (Hoy et al., 2010). Several factors have contributed to this heterogeneity such as the validation of the instruments used to measure prevalence, the methods of selection of the samples as well as their sizes, and the extent of non-response, among others (Hoy et al., 2010). Nevertheless, when compared to other chronic conditions, chronic pain has a high prevalence in Europe (Kleijnen Systematic Reviews Ltd, 2012). Accordingly, some authors have argued that chronic pain has been under-recognised by health policymakers as a serious chronic health problem and should be ranked alongside other health conditions of established priority in Europe (Breivik et al., 2013).

The clinical and social impact of chronic pain may be offered as an argument to draw attention to the relevance of this problem. Research has consistently reported the significant impact of chronic pain on individuals' lives.

Breivik et al. (2006) reported that on average two-thirds of the individuals with chronic pain described it as moderate and one-third as severe. According to Breivik et al.'s (2006) findings a small percentage of individuals experienced pain for less than two years and the vast majority experienced pain from between two to fifteen years (60%). Moreover, two-thirds of the respondents had a sleep disorder associated with their pain and one-half considered themselves too incapacitated to perform daily activities, such as walking (Breivik et al., 2006). Conversely, according to an Eurobarometer survey, one-fourth of all European Union (EU) respondents reported chronic pain - muscle, joint, neck or back pain - of a magnitude sufficient to restrict daily activities (with back pain being the most common type of pain referred) (Directorate General for Health and Consumers, 2007).

Additionally, data from the consensus report developed by a range of European experts in the field of chronic pain, under the scope of an initiative called *Pain Proposal* reported that 27% of the respondents felt socially isolated and lonely because of their pain, 50% were worried about the effect of chronic pain on their relationships and 36% considered their chronic pain to have had a negative

impact on their family and friends (Baker et al., 2010). Approximately two thousand individuals with chronic pain were surveyed, and one hundred were from Portugal (Baker et al., 2010).

Moreover, chronic pain has also been associated with a high percentage of psychiatric disorders and emotional distress (Gatchel et al., 2007; Poole et al., 2009; Baker et al., 2010; Castro-Lopes et al., 2010; Azevedo et al., 2012; Gouveia et al., 2016). For example, in the previously mentioned study carried out by Breivik et al. (2006), 21% of the participants with chronic pain had been diagnosed with depression. Despite the increasing risk of depression identified in people with CLBP (Demyttenaere et al., 2007; Poole et al., 2009; Rayner et al., 2016), it is important to take into consideration that the research on prevalence rates of depression in this population has shown a significant variability, which could be related to the methods used for assessment of depression and study settings (for example, pain clinics or primary care) (Bair et al., 2003; Wörz, 2003). In the review by Bair et al. (2003), estimates of the prevalence of depression in people with chronic pain ranged from 5.9% to 46% in primary care settings. In subsequent studies, this variability has become more evident, ranging from 12.1% to 72% in specialist pain clinic settings (Poole et al., 2009; Proctor et al., 2013; Sagheer et al., 2013). In comparison to the general population, the prevalence of depression in people with CLBP was found to be three to four times greater (Sullivan et al., 1992; Currie & Wang, 2004). Research has also demonstrated that the combination of chronic back pain and depression is associated with higher levels of pain, disability and healthcare use when compared to CLBP or depression alone (Currie & Wang, 2004; Bair et al., 2008; Holmes et al., 2012; Tsuji et al., 2016).

As a multidimensional phenomenon, NSCLBP has a significant impact not only on the individual, but also on professional, economic and social dimensions. Research in this area has demonstrated that individuals with chronic pain are seven times more likely to leave a job because of ill health and are also less likely to return to employment (Eriksen et al., 2003). For instance, 61% of the individuals with chronic pain considered themselves less able or unable to work outside the home and 19% had lost their job in the Breivik et al.'s (2006)

survey. Furthermore, 29% of European individuals with chronic pain were afraid of losing their jobs, 21% were unable to work at all due to pain and 61% considered that their employment status was directly affected by their condition (Baker et al., 2010).

Additionally, the lengthy duration of chronic pain and the complex nature of this phenomenon led to a high dependency on health services by individuals with NSCLBP disorder (Baker et al., 2010; Castro-Lopes et al., 2010). The diversity of perspectives about chronic pain and the previously mentioned limited knowledge about its aetiology are responsible for prolonged and inefficient patients' journeys in the health systems (Baker et al., 2010; Castro-Lopes et al., 2010). According to Baker et al. (2010), European individuals with chronic pain made an average of seven visits to health professionals per year, with 22% visiting ten or more times. One-fourth of the individuals with chronic pain waited one to five years to obtain a diagnosis or reason for their pain and 11% had to wait longer than this.

Previous research has also demonstrated that people with chronic pain tend not to be satisfied with the treatment of their pain (for instance, Deyo et al., 2006; Baker et al., 2010). The reasons for this lack of satisfaction are variable, with several individuals reporting the health professionals' lack of attention to their needs. More specifically, 38% of European individuals with chronic pain reported that their pain was not adequately managed, 49% were unsatisfied with the time it took to reach a diagnosis, 48% were unsatisfied with the time to obtain adequate management of their pain and 50% were unsatisfied with the number of visits that it took to achieve adequate management (Baker et al., 2010). These findings have also been supported by qualitative research carried out on the experiences of having pain in health care services (for instance, Rhodes et al., 1999; Liddle et al., 2007; Howarth et al., 2014). The complementary nature of the data seems to substantiate the relevance of this problem. Indeed, this dissatisfaction seems to be responsible for frequent visits to different health professionals and for a diversity of therapeutic approaches,

which tend to fail in fulfilling patients` needs (Gatchel et al., 2007; Wallace et al., 2009; Baker et al., 2010).

Due to a lack of comprehensive data, the total cost of chronic pain in Europe is difficult to estimate. Research on direct costs (which are described as costs of medical care) and indirect costs (which are described as costs of work absenteeism, decreased productivity while at work, early retirement and general economic impact) is variable, and the methods of calculation also vary significantly across studies (Azevedo et al., 2016). However, available data estimates an overall impact of hundreds of billions of pounds (Kleijnen Systematic Reviews Ltd, 2012). It is estimated that the global costs related to chronic pain are at the same level of those associated with oncology and cardiovascular diseases in Europe. In the vast majority of situations, these costs are not only associated with direct healthcare costs but also with social compensation and retirement pensions (Blyth et al., 2003; Baker et al., 2010).

Despite the heterogeneity of research carried out on the impact of chronic pain, and thus NSCLBP, all studies have highlighted the relevance of this problem as well as the need to consider different strategies in the health care systems to better respond to patients` needs (Gatchel et al., 2007; Wallace et al., 2009; Breivik et al., 2013). Accordingly, research is needed in order to develop a better understanding of this phenomenon. The next sections examine the evolution of different views about the pain phenomenon and their impact on health care and research.

2.3. Views about the pain phenomenon

The considerable increase of research and knowledge about pain mechanisms as well as the development of a multidimensional perspective about health and new models of health care have contributed to considerable changes in the views about the pain phenomenon (Main & Watson, 1999; Barr & Threlkeld, 2000; Waddell, 2004a).

Early theories about pain argued the existence of a pain pathway, which linked the periphery of the body with higher centres in the brain (Main & Watson, 1999). This view, postulated by the Cartesian model of pain developed by Descartes (1596-1650), had a major impact on western thinking about pain (Main & Watson, 1999; Damásio, 2005; Khan et al., 2015). According to this model, pain was viewed as an independent sensation caused by a sequence of neural events activated by any tissue damage (Main & Watson, 1999; Khan et al., 2015). From this perspective, pain was merely viewed as a signal of tissue damage (Main & Watson, 1999; Waddell, 2004a; Khan et al., 2015).

Despite being widely accepted for more than three centuries, this model has been critiqued because of its inability to explain pain in the absence of tissue damage as well as the differences in pain reported by individuals with the same injury (Main & Watson, 1999). As the relationship between pain, physical impairment and disability has become understood as variable, this model has become insufficient to understand this phenomenon (Main & Watson, 1999; Butler & Moseley, 2003; Waddell, 2004a). Nevertheless, Descartes` ideas have still had a significant influence on current thinking about pain as they have been at the basis of the vast majority of health professionals` training (Main & Watson, 1999; Khan et al., 2015).

More specifically, Descartes`s ideas seem to have had some resonance with the biomedical model, since both claim a dualism of mind and body (Lupton, 2012). The biomedical model is defined as a model of healthcare that is based on three assumptions: a disease has a single cause; pathology is always the single cause; and, the removal or attenuation of the disease is related to a return to health (Wade & Halligan, 2004).

The aforementioned idea of dualism may explain the biomedical model focus on treating pain as an entity that is located within the patient`s body and, thus, on looking for its cause within the patient`s body (Lupton, 2012). The conceptualisation and the subsequent approach to patients with pain according to this model has been identified as one of the main reasons for the increase of the impact of chronic pain in western societies (for instance, Rainville et al., 2000; Houben et al., 2005; Coudeyre et al., 2006; Corbett et al., 2009; Darlow et

al., 2012). The problem does not seem to be pain itself, but the way health professionals have conceptualised and approached patients' pain.

Over the last five decades, pain has been viewed as a more complex phenomenon. The seminal work of Melzack and Wall, in the 1960s, has had a major influence on this shift (Melzack & Wall, 1987). Their work was on the basis of the Gate-Control theory, which postulated that pain perception depends on neural interactions in the nervous system (Melzack & Wall, 1987). Additionally, it also argued that the impulses generated by tissue damage could be modified by ascending pathways to the brain and descending pain-suppressing systems (Melzack & Wall, 1987). Several authors have consolidated this theory and it is currently accepted that the aforementioned modification can be mediated by several factors, such as environmental and psychosocial factors (Main & Watson, 1999; Main & Waddell, 2004; Waddell, 2004b; Khan et al., 2015).

The Gate-Control theory drew attention to the variable relationship between pain and injury and stated that one could exist without the other. Thus, pain was no longer considered the product of a passive transmission of nervous impulses from the periphery (tissue damage) to the central nervous system. Rather, it started to be considered as:

“the result of a dynamic process of perception and interpretation of a wide range of incoming stimuli, some of which are associated with actual or potential harm and some of which are benign but interpreted and described in terms of damage” (Main & Watson, 1999, p.204)

In addition, Melzack and Wall (1987) postulated the neuromatrix theory, which reconciled cognitive-affective processing with neurosensory inputs. Melzack and Casey (1968) claimed that the human experience of pain included three dimensions, which are still recognised by researchers: (i) the sensory-discriminative dimension that identifies the location and physical characteristics of the noxious stimulus and prompts reflexes to prevent or limit tissue damage; (ii) the affective-motivational dimension that triggers the unpleasantness related to exposure to a noxious stimulus and activate defensive behaviours in order to enable the individual to cope with that stimulus; and, (iii) the cognitive-evaluative

dimension that determines the appraisal of the meanings and consequences of an injury or pain (Melzack & Casey, 1968; Lumley et al., 2011).

One of the most remarkable aspects postulated by these authors was the influence of psychosocial factors in the activation of descending pain inhibitory systems and the consequent modulation of pain (Melzack & Wall, 1987; Main & Watson, 1999; Khan et al., 2015). The aforementioned theories have prompted research on the influence of beliefs about pain, attention to pain, fear and pain-related coping strategies and more recently, on the individuals' experiences of pain. The individuals' perceptions of their own pain have started to be viewed as relevant, which has had a significant impact not only on research - through the development of research focused on individuals' perceptions about their pain - but also on clinical practice through the dissemination of recommendations to adopt the biopsychosocial model of care (Waddell, 2004c; Sanders et al., 2013).

Thus, over the last four decades, several authors have suggested that the way people react to pain seems to be closely related to psychosocial factors. In addition, cultural values embedded in each society also seem to have a significant influence on individuals' interpretation and response to pain (Kugelmann, 1999; Main & Watson, 1999; Waddell, 2004b; Helman, 2007; Pillay et al., 2014; Khan et al., 2015). The analysis of these assumptions has drawn attention to the influence of cultural context on the experience of pain, which goes far beyond the direct relationship between pain and injury. This latter view of the pain phenomenon corresponds to the view adopted in this study.

Thus, the evolution of the views about the pain phenomenon in the last decades has influenced and been influenced by research and clinical practice in this area.

2.3.1. The impact of different views about the pain phenomenon on research

The above-mentioned gradual changes in the view of pain phenomenon have highlighted its complex and multifactorial nature. In the 1980s, pain research

increased considerably with quantitative methodologies (Cope, 2010). In this context, research carried out under the influence of the positivist and post-positivist paradigms has tried to identify the factors that contribute to the initiation, exacerbation and maintenance of pain (Crombez et al., 2012). A significant body of literature has demonstrated an association between chronic pain and disability, which do not particularly result from tissue damage but from the influence of psychological and environmental changes related to pain. Accordingly, these studies have highlighted the role of psychosocial factors in the experience of NSCLBP (for instance, Vlaeyen et al., 1995; Crombez et al., 1999; May, 2007; Woby et al., 2007; Crombez et al., 2012; Verkerk et al., 2012). Several authors have claimed that NSCLBP patients' beliefs and attitudes regarding their disorder can pose as obstacles to recovery (Main & Waddell, 2004; Heymans et al., 2010; Verkerk et al., 2012). Thus, how people make sense of pain seems to have become central in how they deal with and are affected by pain. In addition, this may also determine their pain intensity and predict the level of disability associated with it (Hayden et al., 2010; Verkerk et al., 2012).

In the last few decades, several studies have been undertaken in order to explain patients' response to pain and the impact of these responses. A diversity of models has been proposed to explain how psychosocial factors relate to pain and disability. The fear-avoidance model is currently considered to be one of the most consistent models in explaining CLBP patients' engagement and perpetuation of a vicious cycle of pain-related fear (Vlaeyen et al., 1995; Leeuw et al., 2007; Crombez et al., 2012). According to this model, pain is responsible for causing a range of cognitive, emotional and behavioural responses that may or may not increase pain and disability (Leeuw et al., 2007; Crombez et al., 2012). The model draws attention to the importance of individuals' beliefs about their pain and their role in promoting disabling fear and avoidance (Vlaeyen et al., 1995; Leeuw et al., 2007; Crombez et al., 2012). In the context of this model, fear-avoidance beliefs have particular relevance, since they seem to influence the transition from acute to chronic pain (Crombez et al., 2012). Fear-avoidance beliefs are described as cognitions and emotions

that are on the basis of concerns and fears about physical activities that are considered as potential harm to the spine (Rainville et al., 2011).

According to this model, if patients interpret pain as non-threatening, they tend to keep their normal daily life activities, making minor adjustments. This is considered a positive response, which is associated with a quick recovery (Crombez et al., 2012). On the other hand, if patients misinterpret pain as a signal of a serious pathology, they tend to develop an excessive fear of pain and injury and a consequent fear of movement. This latter interpretation is responsible for the increasing avoidance of all physical activities that are assumed to be likely to cause pain (Leeuw et al., 2007; Crombez et al., 2012). Although this response can offer some benefits in the short-term, it has negative consequences in the long-term, such as the increase of pain and disability. The avoidance behaviour generates an inability to perform daily life activities, a decrease in positive experiences and social isolation. In addition, the avoidance behaviour is also responsible for a decrease in physical activity, which could lead to physical deconditioning or even to a disuse syndrome and a consequent decrease in the pain threshold (Verbunt et al., 2003; Leeuw et al., 2007; Smeets et al., 2009; Verbunt et al., 2010; Crombez et al., 2012).

Thus, patients' interpretations and attention to pain seem to play the main role in this model. The concept of hypervigilance was introduced in this model to highlight the patients' selection of pain-related information rather than any other information (Crombez et al., 2012). This model has highlighted the importance of psychosocial aspects, by demonstrating that patients in greater fear of pain have higher pain levels (Peters et al., 2005; Woby et al., 2007), greater disability levels (Crombez et al., 1999; Woby et al., 2004; 2007) and a lower physical performance (Woby et al., 2007; Smeets et al., 2009), when compared to patients who refer to less fear of pain.

Although the association between psychosocial aspects, pain and disability has been consistently documented in literature, there are some contradictory findings concerning the association between these aspects and effects in pain intensity (for instance, Woby et al., 2004). Despite the contribution of the fear-avoidance model to increasing knowledge, this model seems to lack guidance to help clinicians in transferring the information provided to the patients'

approach (Main & George, 2011; Crombez et al., 2012). Thus, throughout the last decade research has tried to look at the applicability of this knowledge in clinical practice.

Several psychosocial factors have been consistently identified in research as potentially relevant prognostic factors in response to treatment, such as: depression; somatization (which is defined as the expression of personal and social distress through physical symptoms (McBeth et al., 2001)); fear-avoidance beliefs; self-efficacy (which is defined as the confidence an individual has regarding his/her ability to perform a particular behaviour (Bandura, 1977)); coping strategies and job satisfaction, among others (Hill & Fritz, 2011). However, only a limited number of psychosocial factors have been considered independent prognostic factors, such as self-efficacy, catastrophising or expectations of outcome and illness identity (Foster et al., 2010; Foster & Delitto, 2011; Verkerk et al., 2012). The evidence for psychosocial factors as prognostic factors is still conflicting (Hayden et al., 2010; Verkerk et al., 2012). Nevertheless, given the significant impact of psychosocial aspects, research has highlighted the importance of developing treatment strategies to help clinicians address these aspects (Hill & Fritz, 2011; Foster et al., 2015). Research focusing on psychosocial aspects as treatment effect modifiers (i.e. psychosocial aspects at baseline that influence the relationship between a specific intervention and the outcome) or as moderators (i.e. psychosocial aspects that mediate and act as an intermediary step in the link between a treatment and the desired outcome) is at the initial stages (Hill & Fritz, 2011). In the near future, these studies could support clinicians in selecting the best treatment for their patients according to their psychosocial characteristics at the baseline or in identifying the treatment components that should be strengthened in order to improve the desired clinical outcomes (Hayden et al., 2010; Hill & Fritz, 2011; Verkerk et al., 2012; Gurung et al., 2015; Karayannis et al., 2015).

Accordingly, research concerning psychosocial factors has been mostly undertaken under the influence of the post-positivist paradigm. The research outcomes have helped clinicians to make standardised decisions, applicable to

all individuals with similar characteristics. However, this does not allow clinicians to make decisions considering the complexity of patients' experiences of having NSCLBP. Some authors have argued that research carried out under the scope of this paradigm tends to illustrate a disembodied picture of chronic pain, as the subjective and multi-dimensional nature of this experience of pain has not been fully understood through the use of these methodological approaches (Mitchell & MacDonald, 2009; Osborn & Rodham, 2010).

Despite the important contribution of the post-positivist paradigm, it excludes the influence of both personal accounts as well as social and cultural backgrounds, which seem to play a crucial role in the experience of NSCLBP. Based on these limitations, research has emphasised the need to use a different research paradigm in order to fully explore the richness of the individuals' experiences of NSCLBP.

Considering the literature that emphasises the multidimensional nature of CLBP experience, where patients' beliefs and attitudes about pain play a major role, and taking into account that these aspects can determine treatment results, a significant number of authors has suggested the need to deeply explore patients' perspectives about pain and its management (for instance, Keen et al., 1999; Cook & Hassenkamp, 2000; Brown, 2004; Verbeek et al., 2004; Liddle et al., 2007; Cooper et al., 2009; Slade et al., 2009b; Vroman et al., 2009; Crowe et al., 2010b; Smith & Osborn, 2015). Thus, understanding patients' perceptions of pain offers possible insights into the needs and priorities arising from that experience, which can make a significant contribution to recovery (Crowe et al., 2010b). This also provides an alternative pathway for evaluating and improving health services and creates an opportunity for designing more successful pain management programmes based on the patients' experiences (Verbeek et al., 2004; Slade et al., 2009b; Cooper et al., 2009; Sokunbi et al., 2010).

As a reaction to the need to understand the experience of people with pain, qualitative research has become increasingly recognised within pain research (Mitchell & MacDonald, 2009; Cox, 2015). Qualitative research adopts a range

of epistemological and ontological positions to the dominant quantitative research, which allows researchers to explore the multiple meanings of the pain phenomenon (Crotty, 1998b; Willis, 2007e). In this context, interpretative approaches to research, associated with the use of qualitative methodologies, have become particularly relevant to the body of knowledge related to the experience of chronic pain (Mitchell & MacDonald, 2009; Cox, 2015).

A range of methodologies such as grounded theory (GT), narrative analysis (NA) or interpretative phenomenological analysis (IPA) among others have been used under the heading “qualitative research” to develop new knowledge in the area of pain (Mitchell & MacDonald, 2009; Cox, 2015). In the last few years, a significant number of studies concerning patients` perceptions of pain have been undertaken (for instance, Bunzli et al., 2013; Froud et al., 2014; MacNeela et al., 2015). In the last two decades, research has tried to focus on what patients think about their pain and on what they perceived important for treatment.

More specifically, qualitative research has been interested in exploring the lived experiences of those with NSCLBP from their perspectives (for instance, Osborn & Smith, 1998; Walker et al., 1999; 2006; Holloway et al., 2007; Smith & Osborn, 2007; Snelgrove & Liossi, 2009; McParland et al., 2011; Snelgrove et al., 2013). In this context, the experiences with health professionals have emerged as one of the most important parts of this process. Patients` perspectives about health care have also been explored, with particular emphasis on advice, education and exercise prescription (for instance, Goodyear-Smith & Buetow, 2001; Harding et al., 2005; Campbell & Cramb, 2008; Cooper et al., 2008; Slade et al., 2009b; Toye & Barker, 2012a).

Thus, recent qualitative studies have offered valuable insights into the multidimensional experience of NSCLBP disorder (Mitchell & MacDonald, 2009; Cox, 2015). There are contradictory perspectives about the acceptance of qualitative research with some authors considering it to be an established field (Newton et al., 2012), and others arguing that it is not (Osborn & Rodham, 2010). Nevertheless, it is important to consider that studies carried out under the scope of the interpretive paradigm also had some limitations. For example,

researchers frequently omitted the rationale for the guiding theoretical framework selected, did not justify the decisions made throughout recruitment and data collection, and frequently lacked discussion regarding data saturation (Newton et al., 2012). In addition, the need to explain the qualitative approach, rather than the specific theoretical framework, as well as the use of inappropriate sampling strategies, leave room to hypothesise that some researchers are influenced by positivist ideas (Newton et al., 2012). This possibly reflects the strong dominance of a positivist research heritage, which makes qualitative research difficult to accept by the research community.

Despite the aforementioned contradictions, the existing studies illustrate a significant dominance of quantitative studies (Hellström, 2001; Osborn & Rodham, 2010). In this context, research is still emphasising the need to carry out more studies under the scope of the interpretive paradigm. These recommendations are particularly relevant when it is taken into consideration that the experience of having NSCLBP disorder is deeply influenced by cultural contexts (Yaphe, 2014; Pillay et al., 2014; Khan et al., 2015) and the vast majority of research has been carried in the UK (Newton et al., 2012). The development of qualitative research in unexplored contexts would possibly allow for the exploration of aspects of the pain experience in unique sociocultural environments that have not been studied yet (Wiat & Burwash, 2007; Tavafian et al., 2008).

2.3.2. The impact of different views about the pain phenomenon on health care

The aforementioned developments in pain research have offered a significant contribution to knowledge about pain management (Cope, 2010). Indeed, the traditional disease model, commonly referred to as the biomedical model, became insufficient to approach patients with NSCLBP. It offered a simplistic view of NSCLBP that was mainly focused on the spine and the disease. Thus, a new model that integrated new perspectives about the biopsychosocial influences was needed (Waddell, 2004c).

The biopsychosocial model is based on the idea that illness results from the complex interaction between biological, psychological and social factors

(Gatchel et al., 2007). It is focused on a problem-oriented approach to rehabilitation, where psychosocial obstacles and changing behaviour are as important as physical reconditioning and where a multidisciplinary approach to rehabilitation is asserted (Waddell, 2004c).

This model encourages patients' education on how to deal with their pain and is focused on replacing maladaptive patients' cognitions and behaviours with more adaptive ones (Harland & Lavalley, 2003; Waddell, 2004c). This approach defends that the way in which patients interpret their pain, will affect the emotional and physical disability reported (Gatchel et al., 2007). Literature has suggested that although physiotherapists have begun to embrace the biopsychosocial model, several questions about how this new approach has been implemented remained unanswered (Liddle et al., 2007). Although physiotherapists currently recognise the need to address patients' psychosocial needs, they often feel more confident in prioritising physical problems (Sanders et al., 2013; 2014). Thus, a conflict seems to persist between the traditional physiotherapy paradigm focused on biomechanically orientated treatment approaches and a more recent paradigm focused on psychosocial problems (Sanders et al., 2013; 2014). In the qualitative study by Sanders et al. (2013) on the physiotherapists' accounts of back pain consultations, the participants reported that the integration of psychosocial issues in the approach to patients increased the complexity of the case, and that they often felt they lacked the necessary skills to address these issues.

In this scope, cognitive-behavioural (CB) approaches have been widely recommended for a range of chronic conditions, where NSCLBP is included (for instance, Linton & Nordin, 2006; Dufour et al., 2010; Lamb et al., 2010; Kamper et al., 2014; Hållstam et al., 2016). CB approaches are described as forms of treatment that employ cognitive and behavioural techniques, drawn from evidence-based models (Richmond et al., 2015). These techniques focus on distorted cognitions and maladaptive behaviours that are thought to be responsible for maintaining an illness/ disability (Olatunji & Hollon, 2010). Although theoretical models suggest that symptoms can be improved through the modification of the aforementioned cognitions and behaviours, the

mechanisms underlying the effectiveness of these approaches are not well understood (Olatunji & Hollon, 2010; Richmond et al., 2015). Despite the increasing empirical evidence about the use of CB approaches for the management of NSCLBP (Koes et al., 2010; Hill et al., 2011; Fersum et al., 2013) some studies have revealed inconsistency, which may be related to different methodological approaches or to the content of the interventions tested. For example, Lamb et al. (2010) compared a primary care cognitive-behavioural group intervention (one individual and six group sessions, ninety minutes each) to usual care (advice only) in patients with sub-acute or CLBP. At twelve months, patients in the cognitive-behavioural group scored better in pain (Von Korf scale for pain, 13.4% vs. 6.4% ($p < 0.001$)) and functional disability (Roland Morris, 2.4 vs. 1.1 ($p < 0.001$)). On the other hand, Hållstam et al. (2016) carried out a prospective observational study with a one year follow-up with CLBP patients, who received multimodal rehabilitation conducted according to the cognitive-behavioural principles. Although significant improvement in functional status (Pain disability index, 39.48 SD12.6 vs. 33 SD14.8 ($p < 0.032$)) was found at twelve months, it did not reach the clinically important change. Besides the aforementioned controversies, findings from this latter study also drew attention to the difference between statistical significance – defined if $p < 0.005$ – and clinical importance – defined by the minimal clinically importance difference between groups (Copay et al., 2007; van Tulder et al., 2007). Indeed, in the last decade it has been emphasised that some trials have overemphasised the positive results because they exclusively considered statistical significance (van Tulder et al., 2007). Thus, it seems to be important to use complementary ways to assess clinical practice that may take into account the patients' perceived benefits.

In the scope of the biopsychosocial model several authors have suggested that health care should be patient-centred (Trede, 2000b; Atkins & Ersser, 2008; Cooper et al., 2008). Literature has indicated that re-orientating health care towards a patient-centred approach has the potential to not only improve health outcomes, but also to reduce avoidable demand for health care services (Royal College of General Practitioners, 2014; Stenner et al., 2015). Nevertheless, little

consensus regarding the meaning and application of patient-centred care has been reported (Mead & Bower, 2000; Moore & Jull, 2012; Sanders et al., 2013). For example, while some views of patient-centred care relate it to the provision of information to patients, others relate it to a more complex approach that includes gaining a deep understanding of the patients' accounts and involving them in the decision-making process (Moore & Jull, 2012). The lack of theoretical clarity has created difficulty in developing adequate ways to implement and assess the impact of patient-centred care (Mead & Bower, 2000). Thus, this concept has been explored across a range of disciplines (Moore & Jull, 2012). For example, Mead and Bower (2000) reviewed conceptual and empirical literature so as to develop a patient-centred model of the doctor-patient relationship. Despite the multiplicity of conceptual definitions, they proposed five dimensions to explain the phenomenon under investigation: (i) "biopsychosocial perspective", which emphasised the importance of understanding patients' illness within a broader biopsychosocial framework; (ii) "patient-as-person", which emphasised the need to understand the individuals' experiences of illness; (iii) "sharing power and responsibility", which highlighted the need to promote patients' involvement in health care, through encouraging them to voice ideas, reflecting and promoting collaboration; (iv) "therapeutic alliance", which highlighted a common understanding of the goals and requirements of treatment; and (v) "doctor-as-person", which concerned about the influence of the physicians' personal qualities on the approach to treatment (Mead & Bower, 2000). Conversely, Cooper (2008) carried out a qualitative study where the concept of patient-centredness in physiotherapy was explored from the perspective of the CLBP patient. From the interviews with 25 individuals who had previously received physiotherapy for CLBP, 6 key dimensions emerged as being perceived to be important for patient-centred care physiotherapy: (i) "communication"; (ii) "individual care"; (iii) "decision-making"; (iv) "information"; (v) "the physiotherapists"; and, (vi) "the organisation of care" (Cooper et al., 2008). Considering the limited number of participants included, these findings should be interpreted in terms of theoretical transferability. Theoretical transferability is described as the ability to transfer the study's findings to individuals in contexts that may have some similarities to

the context where the study was carried out (Smith et al., 2009d). Contrary to quantitative research, which considers generalizability as the ultimate goal, qualitative research is more focused on the possible transferability of findings from group to group (Hefferon & Gil-Rodriguez, 2011). Nevertheless, a research account needs to be transparent and sufficiently related to the current literature in order to enable the reader to assess the evidence in relation to their professional context and experiential knowledge (Smith et al., 2009d). Specific information on the study's participants as well as their contexts is fundamental to enable the reader to assess and evaluate transferability (Smith et al., 2009a; Smith, 2011b). Since no specific information on these aspects was provided in the aforementioned study by Cooper (2008), the findings should be interpreted with caution.

Regardless of the differences in the methodological approaches and findings of the two studies examined in the previous paragraph, there are some shared results, such as the active participation of the patients in the decision-making, the focus on achieving goals that are meaningful for patients and the health professionals' responsibility in promoting collaboration.

Accordingly, patient-centredness seems to acknowledge that both patient and health professional bring their own agendas to the clinical encounter, which requires the health professional's analysis of power dynamics and consideration of the patient's experience as an essential component of treatment plans (Trede, 2012). This means that, in the context of patients' education, didactic approaches i.e. simply delivering information to patients, do not seem to fit into the patient-centred concept (Cross et al., 2006; Moore & Jull, 2012). Rather, the importance of identifying patients' learning needs and providing information according to the patients' learning styles has been emphasised (Moore & Jull, 2012). Additionally, involvement in the decision-making regarding the treatment progress and in the self home management process as well as the timing of discharge also seem to be central in non-didactic, patient-centred approaches (Moore & Jull, 2012).

In this context, recent research has emphasized the relevance of tailored approaches to self-management that recognise patients' individuality and

different modes of engagement (Royal College of General Practitioners, 2014; Stenner et al., 2015). Specifically, in what concerns chronic conditions, where NSCLBP is included, the WHO has highlighted the need to promote patients' self-management (WHO, 2013). Despite research's encouragement of health professionals to support patients towards pro-active coping strategies and independent self-care, consistent patient engagement and achievement of effective self-management remain a challenge (de Silva, 2011; Stenner et al., 2015). Part of this challenge seems to be related to health professionals, since the integration of a patient-centred model of care into practice may be particularly difficult in contexts where the biomedical model is deeply rooted (Cruz et al., 2012a).

Despite the widespread authority of the biopsychosocial model, some authors have argued that researchers' and clinicians' overemphasis on psychosocial or biomedical factors may lead to insufficient understanding of chronic pain. Over the last decade, neurobiological research and brain imaging have increased the understanding of the human experience in what concerns the affective dimension of pain experience and the shared neural bases for pain, emotional experience and social attachment (Lumley et al., 2011). This knowledge has strongly motivated further research on the interpersonal and social contexts of pain, where four components – awareness of pain, expression of pain, experiencing of pain and modulation of pain – have been considered relevant in adaptive and maladaptive responses to pain (Lumley et al., 2011). The following section examines studies on the individuals' experiences of pain.

2.4. Research on the individuals' experiences of NSCLBP

In order to develop a better understanding of the experiences of NSCLBP, qualitative research has tried to focus on how patients make sense of their pain and on what they perceive as important for pain management. Several studies have been focused on the individuals' experiences of a range of pain conditions, with chronic pain (from several types, where NSCLBP is included) being one of the most researched. In the last few years a range of qualitative

meta-syntheses have been carried in order to develop a better understanding of the patients` experiences of NSCLBP (for instance, Bunzli et al., 2013; Snelgrove & Lioffi, 2013; Toye et al., 2013; Froud et al., 2014; MacNeela et al., 2015).

In the meta-synthesis of Bunzli et al. (2013), twenty-five articles representing eighteen studies exploring the CLBP experience from the patients` perspectives were included. In total, findings from 713 participants were analysed through a 3-stage process that included: the extraction and coding of findings from each article; grouping findings according to their topical similarity; and, abstraction of findings which included the analysis of the grouped findings in order to identify patterns, overlapped comparisons and redundancies.

Three main themes emerged from data analysis, namely: (i) “the social construction of CLBP”, which drew attention to CLBP patients` biomedical beliefs about their back pain; (ii) “the psychosocial impact of the nature of CLBP”, where the omnipresence of pain was emphasised as well as its unpredictable fluctuations in intensity during both walking and sleeping; and, (iii) “coping with CLBP”, in which the strategies to control the unpredictable nature of pain were emphasised. These authors highlighted the biographical suspension inherent to the experience of CLBP, by stressing the CLBP patients` suspended wellness, self and future (Bunzli et al., 2013). Through the synthesis of the findings from previous studies, Bunzli et al. (2013) developed a conceptualisation of CLBP based on the notion of biographical suspension, which could have an important contribution to clinical practice. However, it is important to address some issues in the interpretation of these findings such as the lack of specific information regarding the methodological approach that was used as well as the inclusion of studies without detailed assessment of their trustworthiness. Indeed, some limitations were identified in the studies included, such as the lack of authors` presentation of their standpoint and insufficient primary data i.e. quotes (Bunzli et al., 2013).

Snelgrove and Lioffi (2013) also carried out a meta-synthesis on the patients` experiences of CLBP. These authors followed a meta-ethnographic

methodology to review the thirty-three articles included, which represented twenty-eight studies published between 2000 and 2012. Overall information on the methodological approach was provided, however these authors did not formally evaluate the quality of the selected articles. The synthesis of themes from the reviewed articles revealed three themes: (i) “the impact of CLBP on self”, which emphasised the persistent, disruptive and distressing nature of this disorder; (ii) “relationships with significant others”, which emphasised the CLBP patients` perceptions of being a problem to their families; (iii) “coping with CLBP”, which addressed the CLBP patients attempts to manage their disorder. Snelgrove and Lioffi`s (2013) meta-synthesis drew attention to the CLBP patients perceived impaired social roles, stigma and changes in identity and substantiated the patients` emphasis in coping with CLBP, which was previously reported by Bunzli et al. (2013). Nevertheless, it is important to consider that the majority of the studies included were carried out in the UK, which may limit the transference of this study`s findings to other cultural contexts.

Toye et al. (2013) carried out a meta-ethnography of patients` experience of chronic non-malignant musculoskeletal (MSK) pain, where thirty articles referred to chronic back pain were analysed (from a total of seventy-seven articles included). Several categories emerged from the data analysis, namely: (i) “struggling to affirm my self”, which emphasised the struggle to hold on to the perceived real self, as it was threatened by continuing pain; (ii) “construction of time altered - unpredictable now and in the future”, which highlighted the participants` perception of their altered self through time; (iii) “struggling to construct an explanation for suffering”, which articulated the need to find an explanation for suffering; (iv) “struggling to negotiate the health-care system”, which emphasised the participants` struggle to negotiate with the health-care system and its processes; (v) “struggling to prove legitimacy”, which highlighted the participants` struggle to prove their credibility; and, (vi) “moving forward alongside my pain”, which described how some participants found ways of moving forward alongside their pain (Toye et al., 2013). The authors developed a conceptual model that highlighted the constant daily struggle facing people

with chronic MSK pain that was different from other kinds of pain, such as cancer pain (where there was no need to prove pain). The model also suggested that despite struggling, patients could also move forward alongside pain (Toye et al., 2013).

It is important to consider that this study's authors emphasised meta-ethnography as an interpretive form of knowledge synthesis aiming to develop new conceptual understandings. This meant that the model developed was acknowledged as the result of the authors' interpretations. Indeed, the authors provided a detailed description of the collaborative process of interpretation, which was based on the analysis of second-order constructs (i.e. the original studies researchers' interpretations based on first order constructs that corresponded to the participants' interpretations in their own words) (Toye et al., 2013).

The subsequent meta-syntheses carried out by Froud et al. (2014) and MacNeela et al. (2015) substantiated some of the previous concepts such as the struggle to meet social expectations, the unsatisfying relationships with health professionals, and the need to learn to live with pain. This may be justified by the inclusion of some studies that had been analysed in the previously presented meta-syntheses (Bunzli et al., 2013; Snelgrove & Lioffi, 2013; Toye et al., 2013).

Accordingly, there seem to be a range of themes that have frequently emerged in these meta-syntheses, which deserve further exploration in the following paragraphs via the examination of some studies, particularly those concerning NSCLBP.

Coping has been one of the most commonly reported themes in the qualitative research regarding individuals' experiences of CLBP (Werner & Malterud, 2003; Harding et al., 2005; Snelgrove & Lioffi, 2009; Crowe et al., 2010a; Snelgrove et al., 2013). The individuals' management of CLBP emerged as an important element in the IPA study carry out by Snelgrove and Lioffi (2009). This study's participants frequently used prescribed medication and personally derived

physical coping strategies, such as the adoption of different postures, the use of heat and a variety of avoidance behaviours. Snelgrove and Lioffi (2009) emphasised the Cartesian dualism effect on these participants' strategies to cope with pain and stated that they were entrapped in their experiences despite trying to maintain some control.

Additionally, Snelgrove and Lioffi (2013) followed the same participants, included in the previously mentioned study (Snelgrove & Lioffi, 2009), over three years and highlighted that they maintained the same strategies throughout the study despite their perceived inefficacy and adverse side-effects. The researchers drew attention to the distress their participants incurred by on-going and generally unchanging CLBP experiences. However, as little information was provided about the participants' life contexts, the transference of these findings to other contexts is limited.

Furthermore, the impact of pain on social interactions constitutes another relevant theme that has emerged from qualitative studies concerning individuals' experiences of NSCLBP (Osborn & Smith, 1998; Holloway et al., 2007; Slade et al., 2009a; Osborn & Rodham, 2010; Dow et al., 2012). In this context, stigma has been presented as a relevant concept in several studies (Smith & Osborn, 1998; Holloway et al., 2007; Dow et al., 2012). Stigma seemed to impact on several dimensions of CLBP patients' lives such as their interactions with significant others or with work colleagues (Smith & Osborn, 1998; Holloway et al., 2007; Dow et al., 2012). In the IPA study carried out by Holloway et al. (2007), the stigma of invisible pain (in which a specific cause could not be identified) was responsible for the participants' distress, and the researchers deemed it an important reason why the participants found it difficult to adapt to their disorder (Holloway et al., 2007).

Since some CLBP patients could not establish the cause of their pain, either to themselves or to others in their social or work lives, they tended to withdraw from social contact (Osborn & Smith, 1998). The invisibility of pain seemed to become a source of frustration for individuals experiencing CLBP (Dow et al., 2012). According to Dow et al.'s (2012) findings the invisible nature of chronic pain made it hard to communicate and be recognised by others. The

participants included in this UK study suspected that friends and family did not believe them or tended to forget that there was a problem (Dow et al., 2012). This may impact on these participants` perceived lack of support from friends and family.

The impact of the experience of living with chronic pain on the self has also emerged in several studies (Osborn & Smith, 1998; Hellström, 2001; Smith & Osborn, 2007; Crowe et al., 2010a). In his IPA study, including Swedish chronic pain patients, Hellstrom (2001) used the expression “living in the past” to describe the way participants dealt with their disorder and hypothesised that it could decrease the capability of adapting to the new life situation (Hellström, 2001, p.121). Hellstrom`s (2001) study was substantiated by a UK IPA study carried out by Smith and Osborn (2007) with participants with CLBP. The findings emphasised the participants` experiences of struggling to maintain a coherent self. The participants also worried about the impact of pain on those around them, which the researchers suggested reflected the strong social component of this experience (Smith & Osborn, 2007).

The unpredictability of CLBP has also emerged as a major issue, since it seemed to have a significant impact on patients` lives and appeared to be responsible for feelings of frustration, worry and lack of body control (Crowe et al., 2010a). In their qualitative study including New-Zealanders experiencing CLBP, Crowe et al. (2010a) emphasised that due to the unpredictability of pain, the participants needed to increase their level of vigilance to manage pain. This changed the way in which they related to their body and also to their sense of self. According to these authors, the experience of pain had not only transformed participants` lifestyles but also their self-image (Crowe et al., 2010a).

Despite the previously reported insights provided by research in this area, it is important to take into consideration that none of these studies were carried out in Portugal. Thus, some contextual issues could have influenced the reported findings. Additionally, no information on the position of the researchers was

provided in the aforementioned studies, which make it difficult to assess the possibility of transferring these findings to other contexts.

The patients and health professionals' difficulties in communicating about pain has also been widely reported in qualitative research (Walker et al., 2006; Slade et al., 2009b; Toye & Barker, 2012a; Dow et al., 2012). The lack of visible evidence seems to be responsible for patients feeling the need to convey the experience of their pain in a credible way during their encounters with health professionals, suggesting that they did not feel they were believed (Werner & Malterud, 2003; Werner et al., 2004). More specifically, themes frequently emerged in the research concerning patients' experiences with health professionals, where the patients appeared to struggle to be taken seriously, treated with dignity and appeared fearful of being judged (Werner & Malterud, 2003; Werner et al., 2004; Walker et al., 2006).

The research carried out into patients' experiences of seeking health care has highlighted a gap between the health care provided and the patients' expectations (Verbeek et al., 2004). Individuals with NSCLBP who sought help from health services seemed to find a biomedical approach, characterised by poor communication and lack of time to listen to their stories and understand their problems (Walker et al., 1999; Osborn & Rodham, 2010). Many patients have expressed dissatisfaction with treatment, emphasising the need for treatments that are related to their own physical and emotional needs (May, 2007; Scheermesser et al., 2012). Furthermore, the patients in these studies seemed not to have received enough information about their condition and did not receive answers to most of their questions (Dow et al., 2012).

For example, Slade et al. (2009c) undertook three focus groups (each with six participants, aged over eighteen) to explore NSCLBP patients' experiences during exercise programmes in Australia. The participants (mean age: 51.2; mean duration of back pain: 20.3 years) were encouraged to discuss their experience of NSCLBP, their experience of exercise programmes and the factors that facilitated or constrained their engagement in the programmes. A

grounded theory approach was employed in the analysis of experiences of participants. Some participants expressed anger, while others expressed frustration in their search for understanding, legitimacy and validation of their pain. All reported that they felt the validity of their condition was in question because there was no confirmation of a specific cause of pain by imaging tests (such as an X-Ray) or any specific diagnosis. The majority of the participants emphasised that their contacts with health professionals were characterized by poor understanding of their needs and reported that they felt blamed and perceived to be accused of imagining their symptoms or seeking secondary gain. It could be argued that these findings should be viewed with caution, as the authors claimed to have used a method of grounded theory, but only included three focus groups. It therefore could be deemed unlikely that data from such a small sample reached a point of saturation in the key emerging categories of their findings (Charmaz, 2000b; Charmaz & Henwood, 2008). The authors also made no references to saturation in this article, which raises further questions regarding the rigour of this study. Nevertheless, these findings highlighted an important point of the therapeutic relationships that seemed to be related to the dominance of a predominantly biomedical model of care.

Slade et al. (2009b) also explored the factors that these participants considered important for their engagement and participation. They identified the ability of the health professional to identify and articulate their own needs as one of the most important factors for engagement and participation. One of the themes that emerged from this study also emphasised the importance of empowering skills of the health professional. All participants recognised the positive impact of motivating health professionals and agreed that these qualities, as well as effective teaching skills, promoted exercise participation and positive therapeutic outcomes (Slade et al., 2009b).

Although previous studies' findings are consistent in terms of patients' perspectives about pain treatment, research has emphasised the need to thoroughly explore patients' experiences of seeking for health care, particularly in contexts where these experiences have not yet been investigated (Pillay et al., 2014).

2.5. The role of culture in shaping individuals` experiences of NSCLBP

Research in the area of chronic pain has emphasised its inherent dynamic process of mutual influence involving pathophysiology, individual neoregulation and cultural factors that impact the individual (Riley et al., 2002; Ruehlman et al., 2005; Pillay et al., 2014). Thus, the perception and behaviours associated with chronic pain are significantly influenced by the socio-cultural context (Helman, 2007; Pillay et al., 2014; Khan et al., 2015). This may imply that different cultural groups perceive and respond differently to pain (Yaphe, 2014; Khan et al., 2015).

Scheermesser et al. (2012) aimed to understand the experience of patients with CLBP from a Southeast European cultural background in multidisciplinary rehabilitation programmes. These authors carried out thirteen semi-structured interviews with patients from a southeast cultural background who were living in Switzerland, five semi-structured interviews and two focus groups with health professionals. After data analysis, Scheermesser et al. (2012) emphasised some barriers to rehabilitation in CLBP patients from Southeast Europe being treated in the German-speaking part of Switzerland. For instance, the authors identified patients` treatment expectations focused on health professionals` help as well as passive coping strategies as quite pronounced barriers. In addition, these patients missed their families during inpatient rehabilitation since they were not use to being separated from them for several weeks. On the basis of these findings, Scheermesser et al. (2012) claimed that cultural factors may have an important role in the CLBP patients` rehabilitation. However, this study had some limitations that should be considered. Specifically, the participants included were all from one rehabilitation centre and all from the region of the former Yugoslavia, which limits the transference of the study`s findings to other contexts. The provision of detailed information regarding the participants` background would possibly facilitate this transference.

Pillay et al. (2014) carried out a collective review aiming to develop a better understanding of the influence of cultural experience in chronic pain perception. The cultural differences and similarities in chronic pain perception were explored, with particular emphasis on the factors that operated in the patient,

patient-provider interactions and health system. In particular, research focused on the factors that operated in the patient emphasised the cultural resources role in the individuals` giving meaning to pain. Pillay et al. (2014) highlighted several differences in perceived control, the perceived efficacy of treatments and scepticism, distrust of Western medicine and barriers to help-seeking or accepting medical interventions. Moreover, significant cultural differences in self-care behaviours, participation in treatment and preferences for pain management programmes were also identified. Furthermore, culturally-differentiated coping mechanisms were also identified, with the use of active and passive strategies varying across cultures. Passive coping - including prayer, hoping or diversions - was related to poorer pain adjustment (Pillay et al., 2014).

Lastly, the authors of this collective review highlighted the need for more research that moves beyond comparisons between categories to answer questions of the lived experience of individuals experiencing chronic pain (Pillay et al., 2014). Thus, the need for qualitative research that is locally and context specific was stressed, since it may enable the development of better a cultural understanding of pain experiences (Pillay et al., 2014) and subsequently the development of culturally appropriate treatment approaches.

Despite the reported impact of the social and cultural contexts on shaping the individuals` experiences of chronic pain, the body of knowledge in this area has been mainly influenced by a few countries such as the UK and Australia, where the majority of studies concerning the experiences of individuals with NSCLBP has been carried out. Given the importance of cultural context in this experience, research has suggested the need to move the focus to unexplored contexts where pain has also a significant impact.

The volume of research undertaken in Portugal within the area of NSCLBP is considerably low. To the researcher`s knowledge the only study regarding the Portuguese individuals` experience of having a disorder was focused on fibromyalgia (Gonzalez et al., 2015). This draws attention to the need to study the phenomenon of NSCLBP in the Portuguese context, by looking at the experiences of those who deal with this disorder in their everyday lives. Thus,

exploring Portuguese individuals' accounts of NSCLBP disorder can contribute to a better understanding of their experiences and can possibly inform recommendations to help improve its management by adapting it to the specificity of the Portuguese context.

2.6. Reflexive account

The diversity of terminologies and definitions of NSCLBP was a challenging part of the literature review process. Qualitative research on health professionals' dilemmas in the approach to NSCLBP helped me to understand and accommodate this diversity. As it was important to define the phenomenon under investigation, I adopted a definition frequently used in some studies. However, I found it important to emphasise the absence of common frameworks to explain this disorder (Kent et al., 2009). This has also had some impact in the epidemiological literature, since the terminologies across studies are variable.

A historical perspective of the views about the pain phenomenon helped me to develop a broader perspective of how influential these perspectives have been in research and health care, especially over the last five decades. Examining the way researchers and clinicians have looked at the pain phenomenon facilitated my understanding of the motivations for research in this area. This led me to understand the powerful impact of the positivist and post-positivist paradigms as well as their insufficiency in allowing the development of a deeper understanding of the pain phenomenon. Thus, the relevance of the interpretive paradigm became clear to me, as well as the challenges inherent to undertaking research under the scope of this paradigm. Indeed, I realised that I would need to deal with what I called internal and external challenges. The internal were related to the need to develop skills to carry out research following a paradigm, with which I had had little contact in my education and training as a physiotherapist. The external were related to the acceptance of the interpretive paradigm in contexts that have been identified as biomedical and clinician-centred (Cruz et al., 2012a) and thus probably more identified with positivist and post-positivist research. In a way, I was expecting the aforementioned internal

challenges, as they were related to the specific learning and reflection required to carry out this study. However, I was not expecting the aforementioned external challenges. As I engaged with the literature, I was disappointed with an apparent conflict between quantitative and qualitative research in the area of pain. Indeed, there were only a few authors advocating the complementary nature of the research paradigms, which underpin quantitative and qualitative studies, in developing a better understanding of the pain phenomenon. Moreover, I was also disappointed with the lack of research exploring the experience of having NSCLBP in countries other than the UK and Australia. Accordingly, the background reading and reflection about the challenges in research in the area of pain led me to articulate studies carried out under the influence of both post-positivist and interpretive paradigms in my literature review. This consolidated the need to embrace the contribution of both paradigms and go further in the exploration of the NSCLBP phenomenon under the scope of the interpretive paradigm.

Despite the significant impact of NSCLBP in Portugal, a closer analysis of the literature on the patients' experiences of NSCLBP highlighted an important gap in the knowledge about this phenomenon in this country. Additionally, literature regarding the impact of social and cultural contexts on shaping the individuals' experiences of chronic pain substantiated the relevance of focusing this study on such an unexplored context.

2.7. Chapter summary

In this chapter, the background for this study has been appraised. The definition of NSCLBP adopted in this study and the impact of this disorder in western societies have been presented. Historical perspectives about pain phenomenon have been outlined as well as their impact on research and health care. Research carried out on the patients' experiences of NSCLBP was examined and the influence of the cultural context on these experiences were considered. The next chapter provides an overview of the Portuguese context and integrates the experience of NSCLBP into it.

Chapter 3: The Portuguese Context

In this chapter, the background context provided in the preceding chapter is developed and specific information about the Portuguese context is explored. The chapter is divided into four main sections. In the first, an overview of changes in Portugal over the last five decades is provided. In order to provide an overall perspective about the specific context where this study was undertaken, information about the political, economic and social contexts is addressed. In the second, the Portuguese national identity is explored and the unique characteristics of Portuguese culture are highlighted. In the third, the current state of Portuguese health is explored, including information about the NHS and its responsiveness. In the fourth, the impact of NSCLBP in Portugal is examined, with particular emphasis on the studies published in the current decade. Finally, a reflexive account on the Portuguese context is presented.

3.1. An overview of Portuguese development over the last five decades

Portugal is a small country located in south-western Europe on the Iberian Peninsula. The country also includes the archipelagos of the Azores (with nine islands) and Madeira (with two main islands) in the Atlantic Ocean (INE, 2014). Some authors have argued that Portugal is one of the least understood European countries (Nielsen et al., 2009). One of the most important episodes in Portuguese history was the political revolution in 1974, which put an end to an almost fifty-year dictatorship. Since then, Portugal has been governed via a constitutional democratic republic (Barros & Simões, 2007). Accordingly, structural changes affected the Portuguese society and were responsible for significant improvements in the population's daily life and a remarkable economic rise (Nielsen et al., 2009).

Over the last five decades, Portugal has suffered significant social changes. According to the results of the last census, the Portuguese population was approximately 10.6 million in 2011 (INE, 2012). Recent statistics demonstrated a decrease to approximately 10.4 million inhabitants in 2015 (Directorate-General of Health, 2015a; PORDATA2015). Some of the factors identified as

the main contributors to this trend were the high migration rates, low birth rates and the increase in longevity (Barreto, 2003a; Bandeira et al., 2014). The last two have considerably strengthened the process of demographic ageing (Mota-Pinto et al., 2011). The average age of the Portuguese population has increased considerably faster than in other European countries (PORDATA, 2015), yet six decades ago, Portugal had one of the youngest populations in Europe. Since 2000 the proportion of over sixty-five year olds in the total population has become greater than under fifteen year old (Barreto, 2003a; Bandeira et al., 2014). According to the last census results 15% of the population was fifteen, while 19% was elderly in 2011 (INE, 2012).

There has been a significant decrease in birth rates, which has become one of the lowest in Europe, yet it had been the highest in the sixties (Barros & Simões, 2007; PORDATA, 2015). From 1970 to 1990, the number of births decreased steadily ranging from 20.0 live births per 1000 population to 11.80 per 1000 population, which was below the EU average of 12.02 for the first time. This decrease has continued to the present day, reaching the lowest levels ever in Portugal (82.367 births in 2014) (PORDATA, 2015). This scenario suggests an inevitable difficulty in regeneration and a decrease of the Portuguese population in the coming decades (Barreto, 2003a; Barros & Simões, 2007; Barros et al., 2011). The demographic changes in Portugal over the last five decades have created new challenges in society, especially for the NHS (George et al., 2007).

Family structures have also suffered dramatic changes. The size of families has decreased considerably, reaching close to 2.6 people per household in 2014 (PORDATA, 2015). The reduction in the number of marriages and the significant increase in the number of divorces have produced significant changes in Portuguese family models, moving from a multi-generational structure to a more individualistic nuclear family without the traditional family support system (Carrilho & Patrício, 2010; Mota-Pinto et al., 2011).

Despite Portugal recently being permeated by more individualistic values, the “familialist tradition” (Coelho et al., 2014, p.1) typical in Mediterranean societies still persists (Coelho et al., 2014). Portuguese families still seem to play a

central role as providers of social support and the strong inter-generational connection is still valued (Coelho, 2010; Ribeiro et al., 2015). Thus, more progressive values and practices in family life seem to co-exist with traditional stances (Coelho et al., 2014).

The labour market has also changed considerably. In particular, the unemployment rate has steadily increased, with a significant exacerbation in the last two decades (Coelho et al., 2014; PORDATA, 2015). Accordingly, the Portuguese economy has suffered a very low and even negative growth over the last few years.

Portugal has been one of the European countries where the global economic crisis has had major impact (Coelho et al., 2014; Correia et al., 2015b). This crisis has had a significant impact on the labour market, with increasing salary cuts, job insecurity and high unemployment rates. Additionally, it has also affected Portuguese families, with a significant number of those living below the poverty line (Coelho et al., 2014; Correia et al., 2015b). In this context, Portugal needed emergency financial aid from the International Monetary Fund, the Central European Bank and the European Commission (Correia et al., 2015b). The Portuguese government signed a financial assistance programme, which was in place between 2011 and 2014 (Coelho et al., 2014; Correia et al., 2015b). This programme included several measures that affected the NHS, such as the reduction of financial support from the government, the reduction of existing staff and limited recruitment, a decrease of overtime and the amount paid for it, a freeze of promotions or the absence of replacement of leavers (Correia et al., 2015b). These measures seem to have prompted the physicians' move from the NHS to private practice – for example, between 2011 and 2014, 1400 physicians decided to leave the NHS, which was more than those who retired (Boquinhas, 2015). Additionally, a significant number of health professionals left the country (Gilles & Buchan, 2014) – for example, in 2013/2014, 25% of the 5388 European entrants to the UK nursing registry were from Portugal (Royal College of Nursing, 2014).

In this context, users of the Portuguese NHS have faced several difficulties in the last few years, such as long waiting lists to for some services and higher

prices, which lead those who can afford it, to use private services (Boquinhas, 2015).

3.2. The Portuguese national identity

Since the 1974 revolution, Portugal has undergone significant changes and it is important to see how these have influenced the Portuguese cultural dimension and the national identity. In the study by Nielsen et al. (2009), exploring the Portuguese national identity, *Fado* emerged as a metaphor that represented the unique characteristics of the Portuguese culture. The etymology of the Portuguese word *Fado* is associated with the concept of fate, embracing the belief of an irrevocable destiny (Nielsen et al., 2009). *Fado* is a Portuguese folk song, described as “a soulful music” (Nielsen et al., 2009, p.291) however, it has been considered much more than this since it represents the Portuguese identity.

According to Nielsen et al. (2009, p.296), the “*Fado music and lyrics communicate the full range of Portuguese experience*”. Thus, the *Fado* metaphor illustrates a diversity of national paradoxes that make up the Portuguese cultural identity. More specifically, the apparent collectivist Portuguese society contrasts with a trend in isolation and loneliness. There is an underlining sense of sadness, nostalgia and melancholy in *Fado*, which communicates a very powerful part of the Portuguese identity. There seems to be a dialectic movement between private and shared emotional space and the Portuguese society seems to value human relationships over task achievement (Nielsen et al., 2009; Coelho, 2010).

Furthermore, there seems to be a cultural tendency to explain suffering as a consequence of external and uncontrollable causes that are perceived to be impossible to change (Ferreira-Valente et al., 2011). However, the fatalism and perseverance embedded in *Fado* demonstrates two dramatically different Portuguese attitudes. The former attitude is associated with the notion of catharsis, as an emotional escape. This is reflected in the Portuguese need to communicate and share their life struggles with others. On the other hand, the second attitude is connected with the idea of become accustomed to something.

This passive coping behaviour seems to be a “significant” and “characteristic” Portuguese response to delay active reaction (Nielsen et al., 2009). These Portuguese “characteristics”, as referred to by Nielsen et al. (2009) may impact the way Portuguese individuals cope with pain however little is known about this.

Fado also embraces a tension between inequalities in the power structure and the desire for equality (Nielsen et al., 2009). The Portuguese society seems to be responsive to dramatic and long-term struggles, defending that everyone should be treated equally under law. However, it holds a dialectic attitude towards power, with immense differences between what is done and what is valued (Moura, 2014).

Portugal has been classified as a “risk-averse country” (Nielsen et al., 2009, p.303), which may reflect a need for security and stability. Anecdotally, this Portuguese attitude seems to be present in several domains of the Portuguese society. For example, despite the lack of satisfaction with a specific health professional’s approach, a patient may still consult him/her. There seems to be a dynamic movement between resignation and revolution (Moura, 2014).

Considering that the way individuals cope with illness is deeply influenced by culture and context (Charmaz, 2000a), it is possible that the aforementioned aspects impact the way pain is experienced in Portugal. However, the absence of research in this area limits the understanding of how Portuguese individuals cope with their health problems, and more specifically with their pain.

3.3. An overview of health in the Portuguese context

3.3.1. The National Health System

The Portuguese health care system is organized around an NHS model, whose planning and regulation is developed by the Ministry of Health, with some increasing responsibilities delegated to regional bodies (Barros et al., 2011).

All residents, regardless of economic and social background, have access to the health care provided by the NHS (Barros & Simões, 2007; Sousa et al.,

2009; Monteiro, 2012). Patients contribute to in financing health care via co-payments and co-insurance. There are some health care services with associated fixed fees and a co-insurance scheme also exists for pharmaceutical products, with a fixed proportion paid by patients (Barros & Simões, 2007; Fernandes, 2011).

Since its creation in 1979, the Portuguese NHS has faced several challenges, such as difficulty in controlling costs related to an increase in health expenditure. In this context several measures in the health context have been implemented, with special emphasis on hospital, primary and continuous care networks (Barros et al., 2011). One of the most important was the establishment of a regime for the creation, organisation and finance of Groups of Primary Care Centres (ACES). In this context, Portuguese health centres were re-organized into ACES, which include Family Health Units, Public Health Units, Community Health Units, among others. Each unit is comprised of a team of physicians, nurses and health auxiliary technicians, physiotherapists, among others. Each team works together with the primary care centres and other units belonging to the same ACES (Barros et al., 2011).

3.3.2. The National Health Plan 2011-2016

In Portugal, the first health strategy was developed between 1996 and 1999. It was called “Health - a commitment: a health strategy for the turn of the century (1998-2002)” and was discarded due to lack of political support. As a consequence, in 2003, the first Portuguese National Health Plan for 2004-2010 (NHP 2004-2010) was widely discussed, which resulted in the definition of future strategic guidelines for that time (Directorate-General of Health, 2004).

Following the NHP 2004-2010 a new health strategy has been developed for 2011-2016. This has included clear guidelines for maximizing the population’s health gains through the combined efforts of all sectors of Portuguese society. This health strategy has mirrored a vision for health development for the year 2016 and it has been presented as the Portuguese National Health Plan for 2011-16 (NHP 2011-2016). It is a plan of action that defines priorities, strategic

guidance and targets to be reached from 2011 to 2016 (Directorate-General of Health, 2012).

Over the last year, the principles of the conceptual model that support the new NHP 2011-2016 have been at the centre of discussions. These discussions have brought new concepts to health planning in Portugal, such as health literacy and patients' empowerment, which may be indicative of efforts being made to move towards a more patient-centred model of care (Gonçalves et al., 2010; Directorate-General of Health, 2012). The quality of health care is another important issue that has been discussed, with emphasis on the importance of satisfaction with care, not only regarding the technical domain but also in terms of interpersonal relationships (Directorate-General of Health, 2012).

The central strategies for the development and implementation of the NHP 2011-2016 have included: (i) recommendations for improving patients' knowledge about their rights and duties; (ii) improving patients' trust in health services; (iii) implementing individualised care and including patients in the decision-making; (iv) implementing self-management programmes, through the empowerment of patients to manage chronic diseases; (v) promoting equity in the access to health care, via the improvement of communication among health services and the empowerment of citizens; (vi) implementing clinical guidelines; (vii) identifying health priorities and subsequent interventions, among others (Directorate-General of Health, 2012).

In order to implement the recommendations on the basis of the NHP 2011-2016, the reorganization of health networks as well as cultural changes in the way health is conceptualised have been considered as priorities (Directorate-General of Health, 2012).

Furthermore, the preventable nature of most of the Portuguese health problems and their tendency to increase have justified the need to develop action programmes that encourage the adoption of healthy lifestyles and reinforce the structural and environmental conditions favourable to health (George et al., 2007). Specific programmes have been developed in several areas, such as diabetes, healthy diets, mental health, AIDS prevention, among others.

Specifically, in 2013, a national strategic plan for prevention and control of pain was developed, with a three-year time frame (Directorate-General of Health, 2013). Chronic pain has been at the foremost of the priorities to be addressed between 2013 and 2016. Some of these priorities have included: the prevention of chronic pain, through the creation of a work group that defines a national plan for preventing the development of chronic pain; the development of specialised units in the treatment of chronic pain that includes, for example the development of a system that refers patients from the units in the NHS to these specific units; and, the development of recommendations for health professionals' education and training in the area of pain (Directorate-General of Health, 2013).

Since the NHP 2011-2016 and the national strategic plan for prevention and control of pain are still in implementation, no information is currently available regarding the assessment of both plans. However, the measures presented have highlighted the increasing recommendations to empower patients to participate in the decision-making as well as to improve the NHS approach to patients with chronic pain.

3.3.3. The National Health System responsiveness

Despite the attempts to improve the services provided by the Portuguese NHS, it continues to face problems such as mixed evidence regarding users of the health service and professionals' satisfaction with health care services. According to the World Health Organisation (WHO), the vast majority of comparable surveys on the Portuguese NHS responsiveness have not systematically addressed all important concepts, but have instead focused on overall impressions of satisfaction/ dissatisfaction (WHO, 2010). Despite this, it is important to note that overall satisfaction with the Portuguese health care system has been among the lowest in the EU.

As a consequence of the results expressed in the surveys, the WHO has produced strong recommendations to assess the expectations of the Portuguese NHS responsiveness, via surveys directed towards specific components of responsiveness and to health care providers (Barros & Simões, 2007). The last published analysis of the Portuguese health system's

responsiveness executed by the WHO indicated that although there were signs of improvement in the access to health services, the results of the surveys have demonstrated that both affordability and availability of services were still a concern (WHO, 2010)

In 2015, a survey on the experience of physicians in the context of the Portuguese financial crisis was published (Correia et al., 2015a). The sample included 3442 physicians from several specialities who completed and returned the survey. Overall, 80% of the respondents reported that the recent measures implemented in the scope of the financial crisis, have affected the quality of health care provided. Moreover, 85% considered that the Portuguese NHS cannot sustain any more reductions in the expenditure without compromising the quality of the health care provided and 14% felt under pressure to spend less with patients (e.g. in diagnostic tests) (Correia et al., 2015a).

With regard to the physicians' perspectives of the Portuguese access to health services, they perceived their practice to have been limited by patients' economic restrictions. More specifically, 70.3% reported that the patients have requested the prescription of cheaper medical drugs more frequently. In addition, 53.3% reported an increase in the patients' abandonment of treatment, which they considered to be motivated by economic reasons. Lastly, 58% reported that the patients have missed appointments or demonstrated difficulty in attending. Rehabilitation medicine was the medical speciality with the highest rate (84.5%) of abandonment indicated by the respondents (Correia et al., 2015a).

Recently, the Portuguese department of quality in health, from the Portuguese Directorate-General of Health published a report on the users of the health service' satisfaction with the NHS (Directorate-General of Health, 2015b). A total of 2300 individuals living in Portugal between 10th of February and 13rd of March of 2015 were interviewed by an independent polling company. Individuals from the five Portuguese regions were proportionally included. In all regions the most frequent responses were from those over sixty-five years. From the respondents, 56.2% reported that they had gone to primary care

health centres most frequently and 18.8% to public hospitals. With regards to satisfaction, 87.2% of the respondents reported to be satisfied with health care services, 83.1% stated that the services provided met their expectations and 90.7% considered that they received appropriate treatment (Directorate-General of Health, 2015b). In addition, almost all the respondents (95.5%) reported that they had not missed appointments due to the lack of transport. However, 36.7% waited for more than four weeks to have an appointment (Directorate-General of Health, 2015b).

Findings presented by the Directorate-General of Health (Directorate-General of Health, 2015b) appeared to diverge from the assessment of the WHO of the Portuguese NHS (WHO, 2010), which could be interpreted as a sign of improvement. However, given the current context of financial crisis, several authors have emphasised a negative impact on the Portuguese NHS (Coelho et al., 2014; Boquinhas, 2015; Correia et al., 2015b). The appraisal of findings from the previously analysed report published by the Directorate-General of Health (2015b) and the study by Correia et al. (2015a), revealed several contradictions between the physicians' perceptions of the impact of the financial crisis on patients' access to health services and the patients' reported impact (e.g. 95.5% of the users of the health services reported that they had not missed appointments due to the lack of transport, while 58% of the physicians reported that the patients had missed appointments or demonstrated difficulty in attending). The use of different samples may justify some of the contradictions found. Nevertheless, the problems regarding the assessment of the Portuguese NHS responsiveness identified by the WHO (2010) have persisted, since mixed evidence about the users' satisfaction regarding the health service and professionals within health care services have still been reported.

3.4. An overview of NSCLBP in the Portuguese context

3.4.1. The impact of NSCLBP in Portugal

In Portugal, research in the area of chronic pain, and in particular NSCLBP, is scarce, with only a few studies being published between 2000 and 2010 (Costa et al., 2004; Rabiais et al., 2004). These studies' findings should be interpreted

with caution since different definitions of low back pain were considered and several methodological problems were identified (e.g. convenience sample, the assessment of prevalence using self-reported questionnaires, with no confirmation from a physician).

Since 2010, research on the impact of chronic pain has increased. One of the first studies on the prevalence of chronic pain in Portugal was carried out under the scope of the Pain Proposal initiative (supported by the European Pain Federation of IASP Chapters) (Castro-Lopes et al., 2010). According to this report, there were 3 million people in Portugal who experienced chronic pain (the Portuguese population in 2010 was approximately 10.6 million) (Castro-Lopes et al., 2010; INE, 2012). The prevalence of chronic pain was estimated at 36%, with 16% of the respondents classifying their pain as moderate or severe (≥ 5 , in a numeric scale from 0 to 10). Of this percentage, more than 40% of the individuals suffered from LBP. Similar to other European countries (Breivik et al., 2006), chronic pain was more common in females and was more prevalent in the lower back region (Castro-Lopes et al., 2010).

Approximately 50% of the Portuguese respondents considered that pain moderately or seriously influenced housekeeping and professional activities, 4% had lost their job and 13% anticipated early retirement due to their pain. Similar to previous literature (McBeth & Jones, 2007), an association was identified between chronic pain and depression: 17% of the respondents with chronic pain were diagnosed as being depressed and 20% reported *“having no pleasure most of the time or always”* (Castro-Lopes et al., 2010).

The prevalence of depression in the Portuguese population attending primary care health services varied between 5.04% in the south of the country to 9.73% in the centre, in 2014 (Directorate-General of Health, 2015c). The analysis of the previously mentioned reports (Castro-Lopes et al., 2010; Directorate-General of Health, 2015c) may be indicative of the impact of depression in the Portuguese population with chronic pain. However, a direct comparison between them cannot be established, as while the first report, by Castro-Lopes et al. (2010), focused on Portuguese population in general, the second report, by the Directorate-General of Health (2015c), focused on those attending

primary health care services. Moreover, in this latter report a characterization of the participants' medical information was not provided, thus the sample may include individuals experiencing chronic pain.

Castro et al. (2010) also emphasised the economic burden of chronic pain in Portugal: individuals with chronic pain had on average fourteen days of sick leave per year, which represented a cost of €290 million (approximately £232 million) sustained by social insurance. In agreement with data from other European countries (Breivik et al., 2006), patients' journeys in the health system seemed to be difficult, lengthy and ineffective. Approximately 35% of the Portuguese individuals with chronic pain considered their pain to have been ill-managed and justified this with the inappropriate prescription of medication as well as the lack of attention and knowledge of the health professionals (Castro-Lopes et al., 2010).

This report provided important insights into the prevalence of chronic pain at a national level. At the heart of these findings is the strong recommendation that the authors have already established concerning the need to develop research in Portugal, which focused on chronic pain in order to improve the quality of health care services as well as health professionals' training (Castro-Lopes et al., 2010). These findings drew attention to the need to develop effective responses to this health problem and to transform it into a priority for the Portuguese Health Services.

From 2012 up to the present, the number of studies focused on the Portuguese population as well as its methodological quality has significantly increased. Azevedo et al. (2012) conducted a cross-sectional nationwide epidemiological study in a sample of the Portuguese adult population, which aimed to describe the prevalence and impact of chronic pain. The sample included 5094 individuals that were selected by random digital dialling. The prevalence of chronic pain was 36.7% (95%CI: 35.3-38.2), considering the definition provided by the IASP (Azevedo et al., 2012).

The findings demonstrated that chronic pain is a relevant problem in Portugal, since it affects a considerable proportion of the population for long periods of time and represents a high burden for the affected individuals and society. More

specifically, pain duration was found to last for an average of ten years, with 25% reporting a duration of more than twenty years. Pain intensity was classified as moderate-to-severe in 68% of the subjects. Additionally, the lumbar region and limbs were the most affected regions and represented two-thirds of the subjects (Azevedo et al., 2012).

With regard to disability, 35% of the subjects reported moderate-to-severe disability. The highest disability rates were found in relation to family/home responsibilities, recreational activities, occupation/work and sleep/rest. Specifically, 49% of the subjects reported that pain affected their professional life. In the preceding six months, they had missed an average of 4.36 working days and 9% had missed more than ten days. The major consequences reported were job loss, an alteration in professional responsibilities, and a change of profession/job, early retirement as well as long-term sick leave (Azevedo et al., 2012).

This study provided important information regarding the prevalence and impact of chronic pain in Portugal. Although it had higher methodological quality than the vast majority of the studies carried out in Portugal until this date, it also had some limitations that should be addressed. For example, there was some overrepresentation of females and the middle-aged, which are common biases in population-based studies.

In a further paper, the same authors undertook an investigation that aimed to describe patterns and determinants of the use of health services by Portuguese individuals with chronic pain. This investigation was focused on medical consultations, diagnostic tests, pain medicine and the use of nonpharmacologic treatment methods (Azevedo et al., 2013b).

This study's findings demonstrated a high level of the use of health services by Portuguese individuals with chronic pain. Only 19% (95%CI: 17.1-21.2) of the subjects reporting chronic pain were not being treated by a health professional. The pain-related disability, pain intensity and duration as well as depression were the most relevant factors that predicted medical consultations (Azevedo et al., 2013b).

General practitioners and private physicians were the health professionals most reported to be treating chronic pain. On average, the number of consultations with these professionals in the preceding six months was 2.28 and 1.87, respectively. Only a minority (1%) of individuals were being treated by a pain medical specialist. Despite a significant proportion of the individuals having reported an average duration of pain for ten years, 50% of them were prescribed diagnostic tests (such as radiography, computed tomography or magnetic resonance) in the preceding six months (Azevedo et al., 2013b).

This was the first study in the Portuguese population that provided detailed information regarding the use of the health services in chronic pain individuals. It also provided important information regarding the main reasons behind the use of the health services. The findings regarding the use of diagnostic tests suggested an overuse and drew attention to the need to follow the existing guidelines more closely (Azevedo et al., 2013b).

In 2016, the same authors went on to explore the total annual direct and indirect costs associated with chronic pain in Portugal (Azevedo et al., 2016). They reported that the annual direct costs per chronic pain individual were €807.37 (95%CI: 744.50-894.60) (approximately £640.44), while the indirect costs were €1.083,30 (95%CI: 1.605,00-1.367,00) (approximately £859.48). Furthermore, the extrapolation for the Portuguese population amounted to a total of €4612 million (95%CI: 3.930,00-5.362,71) (approximately £3659) for direct (42.7%) and indirect (57.3%) costs, which corresponded to 2.71% of the Portuguese gross internal product. It is important to consider that these results are possibly underestimated, since some relevant sources of indirect costs (such as family and carers productivity loss) were not considered (Azevedo et al., 2016). These findings were consistent with estimates from the only additional Portuguese study that looked specifically at indirect costs of CLBP in Portugal (Gouveia & Augusto, 2011).

Although Azevedo et al. (2016) found some associations between the total annual chronic pain costs in Portugal and demographics, socio-economic factors, pain location and psychological distress, only age, professional status and level of education had a significant and independent association. This

strengthened the hypothesis of there being inequalities in the distribution of healthcare resources in relation to socio-economic factors in Portugal.

Gouveia et al. (2016) focused specifically on the prevalence of active CLBP in the Portuguese population. In the context of this study, active CLBP was defined as a self-reported LBP present on the day of the interview and that was present most of the time for at least ninety days. This study was part of a national and cross-sectional study conducted in Portugal between September 2011 and December 2013. From the 10661 individuals interviewed, 1487 self-reported active CLBP. The prevalence of active CLBP in the adult Portuguese population was 10.4% (95%CI: 9.6-11.9), which represented a relevant proportion given that the estimates from previous studies included a range of conditions related to chronic pain (for instance, Azevedo et al., 2012).

Additionally, this study also provided information regarding the average age of the active CLBP population, which was 58.9 (SD 17.2) years. It was more prevalent among women (14.1 vs 6.3% in men) and individuals living in small towns (<2000 inhabitants) appeared to have a higher occurrence of active CLBP (47.8%). The educational level of 59.8% of the individuals was low (0-4 years) (Gouveia et al., 2016).

Regarding pain, the individuals reported a mean intensity of 6.0 (SD 2.14), on a 0-10cm scale. In the preceding 12 months, 97.7% had LBP and reported an average of 233 (SD 187.15) days with pain that prevented them from performing their daily life activities for an average of 45.4 (SD 12.58) days.

Additionally, 63.1% had already sought medical care and 75% had already used analgesics or other pain relief drugs. In the preceding twelve months, 30.6% visited a doctor, ≥ 7 times; 14.3% were hospitalized and 23.3% asserted they were searching for complementary treatments. The self-reported average treatment was 142.3 (SD 384.43) days.

This study provided the first insights into the prevalence of CLBP in the Portuguese at a nationwide level. Besides the high prevalence of CLBP, a range of issues emerged from this study and seems to deserve further exploration, such as the low educational level of CLBP individuals and its possible impact on seeking health care. Additionally, this study also indicated a

high level of consumption of health care resources; however, little information was collected regarding this topic. The reported disabling impact of active CLBP may also raise questions regarding its impact on CLBP individuals' occupations/jobs, however no information regarding this was provided.

Despite the limited number of studies carried out in Portugal, the existing studies that have been conducted in the last few years have supported the relevance of NSCLBP in this country. Since research in Portugal has been particularly focused on the epidemiological impact, little is known about the contextual factors that may contribute to this phenomenon. However, some international studies (for instance, Verbeek et al., 2004; May, 2007; Darlow et al., 2014) may support the argument that the Portuguese patients' beliefs and attitudes could be an important contributing factor to the dimension and impact of NSCLBP. Additionally, Portuguese research has suggested that health professionals' approaches to NSCLBP may possibly be a contributing factor to this phenomenon (Castro-Lopes et al., 2010).

3.4.2. Typical journeys of patients with NSCLBP in Portugal

Recent literature has highlighted the patients' multiple journeys in the Portuguese NHS (Andreazza, 2015). Andreazza (2015) argued that Portuguese individuals' journeys in the NHS are complex and combine several circuits that are established by the individuals, who eventually develop new pathways for healthcare distinct from those established. In this context, the Portuguese individuals' experiences of healthcare constitute a source of learning and understanding about the NHS. A significant part of this learning is developed by trial and error, through observation in the waiting rooms or through contact with patients' social networks. There seems to be two reasons that justify the aforementioned alternative pathways: the prolonged waiting time for an appointment with a specialist in a hospital or for a diagnostic test; or, the severity of the clinical condition (Andreazza, 2015).

Thus, Portuguese individuals tend to go to NHS and private practice interchangeably. For example, in order to obtain a quicker response patients go to a private practice physician a couple of times and then ask the physician to

enable their attendance of public services. Another reason in seeing a specialist in private practice is related to the Portuguese individuals' perceptions that in this context the physician has more time to provide explanations and look at patients (Andreazza, 2015).

Some Portuguese individuals judge the physicians' performance and may abandon treatment if it does not meet their expectations. They search for second opinions and use the Internet to understand their health problems. On the other hand, some continue going to the same services despite reporting that they have not received appropriate treatment (Andreazza, 2015).

Evidence of the typical journey of a patient with NSCLBP in Portugal is quite limited. The aforementioned report developed under the scope of the Pain Proposal initiative provided little information about the journey of Portuguese individuals with chronic pain through the NHS (Castro-Lopes et al., 2010). According to the results of this report, individuals with chronic pain tend to seek health care in primary care centres from the NHS (Castro-Lopes et al., 2010). However, it is important to take into consideration that there is no information about their uptake of private health care.

The vast majority of individuals with chronic pain, who seek help in the NHS, see their general practitioners first and these then make the decision about the need for a referral to another health professional. The diagnosis and the referral to another health professional can take a long time. The vast majority of patients are successively referred to different health professionals, without having any positive consequence. This seems to be justified by the lack of competences and specialist training of the health professionals as well as by the management of the health services (Castro-Lopes et al., 2010).

Portuguese individuals with chronic pain consider the access to health care difficult and the process of diagnosing and referring prolonged (Castro-Lopes et al., 2010). Approximately 35% of Portuguese individuals with chronic pain consider that their pain is not treated and controlled adequately and affirm that the main reasons for this are the inefficacy of medication prescribed and the lack of the physicians' competence in managing their pain (Castro-Lopes et al.,

2010).

The existing information suggests long and inefficient journeys for the individuals with NSCLBP throughout the NHS, which have a significant impact not only on individuals and their families, but also on the costs of health sustained by the Portuguese government (Castro-Lopes et al., 2010).

3.4.3. Health professionals` approach to patients with NSCLBP in Portugal

Research concerning health professionals` identity and values is quite limited in Portugal and little is known about health professionals` approaches to patients with NSCLBP. Nevertheless, health care seems to be influenced by the traditional biomedical model of care (Cruz et al., 2012a) .

A study by Cruz et al. (Cruz et al., 2012a) on the clinical reasoning of Portuguese physiotherapists highlighted their focus on identifying the origin of patients` clinical problems and treating the source of pain. The authors described Portuguese physiotherapists` clinical reasoning approach as a cognitive centred process in opposition to an interactive and person-centred approach (Cruz et al., 2012a). Based on this study`s findings, the authors suggested that the physiotherapists` approaches to patients were consistent with the biomedical model of care, which valued the understanding of the clinical condition over the person (Cruz et al., 2012a).

This study`s findings are supported by the information provided by a report developed under the scope of the NHP 2011-2016 (Gonçalves et al., 2010). According to this report, Portuguese individuals would like to be more involved in the decision-making concerning their health and obtain more information from health professionals about diagnosis, alternatives for treatment, and medication, among others. The six Portuguese families interviewed reported that, in general, they do not receive any information from health professionals and are not involved in the decisions about their health. Furthermore, they highlighted that the health care provided is not directed towards their specific needs (Gonçalves et al., 2010).

In this context, it is important to consider research carried out internationally, which has emphasised that health professionals' approaches may contribute to developing or maintaining patients' disability (Rainville et al., 2000; Houben et al., 2005; Coudeyre et al., 2006; Corbett et al., 2009; Darlow et al., 2012). This seems to be particularly relevant in the area of chronic pain, where the adoption of the biopsychosocial model of care has been consistently recommended (Harland & Lavalley, 2003; Sanders et al., 2013; Kamper et al., 2014). According to the research carried out in this area, physiotherapists whose approach to individuals with chronic pain is based on the biomedical model of care, tend to ignore the growing evidence regarding the influence of psychosocial factors in chronic pain and associated disability. As a result, they explain chronic pain and its impact through physical injury related to sensory input, which promotes inadequate beliefs and behaviours that contribute to the development or perpetuation of chronic pain (Daykin & Richardson, 2004; Houben et al., 2005; Sieben et al., 2009). Thus, the possible influence of the biomedical model on the Portuguese health professionals approach has to be considered.

Recently, a study carried out on the Portuguese physiotherapists' approaches to the treatment of patients with CLBP demonstrated that more than 40 combinations of treatment modalities were employed, which demonstrated the high variability in the approach to Portuguese CLBP patients (Moniz, 2012). More specifically, a prospective cohort study with a sample of 30 physiotherapists and 119 individuals with CLBP was undertaken. The individuals with CLBP were treated in a variety of contexts, such as in primary care centres, public hospitals, private practice or via household physiotherapy (Moniz, 2012). According to this study's findings, exercise was the most frequent treatment (with a frequency that ranged from 77.3%, to 82.4%, and 75.6%, during six weeks of biweekly assessments) (Moniz, 2012). Electrotherapy was the second most frequently used treatment modality (with a frequency that ranged from 68.1%, to 67.2% and 58.8%, during six weeks of biweekly assessments) (Moniz, 2012).

Finally, education/information/advice was the third most frequent approach in the first two weeks of intervention (63%). In the following four weeks, manual therapy alone became the third most frequently approach (with a frequency that ranged from 63.0% and 52.1%, assessed biweekly) (Moniz, 2012).

Findings from this study (Moniz, 2012) indicated that although Portuguese physiotherapists' approaches to treatment of individuals with CLBP were supported by guidelines that have recommended exercise and education, a considerable proportion of physiotherapists used electrotherapy which was not in line with current recommendations for clinical practice (for instance, Savigny et al., 2009; Dagenais et al., 2010; Delitto et al., 2012). In addition, there was no information regarding the specific approaches to exercise or education and, thus a full understanding of the models of practice that orientate the physiotherapists' approaches to patients with NSCLBP cannot be attained.

The prior scenario seems to be coherent with the position adopted by the Pain Proposal Steering Committee of the Pain Proposal initiative, concerning Portuguese health professionals approach to chronic pain. According to this committee, Portuguese health professionals' education in the area of chronic pain is very limited in what concerns its management (Castro-Lopes et al., 2010).

In addition, the WHO's recommendation to improve the quality of health care services in Portugal via health professionals' education (WHO, 2010) seems to be coherent with the aforementioned scenario.

3.5. Reflexive account

Providing a clear perspective of the specificity of the Portuguese context has been a great challenge. As a Portuguese individual, this has required me to observe and interpret my own context from a different perspective. Trying to look at the Portuguese context as an outsider enabled me to question and reflect on Portuguese attitudes, beliefs and behaviours regarding several aspects of reality. Being a PhD student in the UK has facilitated this process, since it has increased my sensitivity to the cultural impact on people's lives. I

found myself immersed in the comparisons between the culture, habits and the meaning of health in both countries. These comparisons helped me to realise that when compared to the British NHS (founded in 1948), the Portuguese NHS is quite recent (founded in 1979) (Carmo, 2012). Thus, although Portugal could benefit from the experience of other countries, the particular social and cultural context needed the development of a NHS that may fit into this context and respond to the Portuguese individuals' specific needs. Nevertheless, despite the investments in the development of the Portuguese NHS, there seem to be several aspects, which remain poorly understood.

Regarding chronic pain, the first national survey on the prevalence of chronic pain was published in 2010 (Castro-Lopes et al., 2010). Since 2012, a number of studies have been published on the prevalence and impact of chronic pain in Portugal (for instance, Azevedo et al., 2012; 2013b; 2013a; 2016) and one study in particular (Gouveia et al., 2016) specifically explored the prevalence of CLBP. Thus, when I proposed the current study I had an overall idea of the possible impact of chronic pain in Portugal based on the aforementioned survey published in 2010. However, my understanding regarding the impact of chronic pain in Portugal, and specifically CLBP, has become considerably more consolidated in the last few years. Indeed, the Portuguese studies published since 2012 have strengthened the relevance of carrying out the current study in the Portuguese context.

Although the focus of this study was not on the Portuguese culture *per se*, detailed information about the Portuguese context was considered fundamental in order to enable readers to assess the transferability of this study's findings. I aimed to provide a detailed picture of Portugal, however I had not anticipated such an absence of research on the Portuguese context. Indeed, the first versions of this chapter (developed in 2010-2011) were mainly based on a significant amount of anecdotal information. However, several research studies have been carried out in Portugal between 2010 and 2016 that have had relevance to my study. This increase of research regarding the Portuguese context had an important contribution to my approach to this study, since it

reinforced my motivation to develop knowledge about how Portuguese individuals make sense of NSCLBP.

Several aspects emerged from the analysis of the literature regarding the Portuguese context, such as the value of human relationships over task achievement, the contradictory attitudes towards practices and values regarding power, and the dynamic relationship between fatalism and perseverance (Nielsen et al., 2009; Coelho, 2010; Moura, 2014). Indeed, all of these aspects seem to be deeply immersed in the Portuguese culture, maybe at a subconscious level, and may influence Portuguese people's attitudes, beliefs and behaviours. Thus, they may have an important impact on the way Portuguese individuals experience NSCLBP. My reflections on this literature attained major relevance in this study, since it helped me to become aware of several aspects that are part of a Portuguese individual's daily life. This process helped me to improve my ability to explore the accounts of the participants included in this study in more depth.

Accordingly, I found the scenario presented coherent with the recommendations from national and international bodies to invest in health professionals' training and on research concerning chronic pain. The combination of all these factors makes this an appropriate time to engage in research concerning NSCLBP in a Portuguese setting.

3.6. Chapter summary

An overall perspective of the Portuguese reality has been provided in this chapter. An overview of the Portuguese NHS has been provided, with particular emphasis on research on the prevalence of chronic pain and NSCLBP.

In the next chapter, the methodological approach used to study the overall concept of NSCLBP in the Portuguese setting is addressed.

Chapter 4: Methodology

This chapter consists of seven sections in which the study's methodology is presented. Firstly, the research question addressed in this study as well as the research aims are provided. In the second section, philosophical considerations for this study are presented, with particular emphasis on the use of the interpretive paradigm and the epistemological and ontological position adopted. In the third section, the theoretical position is addressed and phenomenology and hermeneutics are considered. In the fourth section, IPA is presented as the methodological approach to this study and its strengths and limitations are explored. In the fifth section, considerations regarding data collection are presented. In the sixth section, the importance of reflexivity in this study is examined. Finally, the seventh section includes a reflexive account, in which the position of researcher in this study is particularly explored.

4.1. Research question and aims

The research question addressed in this study was: what are the experiences and perceptions of Portuguese individuals with NSCLBP?

This study aimed to explore the overall concept of NSCLBP in a Portuguese setting. Specifically, the research aims were: (i) to explore the experiences of participants with NSCLBP disorder; (ii) to explore how participants with NSCLBP disorder understand and make sense of their condition.

4.2. Philosophical considerations

4.2.1. Research paradigms - Interpretivism

A research paradigm is "made up of the general theoretical assumptions and laws, and techniques for their application that the member of a particular scientific community adopt" (Chalmer, 1982, p.90). Thus, a paradigm involves a world view that guides research and practice in a field (Willis, 2007f). It explains theoretical assumptions, states ways of applying these assumptions and emphasises metaphysical principles and methodological orientations on how to conduct work (Chalmer, 1982; Kuhn, 2009a).

Some authors focus the discussion about research paradigms around the idea that there are two paradigms – quantitative and qualitative. This point of view seems to oversimplify the discussion about research paradigms, by emphasising data rather than foundational beliefs and assumptions as the core elements that distinguish paradigms (Lincoln & Guba, 2000; Willis, 2007f). The precise number and development of paradigms, as well as the names associated with them, diverge from author to author. The most commonly referred to paradigms of social science research - postpositivism, interpretivism or critical theory - have taken separate paths, in the sense that they have constituted responses to different problems throughout history and have adopted different ways of addressing these problems (Kuhn, 2009b). Because these paradigms were influenced by the cultures in which they were developed, they defend different assumptions about the nature of truth, which determine their conceptions of research (Lincoln & Guba, 2000; Willis, 2007d).

The nature of the research question and aims addressed in this study required an approach located within the interpretivist paradigm, whose foundational assumptions and beliefs are presented in the following paragraphs.

The interpretivist paradigm argues that there is not an independently knowable world as positivists and postpositivists argue, rather, a core position of this paradigm is that meaning is socially constructed (Crotty, 1998b; Finlay, 2006). Thus, there are multiple meanings constructed by human beings as they engage with the world they are interpreting (Crotty, 1998b; Willis, 2007d). These subjective meanings are not simply imprinted within the individuals but are constructed by interacting with others and through historical and cultural norms that operate in the individuals' lives (Crotty, 1998b). These interpretivists' assumptions have important implications on the purpose of research carried out under the influence of this paradigm. Whereas the positivist research looks for universal laws and rules, the purpose of the interpretivist research is to develop an understanding of a particular situation or context (Willis, 2007a; 2007e; Petty et al., 2012). Interpretivist researchers tend to focus on interactions between individuals and the specific contexts in which they live and work. The understanding of contexts in which research is conducted is crucial to the

interpretation of the data collected highlighting the importance of contextualization of knowledge.

Moreover, interpretivists argue that there is no truly objective form of research (Willis, 2007e). Thus, all research is influenced and shaped by the pre-existing theories and worldviews of the researchers. Findings emerge from the interactions between both the researcher and the participants as the research progresses (Creswell, 2003; Crotty, 1998c; Willis, 2007e).

Research carried out under the influence of interpretivism contributes to developing our understanding of different contexts and situations, which is not an understanding of the “right” way of considering a particular situation but an understanding of multiples perspectives on the topic (Willis, 2007e).

In coherence with the interpretive paradigm, in this study the researcher was focused on developing a deep understanding about the interactions between participants with NSCLBP and their personal contexts in making sense of their disorder (Crotty, 1998b; Willis, 2007e; Petty et al., 2012). Throughout this process it was assumed that the researcher’s interpretations about the reality had an important role in data collection and analysis.

4.2.2. Epistemological and ontological position

Research paradigms address assumptions about the nature of reality (ontology) and knowledge (epistemology) that distinguish them (Finlay, 2006; Creswell, 2007b).

More specifically, epistemology addresses knowledge construction and involves a specific understanding of what is entailed in knowing (Finlay, 2006; Creswell, 2007b; Petty et al., 2012). It is defined by Crotty (1998b, p.3) as “the theory of knowledge embedded in the theoretical perspective and thereby in the methodology”. It constitutes an important foundation for research, by referring to what it is possible to know about reality and how it is possible to know it (Finlay, 2006; Willis, 2007f). There is a range of epistemologies that support reflection about the knowledge produced through a specific research approach, such as objectivism, subjectivism or constructionism (Crotty, 1998d).

Ontology refers to “the study of being” (Crotty, 1998d, p.11). It is concerned with the nature of reality and addresses issues about what can exist or what is real

(Finlay, 2006; Creswell, 2007b). Different ontological positions, such as realism (which states that reality exists out of the mind) (Crotty, 1998d), idealism (which argues that reality is confined to what is in the mind) (Crotty, 1998a), relativism (which asserts that the perceived reality is always influenced by experiences and culture) (Willis, 2007a), and rationalism (which considers thoughts and reflections as essential elements to know reality) (Willis, 2007a), reflect the diversity of theoretical perspectives about reality.

Epistemological and ontological position determines the overall perspective from which a research study is designed and carried out (Krauss, 2005). When a research study is conceptualized both epistemological and ontological issues emerge together (Crotty, 1998d).

This study was conducted through the lens of the constructionism view of knowledge as well as the relativism and realist ontology. The rationale for this decision is presented in the following paragraphs.

4.2.2.1. Epistemological position adopted in this study

Constructionism contends that knowledge is socially constructed and has a historical and cultural location (Crotty, 1998a; Young & Collin, 2004; Willis, 2007f). According to this perspective knowledge is constructed through social processes and interaction rather than through individual and cognitive processes. Consequently, the focus of enquiry should be on interaction between individuals and their contexts (Crotty, 1998a; Young & Collin, 2004; Willis, 2007f).

It is important to connect these ideas with this study. The view of the pain phenomenon adopted in this study accepts that pain is deeply influenced by context. In coherence with constructionism, when the researcher asked participants about their experiences, it was assumed that these experiences took place in a specific context and were influenced by the values embedded in this context.

Moreover, constructionism state that knowledge is constructed through engagement with the individual's reality. Thus, subject and object emerge as partners in the construction of meaning, which means that different people may

attribute different meanings, even in relation to the same phenomenon (Crotty, 1998a). In this study, the researcher engaged with the individual's reality by exploring the accounts of Portuguese individuals with NSCLBP disorder. The knowledge produced was the product of this engagement. It is unique, in the sense that it resulted from a co-construction of meaning between both the researcher and the participant (Crotty, 1998a; Willis, 2007e).

4.2.2.2. Ontological position adopted in this study

The epistemological position presented seemed to be coherent with an ontological position that postulates reality as socially constructed. Relativism claims this vision about reality, by emphasising that there are as many realities as the individuals' experiences and interpretations (Crotty, 1998a). This ontological position highlights the possible divergent interpretations of the same phenomena, depending on the historical and cultural frameworks (Crotty, 1998a; Finlay, 2006).

Although the relativist ontology has been more frequently related to the constructionism view of knowledge, some authors suggest that realism is also coherent with this epistemological position (Crotty, 1998a; Willis, 2007d). The existence of an external reality (prior to our experience of it) asserted by realism is not denied by constructionism. However, what constructionists seem to disagree with is the assumption of an independently knowable reality. Rather, they emphasise that a meaningful reality emerges only when human beings engage with the reality they are interpreting (Crotty, 1998a; Willis, 2007d).

When considering the implications of both relativism and realism in this study, it is important to emphasise that a description of the reality that is "out there" was not expected. Rather, the researcher was focused on reporting how the reality, in this case the experience of NSCLBP, was meaningfully constructed by the individuals engaged with it in a given community, in this case the Portuguese context.

4.2.2.3. Rationale for the epistemological and ontological position adopted in this study

The rationale for choosing the interpretive paradigm underpinned by the constructionism view of knowledge, as well as the realist and relativist view of reality was closely related to the nature of the phenomenon under investigation as well as the scope of the research question that informed this study. The view of the pain phenomenon adopted in this study (chapter 2) highlights the importance of interpretation of a pain experience, which constituted the main focus of the research question of this study.

According to the research carried out in this area, the patients' cognitions, which include what they think and how they make sense of pain, influence their response to it (Main & Waddell, 2004). Simultaneously, the behaviour demonstrated by the individual at any point in time is the product not only of their beliefs but also of their social environment, in which the behaviours take place (Main & Watson, 1999; Main & Waddell, 2004).

Several authors have suggested that the way people react to pain and to treatment seems to be closely related to psychological and social factors. Thus, cultural values embedded in each society have a significant influence on individuals' interpretation and response to pain (Main & Watson, 1999; Main & Waddell, 2004). The analysis of these assumptions highlights pain as a socially constructed phenomenon, influenced by both individuals' interpretations and cultural contexts.

4.3. Theoretical position

4.3.1. Phenomenology

Phenomenology is considered a philosophical approach to the study of experience. In its pure form, the focus of phenomenology was consciousness, since it defended the study of "things themselves", i.e. the study of phenomena as they are immediately presented to human beings (Crotty, 1998b, p.78). It was based on the assumption that subjects of social sciences have consciousness while the subjects of natural sciences do not (Crotty, 1998b). Phenomenologists distinguished between "*the real thing that exists in our world*"

and “*our perception*” and its focus was on the perceived thing (Willis, 2007b, p.172). This perception of an external object was assumed as partial and subjective and did not mirror the object/ reality. Existentialists extended these assumptions to human existence, as a subjective experience (Willis, 2007b). In this sense, the phenomenological research is structured upon descriptions of experiences as they are lived by individuals. Its purpose is to understand the meaning a consciousness individual has developed (Willis, 2007b).

There are two main schools of phenomenology, one that follows the descriptive tradition and another that follows the interpretive tradition. These schools are based on different philosophical assumptions, which have a crucial impact on methodological decisions, and consequently in the generation of research findings (Lopez & Willis, 2004). Despite the aforementioned differences, phenomenologists, following both the descriptive and interpretive traditions, share an interest in thinking about the experience of individuals, and provide a framework on how to examine the lived experience (Smith et al., 2009f).

As was mentioned above, phenomenology is considered a philosophical movement, which means that several scholars have influenced it. Husserl was one of the most influential phenomenological philosophers. His ideas gave rise to a descriptive phenomenological approach to enquiry (Lopez & Willis, 2004). Husserlian phenomenology defended that it was essential for the researcher to shed all prior personal knowledge in order to grasp the essential lived experience of those being studied (Lopez & Willis, 2004). This meant that the impact of the researcher in the inquiry should be constantly assessed and biases and pre-conceptions should be neutralised so that did not influence the object of study (Lopez & Willis, 2004; Smith et al., 2009f). It is questionable if this is possible to achieve. In fact, Heidegger (1996) challenged the possibility of any knowledge outside of an interpretive framework. Indeed, it could be questioned whether researchers can put their beliefs and preconceptions aside in order to concentrate on and apprehend the phenomenon under investigation. Thus, while Husserl supported a descriptive phenomenology where the researcher should adopt an external position and a descriptive approach to data analysis, Heidegger advocated an interpretive phenomenology where researchers need interpret data in order to produce meanings (Lopez & Willis,

2004; Smith et al., 2009f). Thus, Heidegger`s ideas moved phenomenology from a descriptive tradition to an interpretive, or hermeneutic research tradition (Lopez & Willis, 2004), which is further explored in the following section.

4.3.2. Hermeneutics

Hermeneutics represents the theory of interpretation and was originally used for the interpretation of biblical texts. It started as an entirely separate body of thought and its roots are much older than phenomenology (Lopez & Willis, 2004). Hermeneutics is concerned with the methods and purposes of interpretation and advocates that it is not possible to dissociate the researcher`s perspective from data analysis (Crotty, 1998c).

Besides Heidegger, several authors must be considered, such as Gadamer, in order to understand the hermeneutics movement (Smith et al., 2009f). The main ideas of Gadamer (2004) are summarised in the following paragraphs, as they have had a major influence on this study.

Gadamer emphasised the notion of historical awareness as something necessary for a hermeneutical understanding. According to him, we are all part of history and consequently the understanding needs mediation between past and present. In this process, we bring together the horizon of the past and the horizon of the present, contributing to the fusion of horizons (Crotty, 1998c). The fusion of horizons is a key concept in Gadamer`s hermeneutics and constitutes the means through which *“we regain the concepts of a historical past in such a way that they also include our own comprehension of them”* (Gadamer, 2004, p.367). In this context, the past horizon represents the researcher`s knowledge at the start of the study. The fusion of horizons occurs when new knowledge is gained by interpreting data collected throughout the study, resulting in a deep comprehension of the phenomenon (Willis, 2007c).

In this fusion of horizons, the interpreter`s own horizons are decisive and carry certain historical “prejudices”. In this context, the word “prejudice” does not have the negative connotation of its modern usage. Instead, here its meaning is concerned with pre-understandings. Gadamer argued that understanding is only

possible through pre-understandings. If they are not considered, there is a risk of failing to understand or to misjudge meaning (Gadamer, 2004).

For Gadamer, the starting point of understanding is not the autonomous individual self, but the tradition in which we are integrated. From this starting point, the movement of understanding happens throughout a circular movement, called the hermeneutic circle. In this hermeneutic circle understanding is gained by alternating between considering a phenomenon as a whole and as something composed of individual parts. When the phenomenon is considered as a whole, the integration of individual parts in order to create and define the entire experience is recognised. Simultaneously, when the phenomenon is viewed in terms of individual parts, the importance of the whole in contextualizing or illuminating each part is recognised (Willis, 2007e). The researcher's task is in expanding understanding throughout this circular movement by moving from the whole to the part and from the part to the whole (Crotty, 1998c; Smith et al., 2009f). According to Gadamer, understanding could emerge only through deep immersion in the text, by repeated readings and repeated asking and answering questions to gain information that explores new directions and possible answers (Gadamer, 2004).

4.4. Introducing methodological approach

Four qualitative approaches were considered for this study: grounded theory (GT), narrative analysis (NA), thematic analysis (TA) and interpretative phenomenological analysis (IPA).

All these approaches may address questions of meaning and understanding, and thus all have some similarities regarding the general process of research, such as the methods of data collection employed (for example interviews, focus groups, observations, documents or audiovisual materials). However, there are differences among them regarding their overall purpose, as well as the nature of the research questions addressed, the assumptions about participants' recruitment, and the focus of data collection and analysis (Creswell, 2007a). This diversity may be seen as an advantage because it allows the researchers

to study the same phenomenon from different perspectives. This diversity of approaches offers a range of options to study the phenomenon under investigation, enabling the researcher to select the approach that best suits the research purpose.

The methodological approach adopted in this study was Interpretative Phenomenological Analysis (IPA). Before discussing the rationale behind the use of IPA, a brief overview of the possible alternative approaches is presented in the following sections

4.4.1. Brief overview of possible methodological approaches

4.4.1.1. Grounded theory

GT comprises a set of differently situated inquiry methods that have been developed since its conception in the 1960s by Glaser and Strauss (Creswell, 2007a). Nevertheless, all the methods provide strategies for the development of a theory from the data (Charmaz, 2000b; Charmaz & Henwood, 2008). The goal of GT is to go beyond the description of the individual's experience and develop an explanatory theory of social processes (Creswell, 2007a). According to this approach, theory emerges from the data - it is "grounded" in the data - as a result of inductive and deductive thinking undertaken by the researcher (Starks & Trinidad, 2007). Through this approach, the researcher generates a general theory of a phenomenon shaped by the views of several participants (Creswell, 2007a).

Researchers following this approach are focused on inquiring how social processes influence the way a specific phenomenon is accomplished. Therefore, it aims to explore multiple dimensions of the social processes under investigation, which implies the recruitment of participants with different experiences of the same phenomenon (Creswell, 2007a). Thus, it requires engagement with multiple samples in order to explore the range of constructs that support a theory. It also involves a constant-comparative process of data generation, data analysis and theory development (or refinement) (Starks & Trinidad, 2007).

Taking into account the purpose of this study, GT was considered in terms of potential strengths and limitations. Thus, the provision of specific guidelines on how to carry out research, the systematic approach to data analyses as well as the derivation of original findings from data analysis through creative and inductive processes were identified as strengths (Charmaz, 2000b; Smith et al., 2009d; Hussein et al., 2014). Nevertheless, its focus on generating a theory on a social phenomenon or process and the subsequent required large samples were seen as limitations (Charmaz, 2000b).

Considering that the purpose of this study was to develop a deep understanding of Portuguese individuals' experiences of NSCLBP and not to generate a theory on this topic, GT was considered an unsuitable methodological approach. Besides, its focus on social processes rather than on the individual's experiences reinforced its inappropriateness in addressing the research question that informed this study.

4.4.1.2. Narrative analysis

As with GT, different methods of NA enquiry have been developed according to the researchers seeking different uses of this approach (Frost et al., 2010; Silver, 2013). Despite being conceptualized in many different ways, narrative research studies the individuals' experiences in the world, by capturing the detailed stories or life experiences of a small number of individuals or of a single life (Clandinin, 2006; Creswell, 2007a).

NA was also considered as a potential methodological approach for this study. Its emphasis on exploring meaning-making through people's stories was identified as a potential strength. However, its focus on the story *per se* may not address the research question of this study (Silver, 2013). NA is concerned with how a story is constructed and why it is told in a particular way (Riessman, 1993). Depending on the research question, the attention of NA can be directed to content, structure, linguistic devices, among others (Riessman, 1993; Smith et al., 2009e).

Considering that the research question was concentrated on how the Portuguese individuals ascribe meaning to their experience of NSCLBP and that the focus was on extracting this meaning from their accounts and not on their wider narrative life or on how this was constructed and communicated, NA did not suit this study's purpose.

4.4.1.3. Thematic analysis

TA is considered a foundational method for qualitative analysis. It has been argued that its use provides the researchers with core skills of inductive reasoning for conducting many forms of qualitative research (Braun & Clarke, 2006). Although some authors characterize TA as a tool to use across different methods, others argue that TA should be seen as a method in its own right (Braun & Clarke, 2006). Considering the latter perspective, TA has been defined as a method that aims to identify, analyse and report themes within and across data (Braun & Clarke, 2006).

As with GT and NA, different possible approaches to TA are used by researchers. Traditionally, TA is essentially related to the organising and describing themes (Braun & Clarke, 2006). Nevertheless, depending on the approach, the development of themes through TA may further the descriptive work and involve interpretation (Boyatzis, 1998). This means that research following this approach can move from a rich description of data, to an interpretation of the meanings and implications of the data (Braun & Clarke, 2006; Clarke & Braun, 2013). Despite its potential use to analyse and interpret data, some authors have claimed that this approach may have limited interpretative power (Braun & Clarke, 2006), when compared to other approaches such as IPA. Although both TA and IPA studies use a form of inductive coding, some authors have argued that a more detailed exploration and level of interpretation is required in IPA (Brocki & Wearden, 2006; Larkin et al., 2006; Smith et al., 2009a; Hefferon & Gil-Rodriguez, 2011). On the other hand, it is important to take into consideration that some authors have questioned whether, or to what extent, IPA is different from a rigorous TA (Collins & Nicolson, 2002; Warwick et al., 2004). Warwick et al.'s (2004) study sheds some light on the differences between TA and IPA. These authors used

TA and IPA to analyse the interviews with woman with chronic pelvic pain. Warwick et al. (2004) indicated that compared to TA, the themes that emerged from IPA added a sense of depth to the analysis, since they provided detailed information on each participant's experience. The authors also considered IPA to be more illuminating in what relates to clinical implications (Warwick et al., 2004). It could be argued that these conclusions should be viewed with caution, as in Warwick et al.'s (2004) study, a pre-defined category system was derived from other studies for the initial stages of TA - this may have contributed to the production of a largely descriptive analysis. The differences between TA and IPA seem to largely depend on how TA is employed and the aims of its use.

When considering the purpose of this study, the organisation and identification of themes within and across the data may be seen as a potential strength of TA. However, its limitation on allowing deep analysis and interpretation conflicted with the aim of developing a deep understanding of the Portuguese individuals' experiences of NSCLBP.

4.4.2. Interpretive Phenomenological Analysis

IPA is an approach to qualitative inquiry focused on how people make sense of their main life experiences (Smith & Osborn, 2008). IPA was considered the most adequate approach to inform the research design of this study. Although it comes from psychology, it is being used by several disciplines such as those in the social and health sciences (Smith et al., 2009f).

Although IPA has only appeared as a qualitative research approach since the mid-1990s, it has a much longer history in the sense that it was influenced by previous concepts and debates from some areas of philosophy of knowledge. More specifically, phenomenology and hermeneutics have been the central theoretical inspirations for IPA.

Thus, it is important to consider how philosophical roots from phenomenology and hermeneutics have influenced IPA approach to research and particularly the approach to this study.

Firstly, IPA focuses on the exploration of human experiences, in the way that this experience could be understood through exploring meanings that individuals attribute to it (Smith & Osborn, 2008; Smith et al., 2009f). Thus, in the context of this study, the aim was to perform this exploration in a way that would make it possible to express Portuguese individuals' personal accounts of their experience of having NSCLBP, rather than producing an objective statement of this experience (Smith & Osborn, 2008). These assumptions link IPA to phenomenology. It is important to consider that IPA does not privilege any particular phenomenologist, rather it is influenced by the central emphases of the approach and by a number of further elements given by some of the most important phenomenologists, such as Husserl or Heidegger (Smith et al., 2009f).

IPA is also concerned with interpretation, which reflects the strong influence of hermeneutics, considered as the theory of interpretation. There are also some authors emerging from hermeneutics, who have a major influence in IPA, such as Gadamer. In his discussion of historical awareness, fusion of horizon or pre-understandings presented in the previous section, Gadamer explored an approach to interpretative process in which IPA is currently underpinned (Gadamer, 2004). He had some contribution on the exploration of one of the most resonant ideas in hermeneutic theory – the hermeneutic circle (Gadamer, 2004). IPA involves a “double hermeneutic” i.e. a two stage interpretation process where the participant is trying to make sense of his/her experience, while the researcher is trying to make sense of the participant's meaning-making (Smith & Osborn, 2008; Smith et al., 2009f). This reflects the dual role of the researcher: on one hand the researcher is like the participant and is trying to make sense of the world, and on the other hand the researcher is someone who only has access to the participants reports about their experience and who is also seeing it through their own lens (Smith et al., 2009f). This double hermeneutic has a major influence on the position adopted by the researcher: the researcher wants to see the experience through the participants' eyes, and simultaneously, wants to look at this from different perspectives, asking questions and giving meanings to what is said (Smith et al., 2009f). Thus, in this

study, the final expected outcome was an account of how the researcher made sense of the participants making sense of their experience of having NSCLBP disorder. In this sense, the process of understanding involved a balance, played by the researcher, between *“trying to see what it is like for someone”* and *“analysing, illuminating and making sense of something”* (Smith et al., 2009f, p.36).

It is also important to consider that IPA has an idiographic element, in the sense that it focuses on a specific issue of an individual's experience. Its task is concerned with the detailed analysis of particular cases of individuals' experience (Smith et al., 2009f). It is important to clarify that this focus on the particular does not mean focus on an individual *per se*, rather it takes into consideration the individual's experience within a specific context (Smith et al., 2009f). The process involved in this analysis starts with detailed exploration of each case and then looks at the similarities and differences between cases in order to illuminate common patterns of meaning as well as variations in the individuals' experiences (Smith et al., 2009f). In this study, the approach was concerned with the detailed analysis of particular cases of individuals' experiences of having NSCLBP disorder, followed by the analysis of common elements and variations in their experiences (Smith et al., 2009f).

To summarise, the combination of both phenomenology and hermeneutics is a core issue to IPA. It is phenomenological because it tries to get as close as possible to the experience of a participant, and simultaneously it is hermeneutical in the way that it assumes that this process is interpretative for both the researcher and the participant. Simultaneously, it uses these approaches with an idiographic sensibility, in the way that it focuses on individuals and tries to understand both shared meanings and individual variations in their experiences (Smith et al., 2009f).

In this study, IPA was used to explore, describe, interpret and situate perspectives that individuals with NSCLBP develop to make sense of their pain experiences (Smith et al., 2009f). Consideration of the meaning of data from

different sources and integration of this information within the whole picture of individuals' experiences of having NSCLBP were used to gain a growing understanding of the issues that affect the individuals' life. New information was integrated with previous knowledge as the study progressed to create an enlightened view of the NSCLBP experience (Zweck et al., 2008). A shared understanding of the experience of having NSCLBP was co-constructed within this study, through analysis and combination of data from a range of perspectives, where researcher interpretation played an important role.

4.4.3. Strengths and limitations of Interpretative Phenomenological Analysis

IPA's theoretical roots from phenomenology and hermeneutics add a sense of depth and purpose to data analysis that other methodological approaches may lack (Pringle et al., 2011). Taking into account the research question addressed by this study, it was considered an advantage to use IPA as a methodological approach given the possible depth of the interpretation of participants' accounts of making sense of their disorder. Moreover, as a consequence of its idiographic nature, IPA offers a different perspective from other approaches such as GT, which usually includes more participants in order to substantiate a theory (Creswell, 2007a). Additionally, the recognition of the contextual factors' influence in meaning-making enables an understanding of both the unique experience as well as the shared experiences (Larkin et al., 2011).

Although IPA was considered to be a methodological approach appropriate for this study, it is important to consider both its potential limitations and the way researchers have addressed these limitations. Although its applicability to several disciplines besides psychology has been reported by several authors, there is a paucity of physiotherapy research using this approach (Dean et al., 2005; Cassidy et al., 2011). Nevertheless, this approach could provide increased insight into the phenomenon of NSCLBP from people who experience it and aid the physiotherapists' understanding.

Some limitations have also been identified regarding methodological issues. Some authors have claimed that the lack of specific advice on how to conduct

IPA studies is a potential limitation that may compromise the quality of these studies (Chamberlain, 2011). However, it is important to take into consideration that guidelines have been provided to help novice researchers engaged with IPA studies (Smith et al., 2009a; Smith, 2011b). Although the approach to IPA has been described in a series of steps, it does not have a prescriptive nature. Thus, a detailed comprehension and understanding of the approach and respective principles is required in order to ensure the quality of research (Smith et al., 2009a; Smith, 2011b).

IPA studies are commonly carried out using small samples sizes in order to enable the researcher to explore each participant's personal account in detail (Smith et al., 2009b). Although small samples may be considered as a potential limitation of IPA studies, it is important to consider that the reduced number of participants allows the researcher to carry out a deeper and more interpretative analysis, anchoring findings in direct quotes from the participants (Smith et al., 2009a; Pringle et al., 2011).

Moreover, IPA studies tend to use reasonably homogeneous samples, in order to allow a detailed exploration of convergence and divergence among participants (Smith et al., 2009f). The use of homogeneous samples in these studies has also been seen as an issue as it may limit the application of this research in a broader context (Pringle et al., 2011). Although this seemed to be an inevitable tension in IPA studies, some strategies have been proposed to overcome it (Pringle et al., 2011), such as providing a contextualisation of the participants, in order to enable the reader to assess and evaluate transferability (Smith et al., 2009a; Smith, 2011b).

The focus on the individual rather than on the context has also been considered a potential limitation in IPA studies (Todorova, 2011). As previously discussed, IPA is committed to an idiographic approach, which requires in-depth analysis of particular individuals, who are located in particular settings. Considering that sensitivity to context is also an important aspect of IPA studies, the capacity to deepen contextualisation while still maintaining the focus on the individual has been identified as one of the current challenges for researchers undertaking IPA research (Todorova, 2011).

Regarding the data analysis, the over-emphasis on the presentation of findings as a range of themes and excerpts has been identified as an issue (Chamberlain, 2011). Recommendations have been made to avoid the selection of themes on the basis of prevalence, but rather on its contribution to deepening the understanding of the phenomenon under investigation (Brocki & Wearden, 2006; Smith et al., 2009a). Indeed, IPA researchers have been recommended to present findings as an interpretative narrative that analysis the experiential themes, interlinking significant excerpts (Smith, 2011b).

Finally, the length of time required to analyse data in sufficient and appropriate depth has been considered a limitation, as novice researchers may fail to move beyond a descriptive analysis (Larkin et al., 2006; Smith et al., 2009a). In order to address this issue, the allocation of time has been considered fundamental as well as the researcher`s engagement in reflexivity (Smith et al., 2009d). This engagement in reflexivity requires the researchers` assessment and critical analysis of their own preconceptions in order to develop a deep understanding of how they inform the process of data collection, analysis and discussion (Etherington, 2004b; 2004a; Shaw, 2010). Further information on this process is provided in section 4.6..

4.5. Considerations regarding data collection

Two methods of data collection were considered for this study: interviews and focus groups. Both methods are frequently chosen for collecting data in qualitative research. Although interviews are more commonly used in IPA studies, focus groups have also been employed in some IPA work (Smith et al., 2009c; Palmer et al., 2010). Nevertheless, the option for one or another method should be carefully considered, particularly in what concerns their capacity to inform the research question addressed in a specific study (Smith et al., 2009c). The interview is commonly described as “*a conversation with purpose*”, which is informed by a research question (Smith et al., 2009c, p.57). The use of in-depth interviews is highly consistent with the intimate focus on the participant`s experience highlighted in IPA studies (Smith et al., 2009c). Interviews are

coherent with the IPA's idiographic commitment and enable detailed exploration of the interviewee's perceptions and experiences of a specific phenomenon (Palmer et al., 2010). They also facilitate the development of rapport, trust and open lines of communication (Flick, 2009d).

The focus group is defined as a discussion-based interview that produces data and insights via group interaction, which would be less accessible without the interaction founded in a group (Flick, 2009c; Millward, 2012). Focus groups enable multiple voices to be heard at one sitting and draw a larger sample into a smaller number of data events (Smith et al., 2009c; Palmer et al., 2010). Focus groups have been considered suitable for IPA studies, since they may provide rich experiential data (Palmer et al., 2010). However, some authors have advised prospective researchers to carefully consider the adoption of this method of data collection (Smith et al., 2009c). It has been advocated that the presence of multiple voices as well as the interactional complexity of a focus group, make the development of the phenomenological aspects of IPA more difficult (Smith et al., 2009c; Palmer et al., 2010).

In this study the method of data collection was expected to enable participants to offer in depth and detailed accounts of their experiences of having NSCLBP disorder (Smith et al., 2009c). Thus, the research method that best suited this purpose and was, simultaneously, coherent with the philosophical assumptions of the working paradigm was the one-to-one interview technique (Smith et al., 2009c). This type of interview was well suited to in-depth and personal discussion and to facilitate a conversational relationship with participants about the meaning of their experience of NSCLBP (Flick, 2009d). Further information on the use of interviews in this study is provided in the fifth chapter.

4.6. The place of reflexivity

Reflexivity has been widely discussed among researchers, with some embracing it, while others question its value (Etherington, 2004c). The value of reflexivity seems to be related to the assumptions underpinning research paradigms. Research following the tradition of the positivist paradigm argues

that the researcher should be neutral and consequently reflexivity is not well accepted (Crotty, 1998e). Research following the tradition of the interpretive paradigm denies the idea of an objective reality separated from those who inhabit the world. Rather, it focuses the interactions between individuals and their worlds, which are determined by the contexts where these interactions take place (Crotty, 1998b; Willis, 2007e). Considering these assumptions, reflexivity assumes a major relevance, which is particularly emphasised in IPA studies (Smith et al., 2009d; Shaw, 2010).

Under the influence of the previously mentioned Gadamer's notion of horizons, IPA studies emphasise the contribution of the researcher's presuppositions in the interpretation of the participants' accounts (Smith et al., 2009f; Shaw, 2010). Thus, in IPA studies reflexivity supports the expected co-construction of meaning, between both the researcher and the participant (Smith et al., 2009f). Specifically in this study, reflexivity can help the researcher address her experiences and contexts and become aware of how they inform the process and outcomes of inquiry (Etherington, 2004b; 2004a; Shaw, 2010). Through engagement in reflexivity, the researcher becomes able to enter into a dialogue with participants and their representations about reality. This dialogue is on the basis of the double-hermeneutic circle and plays a determinant role in data collection and analysis. It helps the researcher make sense of the participants, who are making sense about the phenomenon under investigation (Smith et al., 2009f; Shaw, 2010).

The previous paragraphs highlight the importance of identifying the researcher's interpretative framework at early stages of the research. Therefore, a reflexive journal was used to facilitate reflexivity in this study, by helping the researcher to explore her interpretative framework. The reflexive journal was used as a strategy to improve the quality of the study by providing details about the researcher's thoughts throughout the research. In order to contribute to the transparency of the research process excerpts of this reflexive journal have been presented at the end of some chapters of this thesis (Janesick, 2000). The topic concerning the reflexive journal is revisited in the next chapter.

4.7. Reflexive account

As an interpretivist researcher following both the phenomenological and the hermeneutic tradition, I was aware that I brought my own preconceptions to this study. Therefore, reflections on my role as a researcher as well as on the aspects that could shape my interpretative framework were considerably important in this study (Malterud, 2001; Brocki & Wearden, 2006). Moreover, reflections on my possible biases and taken-for-granted assumptions created an opportunity to see the researcher and the research as intertwined identities. It also increased the transparency of the research process and enables the readers to make different interpretations of the data that was gathered.

In the context of this study, it was important to reflect on my position as a researcher and go beyond personal and social locations. Indeed, research is intertwined with wider contextual factors, which should also be addressed (Etherington, 2004b).

Thus, I considered how my academic training as a physiotherapist and my own process of professional socialisation impacted on my view about the phenomenon under investigation. The following paragraphs address these aspects.

Physiotherapy has been developed from “scientific” foundations influenced by positivism. Epistemologically, positivism assumes that objective knowledge is developed from measure and observation of a stable reality, in a rigorous and systematic way (Petty et al., 2012). Additionally, this is intertwined with the ontological belief in a single objective reality, which has been at the core of scientific thought for more than four centuries (Alderson, 1998; Petty et al., 2012). Indeed, positivism is at the philosophical basis of all clinical trials, experimental and quasi-experimental designs, epidemiological surveys, tests of validity and reliability, and a range of other quantitative designs (Nicholls, 2009). It has supported physiotherapists in establishing their own status as professionals and bringing the profession closer to the medical field (Nicholls, 2009). In the Portuguese context, the physiotherapy practice seems to be dominated by a traditional biomedical model of health care (Cruz et al., 2012a),

which is closely related to the quantitative research carried out under the influence of positivism (Nicholls, 2009).

The aforementioned context had a significant influence on this study. I viewed pain initially as a symptom that indicated something was wrong with the patient's body. As a consequence, the pain was my focus, rather than the person experiencing it.

Although I was encouraged to develop a biopsychosocial approach to clinical practice throughout the four years of my degree in physiotherapy, I had difficulty in implementing this when I started working with patients experiencing NSCLBP. Indeed, the Portuguese curriculum in physiotherapy has been mainly organised around a biomedical perspective (Cruz et al., 2012b).

I have dramatically changed my perspective about the pain phenomenon through reflection about my clinical experience with NSCLBP patients. The incoherence of their physical symptoms helped me to realise that there were possibly more factors to take into consideration in order to understand the patients' real problems and needs. Gradually, I started to expose myself to the complexity of patients' accounts, by asking them open questions, and became aware of the importance of the personal context in the experience of having NSCLBP. Through my experience with NSCLBP patients I realised that the way they interpreted pain played a significant role not only in their response to pain but also in the results of the treatment. Looking back, this was an important change in the way I viewed NSCLBP. Indeed, this experience stretched my views about the pain phenomenon and prompted this research. As a consequence, I came to this study with the assumption that pain was a complex experience that went beyond the biological dimension. I also came with the assumption that the patients' interpretations of their pain significantly impacted their pain experience. However, I did not know how I could transfer these assumptions to research, as I was more familiar with research carried out under the scope of the positivist paradigm.

The literature on research paradigms was quite important, as I immediately identified myself with the interpretivist paradigm. My notions of paradigms,

epistemology and ontology were confusing, and required a long period of study in order to enable me to make decisions regarding these topics. This period of engagement with this literature attained a major relevance, as it gave me an overall perspective from which this study should be designed and carried out. Following this, I had to make a decision regarding the methodological approach. Therefore, the similarities and differences among several methodological approaches were thoroughly analysed, as I was aware that each approach would guide the exploration of the phenomenon under investigation in a slightly different direction. This was fundamental as it helped me to identify my own direction, and supported my decision in choosing the IPA as the methodological approach that would best suit this research purpose. Moreover, to have a deeper knowledge of IPA was fundamental for the subsequent stages of data collection and analysis.

Considering the previously presented thoughts, I anticipated that some conflicts between my “biomedical roots” and my “biopsychosocial motivations” as well as between my “previous positivist view about research” and my “new interpretative vision about research” would possibly emerge on the next stages of this study. Reflection on these stages is presented in the following chapters.

4.8. Chapter summary

In this chapter, the epistemological and ontological bases of this study have been presented. Considerations about methodological approaches and methods of data collection have been presented. The place of reflexivity in this study has also been analysed. The next chapter addresses the specific procedures included in this study.

Chapter 5: Methods

In this chapter, the procedures included in the implementation of this study are described. In the first section, the research population and study setting are introduced. In the second, an explanation about the selection of the participants and detailed information about the inclusion and exclusion criteria are provided. In the third, ethical considerations are addressed. In the fourth, information regarding the pilot study is included. In the fifth, participants` recruitment is addressed. In the sixth, the selection of semi-structured one-to-one interviews as the method for data collection is discussed. The procedures for transcription, translation and data analysis are explored in the seventh and eight sections. The procedures undertaken to ensure the quality and rigour of the research are addressed in the ninth section and finally, a reflexive account related to the topics covered in this chapter is presented.

5.1. Research population and study setting

This study applies to Portuguese individuals with NSCLBP. Inclusion and exclusion criteria were defined in order to promote the homogeneity of participants recruited. This homogeneity was considered important as it was expected to facilitate the process of analysing variability within the group through identification of patterns of convergence and divergence (Smith et al., 2009d).

The study was carried out in an academic clinic located in central interior of Portugal, as well as one primary care centre and one family health unit, both located on the central Portuguese coast. The main reason for choosing these specific locations was determined by the high prevalence of chronic pain in these regions of the country (Pereira & Neves, 2010; Azevedo et al., 2012). The academic clinic in the central interior of Portugal is managed by a Polytechnic Institute and offers economical physiotherapy sessions to the community. The primary care centre and the family health unit are both governed by the same Group of Primary Centres, which follows the NHS organisation as described in the third chapter. The rationale for selecting different health contexts was not

related to representativeness but to an attempt to have a more diverse and richer picture of the phenomenon under investigation. Indeed, in coherence with the epistemological and ontological position that underpinned this study, generalisation was not an aim. Rather, the possibility of readers considering the findings useful for reflecting on the approach to individuals with NSCLBP was expected. In order to facilitate the readers' assessment of transferability for other settings, detailed information regarding the participants and their contexts is provided throughout the thesis.

5.2. Participants

Considering the research question and the aforementioned methodological approach to this study, the participants were selected purposefully (O'Leary, 2004b; 2005c; Flick, 2009e; Smith et al., 2009d). Purposeful sampling was considered more adequate since the purpose was to study in-depth information-rich cases rather than formulate empirical generalisations typical from positivist and post-positivist paradigm (Patton, 2002).

In IPA, emphasis is placed on a detailed understanding of the individual's experience, which means that quality is more important than quantity.

Defining the concrete number of participants included in any qualitative study constitutes one of the most controversial steps in research planning (Morse, 2000). In fact, there is no correct answer to the question of sample size (Morse, 2000). Despite this, there were some factors, such as the area of study, the nature of topic, the richness of the data collected, among others, that made it possible to estimate an average number of participants recruited (Morse, 2000). In this study, it was expected that enough detailed information could be collected to explore individuals' experience of having NSCLBP disorder and to develop meaningful points of convergence and divergence between interviews. Simultaneously, the collection of too much data that would make it impossible to look at the individual was avoided (Smith et al., 2009c).

5.2.1. Considerations for inclusion and exclusion

Participants were selected on the basis of their expected knowledge about the experience of having NSCLBP, which opened access to particular perspectives about the phenomenon under investigation (Smith et al., 2009d). In this sense, Portuguese individuals with NSCLBP disorder were included in this study in order to develop insights and an in-depth understanding of how they understand and make sense of their condition.

As previously mentioned, inclusion and exclusion criteria were defined in order to promote the participants' homogeneity (Smith et al., 2009d).

The following inclusion criteria were used:

- To have experienced “*non-specific chronic low back pain, i.e. low back pain that is not attributable to a recognizable, known specific pathology (e.g. infection, tumour, osteoporosis, fracture, structural deformity, inflammatory disorder (e.g. ankylosing spondylitis), radicular syndrome or cauda equina syndrome*” (Airaksinen et al., 2006, p.208; National Collaborating Centre for Primary Care, 2009; Savigny et al., 2009).
- To have experienced NSCLBP for at least a 12-month period (for the majority of the year) (Korff, 1994), and which was not relieved by previous health care. Although the vast majority of studies carried out in the area of NSCLBP included individuals who have experienced low back pain at least for 3 months (the period suggested by IASP as the normal tissue healing time), in this study this period was increased to at least 12-month in order to ensure that participants had had a prolonged experience and had richer accounts to share with the researcher. This period of time has also been used in other qualitative studies carried out in this area (for instance, May et al., 2000).
- To be aged between 40 and 60 (Rabiais et al., 2004; Breivik et al., 2006; Azevedo et al., 2012). This range was included in coherence with epidemiological research carried out in Portugal and other European countries. Despite the lack of specific research focused on Portuguese individuals with NSCLBP, the few existing studies in this area have demonstrated that acute low back pain and musculoskeletal chronic pain are more prevalent within this age range (for instance, Rabiais et al., 2004;

Azevedo et al., 2012). This is also supported by findings from research carried out in European countries (for instance, Breivik et al., 2006).

- To have intellectual capacity and psychological maturity to understand the nature of the research and his/her involvement and the ability to make self-directed and self-determined choices, in order to guarantee ethical precautions as well as the quality of data collected;
- To be able to communicate effectively in Portuguese, in order to guarantee the expected flow of the interviews as well as the collection of comprehensible data (for instance, Smith & Osborn, 2007; Snelgrove & Lioffi, 2009).

Simultaneously, the following exclusion criteria were used:

- Spinal surgery in the last two years.
- The presence of any chronic diseases that could influence the participants' experience of having NSCLBP or move participants' discourse from the focus of the research question that informed this study;
- Participants with any nationality other than Portuguese, due to the cultural basis of this study.

5.3. Ethics and governance

Literature regarding ethical guidelines for health research has highlighted three basic ethical principles: the respect for persons, which incorporates the respect for autonomy and protection of those who are dependent or vulnerable; beneficence, which refers to the obligation to maximize benefit and minimize harm; and, justice, which implies to treat each person according to what is morally right and proper (Council for International Organizations of Medical Sciences, 2002; WHO, 2011).

Ethics approval for the study was obtained from the Faculty of Health and Social Science Research Ethics & Governance Committee of the University of Brighton (FREGC) (appendix 2), as there are no identified Ethic Committees in Portugal relevant to this study. The study was submitted twice (appendix 1), as the reviewers requested some issues to be clarified after the first submission.

Procedures regarding the participants' information and consent, confidentiality and anonymity as well as protection from harm were considered in this study (O'Leary, 2004c; 2005b; National Patient Safety Agency, 2007; Flick, 2009b; Smith et al., 2009d). Further information concerning these procedures is provided in section 5.5.

Moreover, procedures regarding data protection as well as dissemination of findings were also taken into consideration. In order to guarantee restricted access to the data (which included audio-files and transcription documents), the researcher stored them in a safe and secure place, which only she could access. All names were removed from the data and pseudonyms were used. The audio-files will be preserved until the end of the PhD study (when they will be destroyed), and the written data will be preserved for a maximum of five years at the end of the study. The researcher guaranteed the need for permission for subsequent use of the data (for publishing in scientific journals or conferences' presentations) (Flick, 2009b).

5.4. Pilot study

Prior to this research, a pilot study had been carried out in order to test the participants' recruitment as well as the interview schedule. The pilot study was carried out after obtaining ethical approval from FREGC (appendix 2). It was carried out in a health centre located in the south of Portugal. This centre was part of a Health Unit that follows the organisation of the NHS, as described in the third chapter of this thesis. From the health centres that constitute this Unit, this particular health centre was identified as the most suitable place for the participants' recruitment due to its geographic location. This health centre was based in one of the Portuguese regions with a higher prevalence of chronic pain (Azevedo et al., 2012). Permission to carry out the pilot study was given via e-mail (appendix 3).

As a consequence of the pilot study, the interview schedule remained the same, however part of the recruitment process concerning the inclusion and exclusion criteria was adjusted. More specifically, the criterion regarding the definition of

NSCLBP was altered. A more specific definition was introduced, because a participant experiencing chronic neck pain was identified by a physiotherapist (who participated in the recruitment process) as a potential participant. Additionally, the criterion regarding the age range was adjusted. The age range changed (from 25-65 to 40-60 years) in order to diminish the potential variability, related to the diversity of experiences in different life stages. Finally, the exclusion of individuals who had had recent spinal surgery in the previous two years was introduced, because a participant who had recently undergone spinal surgery was identified by a physiotherapist as a potential participant in the pilot study (the spinal surgery may be indicative of a specific cause for CLBP). Detailed information about the procedures included for the pilot study, and specifically about the adjustments in inclusion/exclusion criteria, can be found in appendix 4. As only minor adjustments were made, re-submission to FREGC was not considered relevant.

5.5. Recruitment strategies

Between November 2011 and July 2012, individuals with NSCLBP disorder referred to physiotherapy, in the academic clinic and, in the primary care and the family health unit, were invited to participate in this study.

The recruitment process included three phases. The first phase concerned the preliminary selection of health services, according to the factors mentioned in 5.1. In this first stage the researcher gathered information about epidemiological data in Portugal and took into account the pragmatics of travelling to the suitable areas. More specifically, the distances and expected time spent travelling were considered. The academic clinic was 260 km away from where the researcher was based, one of the health centres was 8 km away and the other in the city where the researcher was based.

The second phase included the contact with key people (the head of services) in each site. A letter of introduction to the head of each health service was sent by registered mail (appendices 5 and 6). The researcher provided her contact

telephone and e-mail in order to book an appointment (to present and discuss any additional information requested) with the head and/or members of each service, at a time and date convenient to them, in their own service. All services approached granted permission, via letter (appendices 7 and 8), without requesting the appointment. After this, the researcher contacted each physiotherapist in order to arrange a meeting. In these meetings the main information about the study was given as well as more detailed information about participants inclusion and exclusion criteria and procedures to be carried out by both the physiotherapists and the researcher (appendices 9 and 10).

The third phase included the specific patients being invited to participate in the study according to the inclusion and exclusion criteria. The physiotherapists were asked to identify potential participants for this study (taking into account information provided regarding the recruitment process – appendices 9 and 10), and then giving each of them an envelope containing a letter of invitation (appendices 11 and 12) to participate in this study, an information sheet (appendices 13 and 14) with more detailed information about the study and a stamped addressed envelope for those who were interested in participating.

The researcher contacted those participants, who had returned the stamped addressed envelopes, by phone to answer any questions and determine if they were still interested in participating. The individuals who decided to participate were invited for an interview in the health service department where they were being treated on a date and time convenient to them.

When participants went to the health service department, the researcher provided a verbal explanation and a copy of the information sheet to those who did not bring their own. They were given time to read it again and to ask any questions they might have about the study. Then, they were asked to give their informed consent (appendices 15 and 16). The informed consent was dated and signed by both the participant and the researcher and a copy of this was given to the participant (National Patient Safety Agency, 2007). The participant information sheet and informed consent were used to ensure that the participants were not deceived about the purpose of the study (O'Leary, 2004c; 2005b). Participants were also informed that the researcher would send them a

copy of their own transcript as well as the main themes that would emerge from their interviews by registered mail.

Finally, the interviews took place in a quiet room to guarantee the participants' privacy. This also enabled the participants and the researcher to hear and listen to one another and ensured the sound quality for the transcript.

5.6. Data collection

One-to-one interviews were used as a means for exploring and gathering insights into the experiences and perceptions of Portuguese individuals with NSCLBP. Thus, it was very important to use specific strategies to facilitate this approach. Indeed, verbal and non-verbal communication was used to minimize any distance between both the interviewer and the participant (e.g. use of lay language, empathic tone of voice, avoiding sitting directly facing the interviewee and turning away by 45 degrees). Additionally, a private room where the participant felt comfortable to share his/her account was chosen (Smith et al., 2009c).

Participants were given the opportunity to talk about their experience by the use of open questions such as *"Please tell me about your experience of living with chronic low back pain"*, *"Can you describe a typical day when you have pain?"* or *"How has this plain influenced your life?"*. They were encouraged to speak freely, talk about their experience and reflect on their ideas (Smith et al., 2009c). Semi-structured interviews were used, which means that they used neither a fully fixed nor a free structure (O'Leary, 2004a; 2005a). An interview schedule (appendix 17) was developed in order to help the researcher to focus on the topics for discussion (Smith et al., 2009c). The interviews started with some of the questions included in the interview schedule and then the researcher moved forward according to the discourse of the interviewee and the interaction established. Probing questions were introduced over the course of the interviews, in order to help the participants make sense of their experiences (Flick, 2009d; Smith et al., 2009c).

The interviews lasted between one hour and one hour and a half and were audio recorded and converted into audio-files, which allowed their preservation for analysis at a later date. Two digital recorders were used in order to minimise possible technical problems, however only one file was preserved after each interview. Both digital recorders were placed as discreetly as possible in order to avoid participant anxiety.

Prior to data collection the researcher practiced several interviews with friends, colleagues as well as with a researcher, who was experienced in interviews. All these individuals provided useful feedback on the performance of the researcher. This process was fundamental to develop skills to perform interviews, establish rapport and invite participants to speak freely (Meyrick, 2006; Smith et al., 2009c).

5.7. Transcription and translation

The interviews were transcribed verbatim to provide a text with which to engage in dialogue. It is important to note that text is not only the written transcript, but also the taped words as well as the field notes. All of these aspects can influence understanding and therefore can be considered “text” (Fleming et al., 2003).

Field notes included the researcher`s observations and written comments about the interview situation. They were important for data analysis since they provided details on the participants` non-verbal communication that would not be available in the audio-record (e.g. smiles, avoidance of eye contact when talking about sensitive topics, body language, among others). These notes also included the researcher`s thoughts and reflections immediately after each interview (e.g. first impressions regarding the topics that were explored by the participant).

Transcriptions included all the words as well as hesitations and emotional reactions such as a laugh or a cry. Since there are different transcription systems available and a standard has not yet been established yet (Flick, 2009a), the following transcript conventions were used: ... – short pause; **(text)**

– emotional reactions; **[text]** – explanatory information introduced by the researcher; **X** – names of organisations, places or individuals mentioned by the participants; and, (...) – words omitted to shorten the excerpts selected for presentation in the findings chapter, as these were not considered relevant to meaning.

The final transcriptions were then copied into a table that provided enough space for notes related to the analysis. Pages and lines were assigned to each page, in order to facilitate the location of quotes. An excerpt of one interview is provided as example in appendix 18.

The researcher personally carried out all the transcriptions and then checked them against the audio-file for accuracy. Although this process was very time consuming, it was considered extremely useful since the repeated listening helped the researcher's engagement with the data. The NVivo 7 Research Software was used to manage and organise data.

The translations of the selected excerpts from the interviews were carried out by the researcher and then checked by a certified bilingual translator. The accuracy of these was subsequently reviewed by the researcher.

5.8. Data analysis

In order to contextualise participants, their personal accounts were presented as short vignettes. Vignettes were useful in placing the participants' contexts in the analysis. In coherence with the methodological approach selected, this strategy aimed to allow readers to situate participants as individuals in "parts" of the text and then relate them to the "whole". The vignettes outlined the main information about their personal accounts and included details about age, gender, living context, family, profession, current employment status and perceived total length of time with NSCLBP disorder, providing a context for each participant's experience (Smith et al., 2009f).

The process of data analysis through engagement with transcripts required flexible thinking, creativity, innovation and capacities of reduction, expansion and revision (Smith et al., 2009a). It required a dynamic movement between the parts and the whole (Smith et al., 2009a). This movement from the whole to the parts and back to the whole is known as the hermeneutic rule of movement and provided an essential framework for data analysis in this study (Gadamer, 2004; Smith et al., 2009f). It is important to note that in Gadamer's description of hermeneutic circle, the concepts of "whole" and "parts" should be given a broad and liberal interpretation. "Parts" can be pieces of a historical story, and the whole is the proper perspective of the historical context. They can be pieces of text in the whole transcript. Alternatively, these parts can be the interpretative researcher's and the participants' preliminary understanding (i.e. pre-understandings) in the study. In this context, the whole represents the shared meaning emerged from the interactions between them, in an interplay defined as the hermeneutic circle (Willis, 2007e).

There is no a single method used in performing data analysis in IPA. Instead, authors have suggested a set of principles, as the commitment to understand participants' point of view, processes, such as the hermeneutic rule of movement described above, and some specific strategies. The use of these principles, processes and strategies should be managed by researchers in order to approach data analysis (Smith et al., 2009a).

Smith et al. (2009a) have suggested six steps to conduct IPA analysis in order to provide some guidance on this process. The non-prescriptive nature of these steps has been highlighted and recommendations for using them as orientations have been made (Smith et al., 2009a). The use of these steps has acquired considerable importance, especially for novice researchers, in the process of becoming familiar with this approach. As the work progresses the researcher can adapt these steps, since the principles of theoretical perspective remain respected (Smith et al., 2009a).

Data analysis took into consideration the aforementioned orientations and was as follows:

- The first stage involved immersing oneself in the data, through reading, re-reading and listening to the recordings. In this first stage, it was particularly important to ensure that the participant was the focus of analysis. The researcher began the process of entering the participant's world, through an active engagement with data (Smith et al., 2009a).
- In the following stage, data analysis became more detailed and time consuming. The researcher tried to maintain an open mind and note anything of interest in the transcript. The aim was to produce comprehensive and detailed notes and comments on the data, using the participant's own words as closely as possible. Throughout this process, the researcher gradually looked at more complex issues, starting with descriptive comments focused on describing the content and moving to linguistic comments concerned with the specific use of language and to conceptual comments focused on engaging on a more interrogative and conceptual level (Smith et al., 2009a).
- At the third stage, the amount of data was considerably higher than at the beginning of this process. The researcher was focused not only on the interview transcripts, but also on the notes and comments added in the last step. The aim was to reduce the volume of detail without losing its complexity. In identifying emergent concepts, the researcher began the process of breaking up the narrative flow of the interview. This process was orientated by the hermeneutic rule of movement between the parts and the whole: as the researcher conducted the analysis the original transcript became a set of parts, which then came together in a new whole at the end of the analysis. As the concepts emerged, the researcher maintained the focus on capturing what was essential at this point in the text and simultaneously on thinking about the whole text, which reflected once more the hermeneutic movement. The concepts that emerged at this stage resulted from a co-construction of meaning, in the sense that they included not only the participant's words but also the researcher's interpretation (Smith et al., 2009a).

- The fourth stage involved the development of charting how the concepts fitted together and underpinned the emergent themes. The aim was to find a way of drawing together the concepts and themes and producing a structure that reflected the participant's specific account. Some strategies to find connections between concepts and identify the emergent themes were used at this stage - such as abstraction (defined as a form of identifying patterns between concepts and developing a sense of what connect them), subsumption (when a concept acquired the status of a theme, as it brought together several related concepts), polarization (when the examination of the transcripts was focused on the differences rather than on similarities), contextualization (when the identified concepts were related to the contextual elements) and numeration (when the frequency of a concept was considered) (Smith et al., 2009a). At the end of this stage, a narrative account including the emergent concepts and themes identified for the participant was developed.

- The following stage involved moving to the next participant's transcript and repeating the whole process. In order to respect the idiographic nature of IPA, it was important to manage the next transcription on its own terms and to allow the emergence of new themes. This process required an important skill in IPA, which was the capacity of bracketing the ideas, emerged from the first analysis, while working with the second. Inevitably, the researcher was influenced by the previous analysis in the sense that her pre-understandings were changing as the analysis progressed. This process continued for the next transcripts (Smith et al., 2009a).

- At the sixth step the researcher focused on looking for patterns across the cases, which involved looking across all of them and asking questions about their relations. The result was a table of themes for the group, illustrating how themes were organized and how each participant was connected with each theme (Smith et al., 2009a).

Feedback from the supervisory team on this process was integrated into the analytic process. This feedback was not designed to be a form of “inter-rater check”, but rather a process of prompting depth to the researcher’s reflection and interpretation. Specific examples about how this feedback was managed are provided in chapter 7. In addition, specific examples about each step described are provided in appendix 19.

5.9. Ensuring quality and rigour

Concerns about assessing quality in qualitative research have been reported by several authors. Traditional research evaluation criteria were originally developed for quantitative research (Yardley, 2000; Carpenter & Suto, 2008). A number of authors have reported its inappropriateness for qualitative research (Mays & Pope, 2000; Malterud, 2001; Golafshani, 2003; Johnson & Waterfield, 2004; Sale, 2008). Since the seminal work of Guba and Lincoln (1989), that suggested alternative criteria to assess quality in qualitative studies, several authors have been proposing criteria and strategies to do it. This has contributed to a proliferation of critical appraisal criteria for assessing the rigour in qualitative research (Mays & Pope, 2000; Sale, 2008).

The literature concerning this topic has presented two main problems: (i) some criteria position qualitative researchers within a post-positivist paradigm - they tend to consider the methodological differences between quantitative and qualitative research, but do not address the philosophical differences; (ii) some criteria do not take the differences between qualitative traditions into consideration - they treat all qualitative research the same (Sale, 2008).

In order to ensure the quality of this study, two authors’ perspectives were combined: Meyrick’s (2006) model and Yardley’s criteria (2000). The former presents an approach to rigour based on two common principles of good qualitative research, *transparency* and *systematicity*, and supports the researcher in using these principles at each stage of the research in order to establish rigour (Meyrick, 2006). It offers an overall perspective about the issues that should be taken into account to ensure rigour and quality in any qualitative

study. Yardley (2000) has suggested four broad principles to assess the quality in qualitative research, *sensitivity to context*, *commitment and rigour*, *transparency and coherence* and, finally, *impact and importance*. The use of Yardley's (2000) principles has been considered suitable for IPA studies (Smith et al., 2009b).

The combination of Yardley's (2000) principles and Meyrick's (2006) model provided the following orientations:

- Sensitivity to context – which can be demonstrated in different ways such as being sensitive to the context of theory developed by other researchers, the sociocultural settings, the participants perspective, among others (Yardley, 2000; Smith et al., 2009b).

Specifically, in this study sensitivity to the context of literature developed in the area was demonstrated from the early stages through a careful analysis of qualitative literature on the topic under investigation as well as literature using IPA as research approach. This level of specificity required the development of knowledge about the philosophy of the research approach adopted, which consequently contributed to a deeper analysis (Yardley, 2000). This sensitivity to literature was also expected in the discussion of findings, through a close dialogue between data collected and the existing literature.

Additionally, sensitivity to the context, in particular to the sociocultural setting, was demonstrated by providing information about the Portuguese context as well as about the sites where data collection took place.

Finally, sensitivity to participants' perspectives also acquired a great importance for the quality of this study. This sensitivity was important throughout data collection, which required the ability to establish rapport with the participants. Thus, the researcher's abilities to perform interviews had a major importance in the quality of data collected. The previously mentioned researcher's practice in carrying out interviews prior to data collection attained major relevance here (Meyrick, 2006; Smith et al., 2009c). This sensitivity was also important during data analysis. At this stage the researcher needed to be focused on the participants' accounts in order to

understand what could be gleaned from them (Smith et al., 2009a). Sensitivity to participants' perspectives was demonstrated in this study through the use of a number of verbatim extracts from the participants' interviews in order to support data analysis.

- Commitment and rigour – the former requires prolonged engagement with the topic, the development of skills to use the method of data collection as well as the ability to immerse in the data analysis (Yardley, 2000). According to Smith et al. (2009b) commitment can also be demonstrated through attentiveness to the participants throughout data collection by ensuring their comfort. This was taken into consideration in this study in several occasions. For example, the researcher paused and stopped the recording in some sensitive moments of the interviews. In these situations (e.g. if the participant had a prolonged pause or was near to crying), the researcher asked the participant whether he/she wanted the recording to be interrupted. Then the researcher kept talking with the participant and when he/she felt ready, the recording was restarted after his/her permission. Moreover, participants were provided with information to apply for free psychological support after the interview, if needed. This support was given by a psychological support centre, whose contacts were provided in the participant information sheet (appendices 13 and 14).

On the other hand, rigour relates to the thoroughness of the study and includes the selection of an appropriate sample, as well as the quality of both data collection and data analysis. Thus, sampling was carefully carried out in order to guarantee its appropriateness (Yardley, 2000; Smith et al., 2009b). The sample was selected purposefully in order to ensure that it included participants who could help the researcher to address the research question. Considering the specific nature of IPA studies, some efforts were undertaken to ensure participants homogeneity. Specifically, a common definition of NSCLBP disorder and a range of inclusion and exclusion were defined (Smith et al., 2009d).

The rigour of data collection was also a concern. After the practice in performing interviews, the researcher piloted the interview schedule in order to ensure the smooth running of the subsequent interviews.

Furthermore, attention was given to moving beyond a simple description of data to a deep interpretation of its meanings. In this context, data analysis was focused on saying something important about each participant as well as about the themes that were common amongst participants (Smith et al., 2009a). It is important to highlight that although the data analysis was the researcher's main responsibility, the process was closely accompanied by the supervisory team. For example, one of the interviews carried out was translated from Portuguese to English in order to be analysed by both the researcher and one element of the supervisory team with expertise in IPA. Both perspectives were discussed and integrated in the final analysis. From the beginning, the data was always analysed in English. This allowed the supervisory team to follow, discuss and give feedback on this process. Supervisory sessions discussed the analysis of each interview individually, and then the combination of the analysis of all interviews.

- Transparency and coherence – the former concerns the clear description of each research stage, while the latter ensures the “fit” between each one of these stages (Yardley, 2000). This broad principle is supported by Meyrick's (2006) model, which provides clear guidance on how to address this principle at each stage of research.

According to Meyrick's (2006) model it is crucial to ensure a systematic documentation of all steps and relevant decisions in the research process in order to make it as transparent as possible. By using this model it becomes possible to provide detailed information about the process, which enables readers to assess the rigour and quality of this study (Meyrick, 2006). In order to demonstrate coherence, specific information about the epistemological and ontological position adopted as well as their historical development and relevance to this study was presented (Meyrick, 2006).

In addition, detailed information about the sampling and the recruitment process has been provided, as well as the rationale and the theory behind

these decisions. Detailed information about participants and their contexts has been offered in order to allow readers to transfer findings to other groups (Meyrick, 2006).

Specific information about data collection as well as the context in which it was carried out was also presented (Meyrick, 2006). Additionally, an audit trail aiming to produce a detailed pathway of decisions made during data analysis was developed (appendix 19) (Miles & Huberman, 1994; Johnson & Waterfield, 2004; Meyrick, 2006; Willis, 2007c). It provided information about all steps included in data analysis and aimed to allow readers to follow the process of generation of themes. Additionally, several quotes from each participant were provided in order to support the researcher's interpretation.

As previously mentioned, in the fourth chapter, a reflexive journal was used to document the researcher's thoughts throughout the research process. It offered the possibility of documenting a critical and reflexive account of the researcher's approach to data collection and analysis (Willis, 2007c). The nature of the researcher's relation with the data aimed to be clearly established (Meyrick, 2006). In this context, the researcher's pre-existing assumptions were made clear through the use of reflexivity. These procedures aimed to enable readers to follow the process of interpretation and assess its rigour (Meyrick, 2006).

- Impact and importance – which draws attention to the utility of a piece of research (Yardley, 2000; Smith et al., 2009b). This study was particularly focused on the Portuguese context, which was important for the Portuguese context itself. Considering that individuals' experiences of health and illness can be "substantially altered" by research (Yardley, 2000, p.223), this study called attention to the experience of having NSCLBP in Portugal. The development of new knowledge in a topic that has not been yet investigated in this country, could have broader social effects such as: stimulating health professionals to reflect on their approach to patients experiencing NSCLBP; including the patients' experiences of NSCLBP in Portuguese physiotherapy undergraduate and postgraduate curricula; open up policymakers' new ways of understanding NSCLBP; promoting health care services reorganisations;

or even, improving the experience of those living with NSCLBP by identifying themselves with this study's participants and reinterpreting their own experiences. Additionally, it also could have impact and utility in foreign contexts, due to the possibility of comparing and contrasting this study's findings with other studies or other contexts of clinical practice. In order to facilitate this process of comparing and contrasting the aforementioned audit trail documented all relevant steps of the data analysis (appendix 19). This information was used as a means to promote the transparency of the process by providing detailed information about the researcher's decisions and facilitate the reader's assessment of analysis (Willis, 2007c; Smith et al., 2009c).

5.10. Reflexive account

Considering that the researcher's abilities to conduct interviews could influence the quality of data collected, the previously mentioned practice in conducting interviews attained major relevance. To develop my interviewing skills, I practiced with several individuals using different interview schedules (all based on a life experience that was relevant to each person). All these interviews were video-recorded, which gave me the opportunity to critically analyse my performance and discuss it with the supervisory team. I also interviewed a physiotherapist/researcher with experience in supervising doctoral students in qualitative studies, who also gave me important feedback. Subsequently, the pilot study was also an opportunity to develop my interviewing skills.

I was familiar with the interview techniques since I had had some experience in interviewing physiotherapists in the scope of a study carried out in the final year of my physiotherapy degree in Portugal. Overall skills, such as establishing rapport or inviting participants to speak freely were easily improved. However, the interviews carried out in the scope of the current study led to new challenges. For example, one of the participants in the pilot study had a very emotional moment, in which I had to interrupt the interview and stop recording. Another participant occasionally mentioned suicidal thoughts, which required

me to reinforce the information previously provided in the participant information sheet, regarding the access to psychological support. Indeed, these examples gave me the opportunity to test the procedures that were previously planned to address possible issues.

In addition, the participants' personality traits were also an important aspect that could influence data collection. For example, two of the participants started the interviews emphasising that they were very reserved and were not used to speaking about themselves. Furthermore, most of the participants revealed that they were not used to talking about their NSCLBP. This would potentially compromise the data collection, since it was focused on the participants' personal experiences. Nevertheless, the interviews eventually provided detailed accounts of the participants' experiences, where they explored several issues of their daily experience of having NSCLBP in depth. The researcher's capacity to establish rapport and develop empathic relationships with the participants, attained a major relevance in optimising this process.

As previously mentioned, the interview schedule was based on a series of open questions that aimed to encourage participants' to speak freely about their experiences. The interviews were also prompted by probing questions introduced by the researcher in order to facilitate the participants' sense making of their experiences. This was an important strategy since it provided the participants an opportunity to broadly explore their experiences of having NSCLBP. Indeed, data collected was not only focused on specific situations related to NSCLBP but also with other situations of the participants' daily life that provided a detailed overview of their contexts.

Furthermore, reflections on my position as a researcher were also important to improve my performance as an interviewer. I was aware that my biomedical influences were deeply rooted in the way I looked at the phenomenon under investigation, influencing the collection of data. For example, throughout the first interviews, I had to make an effort not to think about the pain mechanisms that were responsible for what participants were telling me and to be open to exploring how they understood and made sense of their condition, which was

the main purpose of this research. This was an immediate issue in the development of the interview schedule and led me to make a conscious effort to move from what I called “the physiotherapist’s questions” to “the researcher’s questions”. This effort persisted in data analysis and helped me to focus on “the researcher’s interests” rather than “the physiotherapist’s”. Indeed, being aware of this underlying conflict was quite important as it gave me the opportunity to reflect deeper on my role as a researcher and make a conscious effort to ask questions that were coherent with the purpose of this research.

5.11. Chapter summary

In this chapter, the procedures carried out in this study have been presented. Details about participants’ recruitment and ethical considerations have also been examined. Moreover, methods of data collection and analysis as well as the strategies used to ensure the rigour and quality of this study have been presented. The next chapter addresses the findings of this study.

Chapter 6: Findings

Findings from the interviews carried out with this study's participants are presented in this chapter, which consists of six sections. In the first section, the analytic approach is presented. In the second section, an overview of the presentation of the findings is provided. In the third section, the participants of this study are introduced, with particular emphasis on the complexity and diversity of their personal contexts. The themes, sub-themes and concepts that emerged from data analysis are explored in the fourth section. The key findings and interrelations between themes are presented in the fifth section. Lastly, in the sixth section a reflexive account on the process of data analysis is provided.

6.1. Analytic approach

As previously mentioned in chapter 5 (section 5.8.), data analysis followed the orientations provided by Smith et al. (2009a). Given the non-prescriptive nature of these orientations, the researcher developed several adaptations and strategies as the analytic work progressed. This section expands on the overview of data analysis provided in chapter 5, by providing detailed information on the specific strategies that were part of this process. The following paragraphs illustrate an overview of the main stages of data analysis and include information on the specific strategies developed by the researcher. Some examples of the material produced are also presented.

First Stage

The researcher immersed herself in the data and focused the analysis on a specific participant (Smith et al., 2009a);

Strategies

- The first transcript and recording were read and heard several times.

Second stage

The researcher developed comprehensive and detailed notes and comments on the data, and gradually looked at more complex issues, moving from descriptive to linguistic and conceptual comments (Smith et al., 2009a);

Third stage

The researcher identified the first emergent ideas, which resulted from a co-construction of meaning since they included not only the participant's words but also the researcher's interpretation. This process was orientated by the hermeneutic rule of movement between the parts and the whole – the original transcript became a set of parts, which then come together in a new whole at the end of this stage (Smith et al., 2009a);

Strategies

- The transcript was introduced into a table, which included four columns:
 - the first (from left to right) included the line numbers;
 - the second included the exploratory comments that gradually addressed more complex issues, firstly, via descriptive comments focused on describing the content, secondly via linguistic comments concerned with the specific use of language, and finally via conceptual comments focused on engaging at a more interrogative and conceptual level (Smith et al., 2009a); comments from supervisory team were also integrated (as a strategy for prompting depth of the researcher's reflection and interpretation);
 - the third column included the original transcript;
 - the fourth column included the first emergent ideas (which were considered as preliminary concepts that represented both the participant's words as well as the researcher's interpretations).

Fourth stage

The researcher explored ways of charting how the ideas (from the previous stage) fitted together and underpinned the preliminary emergent themes (which combine a range of related ideas). This aimed to find a way of drawing together the ideas as well as preliminary themes and producing a structure that reflected the participant`s account (Smith et al., 2009a);

Strategies

- The content of the right hand column of the previous table was manually introduced into the N-Vivo 7 research software. Each emergent idea was converted into a free node that was codified as follows:
 - **e.g. 4_Laura_032_Hipotesising something serious (L.12.245)**.
In the previous example: **4** identified the number of the interview (in chronological order), **Laura** the participant`s pseudonym, **032**, the number attributed to the emergent idea (in chronological order), **Hipotesising something serious** represented the emergent idea, and **(L.12.245)** represented a code that enabled the excerpt correspondent to the emergent idea in the transcript to be located easily (**L** - first letter of the participant`s pseudonym, **12** - table transcription page number, **245** - table transcription line number). This record helped the researcher to quickly relate the first identified ideas and the excerpts from each interview;
- The list of free nodes was exported to an excel document, which was used to preserve a detailed record of the development of the emergent themes and concepts. A 5-columned table was created in order to represent the process that lead to the development of the preliminary themes in the interview as well as the concepts and related excerpts. The development of the content in the aforementioned table included several strategies, such as:
 - using a colour classification to identify ideas that were related to the same subject - each colour represented a specific subject and the same code was used in all interviews;

- collapsing similar ideas, without losing the previously selected excerpts;
 - grouping ideas related to the same subject (preliminary concepts and themes);
 - searching for connections across themes via strategies such as abstraction and subsumption (chapter 5, section 5.8);
 - additionally, two strategies were included in this process in order to engage in a deeper level of analysis: the development of a conceptual map and an individual narrative that integrated both the researcher`s interpretation and the participant`s selected excerpts (Smith et al., 2009a). It was certified that all emergent themes were part of this, avoiding the loss of any theme or concept at this stage;
- In order to keep a record of the decisions undertaken in the previous stage, a tree node was developed using the N-Vivo 7 research software.
 - The tree node included the emergent themes and the concepts included in each theme;
 - Additionally, the transcript of the interview was revisited and codified in order to associate the participant`s excerpts to the correspondent elements of the tree node. This enabled the researcher to click on the themes/concepts of the tree node and have a quick visualisation of the excerpts from the interview that supported them.

The following figure (figure 1) provides an excerpt from the tree node developed during the analysis of Laura`s interview. In this figure, “4_Laura_interview” is the root node, the parent nodes (e.g. “Always the same unanswered questions”) represent the themes and the child nodes (e.g. “Having a diagnosis would give me hope”) represent the concepts.

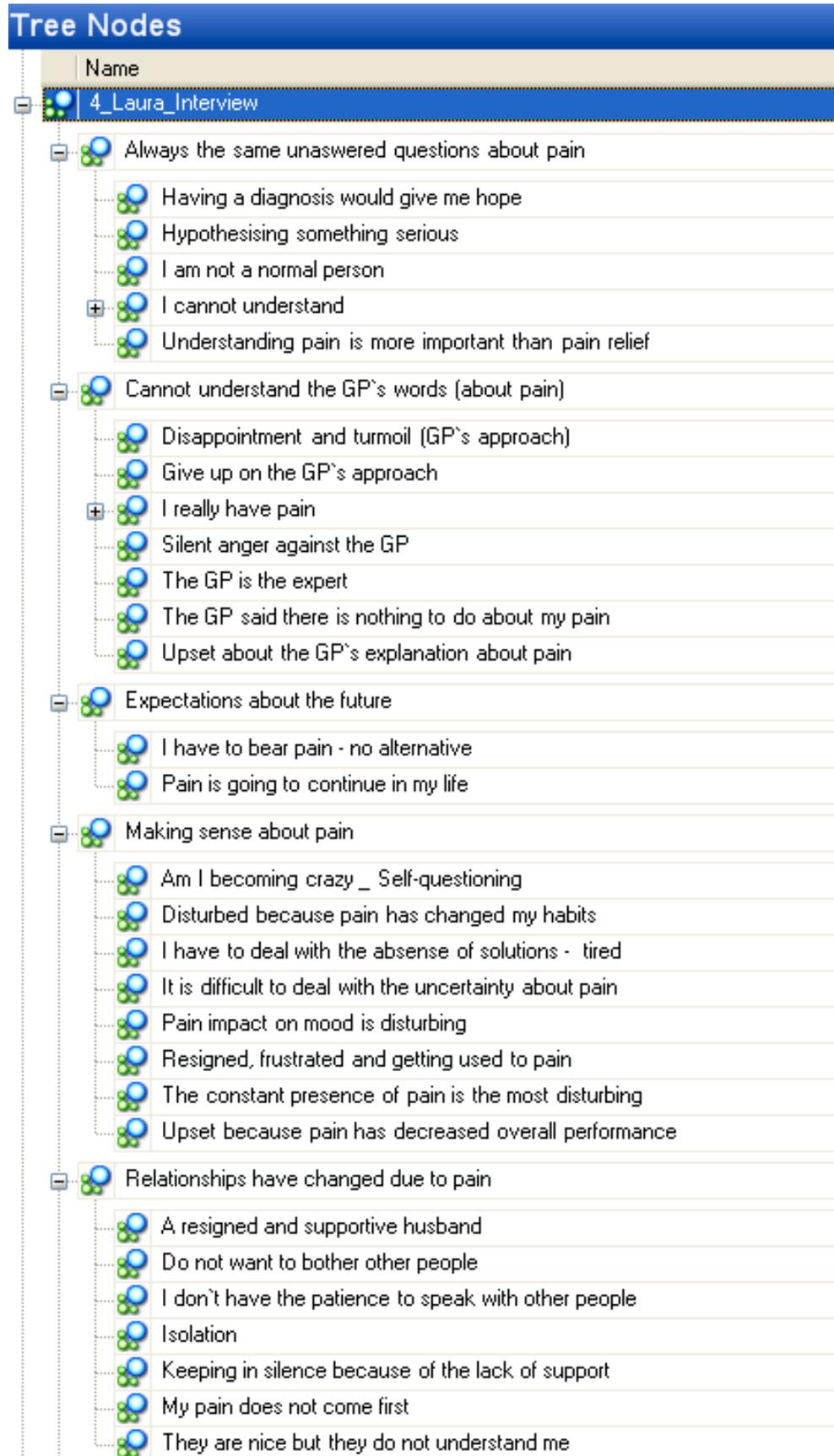


Figure 1 – Excerpt from the tree node of Laura's interview
(Print screen from N-Vivo 7 research software)

Fifth stage

The researcher moved to the next participant's transcription and repeated the whole process. Each transcription was managed on its own terms in order to respect the idiographic nature of IPA (Smith et al., 2009a);

Sixth stage

The researcher looked for patterns across the cases (each participant). A table of the preliminary themes from each participant was developed (Smith et al., 2009a);

Strategies

- An 8-columned table was developed, each column corresponding to one participant.
 - Each column was exported from the fifth column of the previously developed (fourth stage) tables (one for each participant). This helped the researcher have an individual perspective of all themes and concepts that emerged in each interview. Additionally the colour classification provided a quick visualisation of possible convergence and divergence among the interviews.
 - Several strategies, such as conceptual maps or notes in the reflexive journal, were also used in order to increase the depth of analysis (Smith et al., 2009a) and develop the final themes that combine the analysis of the eight interviews (presented in section 6.4).

The following figure (figure 2) illustrates a short version of the aforementioned table as it offers an individual perspective of the preliminary themes emerged from each interview. For the purpose of this thesis, the concepts were removed from the table in order to facilitate reading.

Alice	Eva	Helena	Laura	Rita	Fernanda	João	Marília
Why do I have pain?	Trying to understand pain	Pain explanation –asking herself several questions	Always the same unanswered questions about pain	Trying to understand pain	It is very difficult to find an explanation	Cannot explain pain	Resigned to the lack of understanding about pain
Alice and other people `s explanations	Experiences with health professionals	Disappointed with health professionals	Cannot understand the GP` s words (about pain)	Making sense of pain	Health professionals do not “solve” problems (pain)	The GP drew attention to the idea of a fragile spine	The GP knows the reason for having this pain
Experiences with health professionals	Living with pain and making sense of pain	Living with pain and making sense of pain	Making sense of pain	Pain story as life story	Making sense and dealing with pain	Pain impacts on daily life	This pain is really strong
Making sense of pain	Pain as part of daily life	Pain as part of daily life	Pain is deeply incorporated and has a strong impact on daily life	Doing what needs to be done no matter the pain	This pain is really strong	Pain story as life story	Resigned to live with pain
Pain as part of daily life	Dealing with pain in daily life	Trying to live (survive) with pain	Relationships have changed due to pain	Son as young carer	Have to live with this pain	Several episodes have damaged spine – need to protect spine	Taking care of herself
Dealing with pain in daily life	Cannot relieve pain	Need to survive – need to support family	Expectations about the future	Strong enough to bear pain	Cannot be sick	The impact of pain interpretation on expectations about the future	Not disabled because of pain
Cannot find a way to relieve pain	Pain and other people	Family vs other people	The altered self is the most disturbing	Pain is not that important		A contradictory vision about himself	Doubting herself
Pain and other people	Expectations about the future	Expectations about the future					
Expectations about the future							

Figure 2 –Preliminary themes emerged from each individual interview - each column indicating the themes from each participant

More detailed information about the procedures involved in data analysis as well as detailed examples of the material developed can be found in the audit trail presented in appendix 19.

6.2. Overview of the presentation of the findings

The focus of the analysis was concerned with the participants' experiences of having NSCLBP and the meaning they made of their disorder. The findings present an account of how the researcher made sense of participants making sense of their disorder (Smith et al., 2009a).

Following an inductive process of data analysis, five themes emerged to help understand the experiences and perceptions of Portuguese individuals with NSCLBP disorder.

The themes reflect both the participants' shared experience of the phenomenon under investigation as well as the particular way in which each participant experiences this phenomenon (Larkin et al., 2006; Smith et al., 2009a; Smith, 2011b; 2011a; Smith & Osborn, 2004). Given the idiographic nature of IPA, where the unique experience of each participant is emphasised, each theme is split into sub-themes and concepts, which provide detail and highlight the individual variations (Smith et al., 2009a). It is important to emphasise that although all participants contributed to each theme, not all developed all the concepts. The labels selected for themes, sub-themes and concepts aim to reflect the participants' words as much as possible. It is important to highlight that the account produced is based upon, but may transcend or exceed the participants' own terminology (Smith & Osborn, 2004).

Findings are presented and contextualised combining the participants' words and interpretations with the researcher's interpretations. Translated excerpts from the interviews are presented to support the researcher's analysis. The selection of these excerpts were considered to best illustrate and provide depth to the concepts being discussed, while finding a balance between this and the prevalence of participants within each theme. The punctuation in these excerpts

tried to reproduce the participants' speech (e.g. commas meant small pauses; suspension points meant longer pauses; exclamation mark expressed strong intonation, statements). Even with incorrect punctuation, it was considered important to maintain this in the interviews' excerpts, in order to preserve the content from the Portuguese version. Additional excerpts supporting the themes can be found in appendix 20.

The participants' pseudonyms, the transcript's page number and the line number are introduced after each excerpt.

6.3. Participants' vignettes

From the nine individuals who demonstrated interest in being interviewed, one was not included due to exclusion criteria – the individual had not experienced low back pain at least during 12-month period, for the majority of the year.

The following paragraphs contextualise the eight participants and aim to place them in the study. In coherence with the methodological approach, this strategy aims to help readers situate the participants as individual parts in the whole account produced. Participants' personal accounts are presented as short vignettes that outline the main information about their personal context, including details about age, living context, family, profession, current employment status and perceived total length of time with NSCLBP (Smith et al., 2009d). Moreover, details that capture the essence of each participant's background, understanding and making sense of their disorder are also highlighted, in order to facilitate the recognition of each participants "voice" in the final account presented.

Alice was forty-eight years old. She lived with her husband and her adolescent daughter in a small city in central interior Portugal. She left school at a very early age and started working as a dressmaker to help her family. She also worked as a shop assistant, a cook and at the time of the interview she was a cleaner in a University. She described herself as a very reserved person without friends.

Alice had had low back pain since she was very young and could not identify when it started. She related her NSCLBP to her jobs, but needed to work in

order to support her family. Everything in her life seemed to be about doing whatever needed to be done in order to support them. Alice appeared to have restricted her life to what was absolutely necessary: her job and taking care of her family. She had always been used to taking care of others, and felt that responsibility. Alice reported being ashamed of asking for help, even when she was in pain.

Eva was forty-six years old. She lived with her husband and her adult daughter in a small city in central interior Portugal. Eva was a librarian. At first glance, she was a very positive and communicative person and spent the whole interview smiling and laughing. She seemed to avoid thinking about negative issues, focusing her attention on the solutions rather than on the problems. Despite this, she admitted that it was very difficult to talk about her NSCLBP. Eva recalled having low back pain since she was very young. She hypothesised that it was connected to a car accident that had occurred when she was eleven years old, but was still looking for a doctor to confirm this. She had had pain since this episode, but it had become more intense and frequent in the last two years, in which she reported experiencing pain on a daily basis. She had tried different strategies to relieve pain, but had not been successful. Although Eva emphasised that she had a positive attitude regarding the future, she believed pain would never disappear from her life. She feared losing her autonomy and becoming dependent on other people. Due to this fear, she reported that she kept pushing herself to her limits and described herself as someone who never says “I cannot do it”.

Helena was fifty-four years old and lived alone in a small city in central interior Portugal. She reported having great support from her son and nephews. They all had a close relationship, as they had lived together for many years. She was a civil servant, working as a secretary in an open office space. Her working environment seemed to be uncomfortable for her, as she reported being teased about her pain. She admitted dealing with situation by isolating herself. She also explained that it was difficult to talk about her NSCLBP because she was a reserved person. During the interview she appeared to be shy and

uncomfortable with being the centre of attention. She did not seem to be used to talking about herself for so long.

Helena had NSCLBP for approximately fifteen years and could not recall a specific incident that may have triggered it. She reported that she had knee pain before having low back pain, but she did not know if there was any connection. Although Helena perceived her NSCLBP as disturbing, she considered that she had suffered more from the death of close relatives. She repeatedly emphasised that: “I need to keep fighting for my life because my family needs me”.

Laura was forty-eight years old and lived with her husband in a small city in central interior Portugal. They had two sons who were living and studying at university in another city. She worked as an assistant in a nursery and emphasised that she loved taking care of babies. She believed that her job caused her to experience pain, but planned to keep it because she enjoyed it. She reported that NSCLBP was a distressing experience as it changed her as a person.

Laura had had NSCLBP for the last four years. She could not associate her pain with a specific episode in her life but she highlighted that it had coincided with the move of her older son to another city. She emphasised the disabling nature of NSCLBP, as she had stopped doing activities that she liked.

Rita was forty-three and lived with her husband and their two children (eight and sixteen years old) in a small town near the central Portuguese coast. At the time of the interview, she was as a cook at a social welfare institution. After her mother`s death and her father`s alcohol dependency, she started farming (from fourteen to seventeen years old) to ensure her and her sister`s survival. She moved from the North of Portugal to the central coast looking for better life conditions. She took a seamstress training course and worked in clothing factories for eight and a half years. Although she said she loved to sew, she did not like to work in the factories, not because of the difficulties of the job, but because it was very monotonous. The factories closed down and she started working as a cook – first at a private individual`s house, and then in her current

job. To make ends meet, she also worked from home making codfish pastry to sell.

Rita could not recall a specific episode that may have caused her NSCLBP, however she related it to the physically demanding jobs she had had since her adolescence. In her account, she repeatedly changed the subject from herself to her everyday life activities. She seemed to be focused on ensuring her family's sustainability and emphasised her hope of raising her children and giving them a better life than what she had had.

Fernanda was fifty-three and lived alone in a small city in central interior Portugal. She got divorced more than twenty years ago and had one son (twenty-six years old). She did not maintain regular contact with her relatives: her son was living in another city with his family; her mother died some years ago and since then she had not spoken to her father and brother. She was a special needs-young learner teacher. Her background was in public relations, but fifteen years ago she had training in mental and motor disability, which led her to start working with special needs children.

Fernanda had had NSCLBP for the last five years and throughout this period had some acute episodes, where she described pain as being "*awful*" and responsible for making her "*crazy*". She related her NSCLBP to expected degenerative processes that result from ageing. She described the overall experience of NSCLBP as "*horrible*" because on some occasions the pain was so strong that it prevented her from going to her job or caused her to arrive late and miss the first lessons of the morning.

João was forty-seven. He lived with his wife and their two children (twelve and thirteen years old). At the time of the interview, he was starting a new business in the area of biological farming. He had run other businesses - a domestic appliances shop for approximately twenty years and then a real estate agency for a couple of years. The Portuguese economic crisis and the subsequent fall in the real estate market led him to abandon the latter.

The first memories of having NSCLBP were in his twenties, which was when he had his first and only appointment regarding this problem. He could not identify

a specific episode as responsible for his pain. Rather, he believed that it was the result of several events in his life, in which his physically demanding jobs were perceived as having major relevance. For him, NSCLBP was an “*up and down experience*” – some days he felt better, some days he felt worse. This really depended on the stage – more or less acute - of this chronic experience.

Marília was fifty-seven. She lived with her husband and her youngest son in a city near the central Portuguese coast. She had two children - a girl (when she was sixteen) and a boy (when she was thirty-four). At the time of the interview, she was sewing at home and had a part time job cleaning medical clinics. She had started working when she was fifteen as a design assistant, designing labels at a printing company. Years later, this company went bankrupt and she moved to another printing company at the age of thirty-three, where she was responsible for organising the pages of newspapers and had a very busy schedule. She worked in this area for thirty-six years, but was made redundant after the death of her last boss. Her unemployment motivated her to make a big change in her life and she decided to start a new business – a café – with her husband. Soon after, they closed the café, as it was very tiring.

Marília did not remember when she started having NSCLBP, but she associated it with the early years of her professional life. Although she recognised the impact of NSCLBP in her everyday life, she emphasised that she was focused on finding strategies that could help her deal with and minimise its impact.

6.4. Analysis: emergent themes, sub-themes and concepts

The participants` accounts of NSCLBP appeared to be indicative of the disruptive nature of this experience. Seemingly, the structures of their everyday life and the forms of knowledge that underpin them seemed to be changed as a consequence of NSCLBP. More specifically, these participants seemed to be living a deferred life (theme 1) where they were focused on: (i) searching for the meaning of NSCLBP (theme 2); (ii) searching for someone who could solve it (theme 3); (iii) trying to prove its legitimacy (theme 4); and, (iv) trying to prove their own credibility as individuals experiencing NSCLBP (theme 5). The main

emergent themes are represented in the figure below. These themes are expanded into sub-themes and concepts in the following sections.

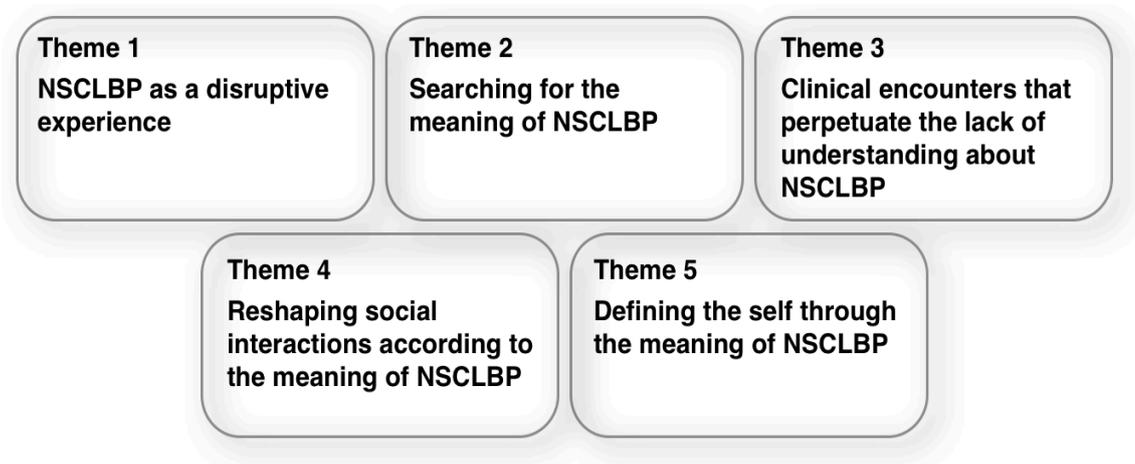


Figure 3 – Overview of the themes emerged in this study

6.4.1. Theme 1: NSCLBP as a disruptive experience

In this theme the disruptive nature of the participants` experience of NSCLBP was articulated. The impact of NSCLBP was examined with particular emphasis on the participants` own restrictions on their everyday life. Also discussed were the participants` attempts to deal with NSCLBP. In particular, the participants` endeavours to gain control of NSCLBP and the inherent obstacles were highlighted. This theme was formed by two sub-themes that are represented in the figure below. Each sub-theme was underpinned in central concepts, which are also represented below and discussed further.

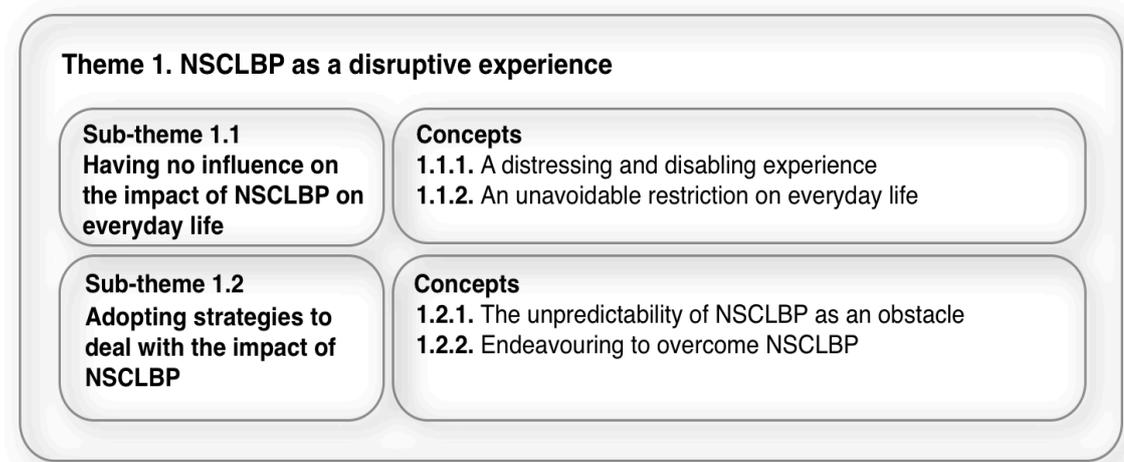


Figure 4 – Overview of the sub-themes and concepts included in the first theme

Sub-theme 1.1. Having no influence on the impact of NSCLBP on everyday life

The experience of NSCLBP seemed to be perceived as disruptive, since the participants emphasised its debilitating and restrictive impact. This idea was particularly highlighted by the participants with shorter experiences of NSCLBP for whom comparisons of before and after seemed easier. However, even those participants with longer experiences supported this idea. In this context, the impact of NSCLBP on the participants' everyday life emerged as one of the most immediate topics in the participants' accounts. This sub-theme articulated the participants' perspectives on this impact and was organised into two central concepts: a distressing and disabling experience; and, an unavoidable restriction on everyday life (figure 4).

Concept 1.1.1. A distressing and disabling experience

When prompted to explore their experience of NSCLBP, some participants used words such as "difficult" (Laura.2.39) or "agonizing and tormenting" (Eva.2.35-38) to describe it.

"Sometimes I let it go... A person gets used to living with this [NSCLBP], but sometimes it's a bit difficult..." (Laura.2.36-39)

"It's agonizing and tormenting... It gets worse and worse... With the passing of time, it gets worse... because it stopped being something occasional and started being something that happens on a daily basis..." (Eva.2.35-38)

Interestingly, the use of these words suggested an underlying suffering, which appeared to be related to the chronic nature of this experience. Although Eva reported some episodes of strong pain, it was not the intensity but the frequency that most disturbed her.

"This is a pain that... I mean, I... I feel this pain every day and on several occasions during the day... So, you see that... it's there while I'm walking... it's there during some professional tasks... during

housekeeping... it's always there... After all, it's there on work days, weekends... every day..." (Eva.15.325-331)

Similarly, the constant presence of pain seemed to be the most disturbing in Laura's experience. Although accustomed to living with NSCLBP, she emphasised its distressing impact.

"Because this pain is exhausting... I don't know how I can explain this! I don't know how I make myself clear! It's exhausting, exhausting because it's always... always there. For example, we've got a pain in our foot, but after a while it goes away... but this pain, it's always here! For example, we have pain somewhere... we take an anti-inflammatory, it's not an anti-inflammatory it's a pain killer... For example a headache... we take a pain killer and after a while it's gone, everything is all right. But this pain... it's always here... constantly... wearing you down" (Laura.39.857-867)

Furthermore, the participants' words to describe their experience of NSCLBP also seemed to emphasise its disabling impact. Interestingly, despite the various lengths of time with NSCLBP, ranging from approximately four years (Laura's account) to forty years (Marília's account), all participants emphasised the influence of NSCLBP on several dimensions of their life. The majority reported this influence on a professional level. For example, Alice and Eva reinforced their difficulty in performing some professional tasks.

"So, on some days it's really difficult to work... it's a huge sacrifice. Some days, I need to... carry the rubbish at the end of the day... when I bend down... also when we had to push furniture... moving tables from one place to another, this is... Some days, I'm in tears... it's such a pain... it's such a bad feeling and it hurts! (...) Some days it's a real sacrifice..." (Alice.4.65-77)

"My job... I work at the library... One of the most difficult tasks is to put the books back on the lower shelves... sometimes I have to... no one knows

and no one notices... but I have to get into a strange position... I need to be close to the chairs or the tables, so I can get up. Because, if I'm not close to any chairs or tables it's like this: I need to sit on the floor, knees on the floor and that's that... and then grab something so I can get up... This task is really difficult for me and I need to do it on a daily basis... and it's really hard... the last two shelves are terrible... especially the last one... It's really, really hard. So painful..." (Eva.15.309-326)

Fernanda also highlighted the interference NSCLBP had on her job. However, while in the previous examples it made the participants' professional tasks more difficult, in Fernanda's account it prevented her from going to her job.

"In my experience... it was horrible... I would get up in the morning... tears streaming down my face while putting on my tights and at that time I was teaching in X, and I had to call my colleagues many times to tell them not to expect me, because I couldn't go... I couldn't get dressed in time... I had to miss the first class because I wasn't able to... even to get up... I couldn't stand... the pain was... in my lower back..." (Fernanda.2.23-33)

Moreover, NSCLBP also seemed to have a considerable impact on a personal level. For example, Eva, João and Laura emphasised how NSCLBP impacted on their family life, daily life activities and leisure.

"It's awful! For example, making the bed, cleaning the bath... It's awful! (...) Really awful! I've never cleaned the bath without being in pain... Do you understand? It's related to the position you get into, I can't clean it (...) Some tasks are really difficult for me, but I need to do them..." (Eva.53.1158-1172)

"When they were babies just to hold them in my arms.... I had pain and I had to... it's the same pain I have when I'm in the kitchen and need to carry something.... I have to put the object down and sit down... so you

can imagine. So, obviously this has had a great impact in my life...”
(João.55.1203-1209)

“Imagine, in the supermarket, you need to go from one aisle to the next to pick up this and that... This is like torture... So, I make a list and ask my husband to do it... I prefer to stay at home...” (Laura.4.78-83)

Laura`s use of the word “torture” may be seen as a metaphor that reinforced the previously mentioned distressing and disabling impact of NSCLBP expressed by other participants. This metaphor could be also interpreted as an underlying lack of control, as those being tortured are not in control of a given situation.

Moreover, the use of words such as “awful” or “torture” in the previous excerpts also suggested the participants` perception of having to deal with more adversity in life than people who did not report pain. In the following excerpt, Eva emphasised this idea.

“Why does it have to be like this? As I usually say, why does a person suffer like this in life? Just to do... sometimes, it`s about very simple tasks... so simple! So simple... and I need to make such a huge effort to do those tasks... and other people don`t have to... my effort is much greater, do you understand? It`s greater, much greater!” (Eva.63.1374-1382)

There seemed to be an underlying sense of unavailability inherent to the aforementioned adversity. Eva`s question, “Why does it have to be like this?”, may be indicative of her perception of having little influence on the impact NSCLBP had on her life. Indeed, there seemed to be a tendency to explain the aforementioned distressing and disabling impact of NSLCBP as a consequence of external and uncontrollable causes.

Concept 1.1.2. An unavoidable restriction on everyday life

The impact of NSCLBP seemed to lead the participants to a progressive abandonment of leisure activities, as there seemed to be no room for these

aspects. The exploration of their routines indicated an apparent concentration on the activities that were perceived as duties or obligations.

“I thought... I need to work, I have to raise my son, he needs to study... And I`m a single mother... although I`ve got some support from relatives... but this is my main responsibility, right? So, I need to forget this pain, in this situation I need to forget pain because I need to move on, I need to fight for my life, I need to fight... And no matter how painful it is, I need to keep doing my tasks... I can`t sit down complaining – Ow, I`m in pain! My back hurts! I can`t move! I can`t work! – What would happen with my life? So, I needed to move on, needed to fight, needed to work, I still need to work! So, I come in second, or third place, depending on the circumstances, right?” (Helena.41.900- 916)

The participants` lives appeared to be focused on the idea of ensuring their own and their family`s sustainability. They seemed to be driven by the fear of what would happen to them, and especially their relatives, if they could not follow through with their obligations.

Thus, they were focused on accomplishing their duties, while hiding their pain from others. Such an apparently absorbing task seemed to lead them to gradually restrict their lives to what they perceived to be mandatory tasks (such as housekeeping or professional tasks), as their accounts were focused on taking care of family and working. Thus, in order to accomplish the aforementioned mandatory tasks, they seemed to have restricted other dimensions of their lives, as there were no references about them in their accounts.

In this context, some accounts may call into question the motivation behind the participants` commitment to their duties. For example, Rita`s phrase “I`m supposed to” in the following excerpt may support this idea as it was unclear whether her commitment was the result of her free choice or her perception of what others expect from her.

“I have had this pain for many years... Some days are better, others are worse... It also depends on the physical effort I make, but there were movements that were very hard for me to do. I used to do everything, I’d go about my normal life, because I’m supposed to, right?” (Rita.1.4-9)

Rita’s phrase “I’m supposed to” may also be indicative of an underlying resignation to the impact of NSCLBP on her life, and to the subsequent restriction of everyday life. The participants’ accounts seemed to illustrate an underlying tendency to explain the distressing and disabling impact of NSCLBP as a consequence of external and uncontrollable causes that are perceived to be impossible to change.

Sub-theme 1.2. Adopting strategies to deal with the impact of NSCLBP

Notwithstanding the apparent unavoidable impact of NSCLBP, the participants were compelled to reorganise their everyday lives. Despite the apparent fatalism of their words, there seemed to be a common desire to overcome pain. When adopting strategies that could help them to deal with their NSCLBP, its unpredictable nature seemed to present an obstacle. Their struggle to deal with this unpredictability called attention to the participants’ endeavours to gain control of their NSCLBP. This sub-theme was organised into two concepts: the unpredictability of NSCLBP as an obstacle; and, endeavouring to overcome NSCLBP (figure 4).

Concept 1.2.1. The unpredictability of NSCLBP as an obstacle

In the context of participants reorganising their everyday life to deal with NSCLBP, nearly all emphasised their difficulty in doing so.

“I believe that depending on the physical effort I’m making... or... any physical task in which I need to... lift something, for example... anything... it’s painful... but sometimes, it’s not... Sometimes, I don’t do anything... (...) I don’t know... I don’t know.... I don’t know... This happens... frequently... Sometimes, that task is painful, sometimes it isn’t...”
(João.29.620-631)

The unpredictable nature of NSCLBP seemed to explain the participants' difficulty in controlling its impact on their lives. Fernanda reinforced this idea by emphasising the disturbing effect of not being able to anticipate how her pain would manifest itself in a few hours.

“This [the unpredictability of pain] scared me incredibly, because when I laid down at night, I didn't know how I would wake up... So, I could never predict if I could go to work or not. Because when I woke up in the morning... So, I would lay down without pain and would wake up with that horrible pain in the morning...” (Fernanda.10.206-212)

Concept 1.2.2. Endeavouring to overcome NSCLBP

Despite the participants' difficulty in dealing with the unpredictability of pain, all seemed to have adopted their own strategies to keep doing the activities they reported as essential. Nevertheless, not all of their strategies seemed to be effective since the participants appeared to be prevented from doing several activities. More specifically, regardless of the efficacy of the aforementioned strategies, the participants seemed to keep using them, as alternatives were not available. For example, some participants used to take medication, rest or perform painful tasks in one go, ignoring the pain. The following excerpts, from Helena and Eva exemplify these strategies.

“Sometimes pain is really strong, really strong... Sometimes, my eyes fill with tears... when I'm doing the housework... cleaning the floor... I've got a big terrace and when I'm cleaning the floor... (...) that movement, using the broom... I need to stop several times... I have to! To sit down... stand up... lie down... I have to! This is really painful” (Helena.2.21-31)

“If I stop doing the task... then... No one can ask me to do anything because I can't do anything else! I'm at the limit! I reach the limit... (...) No way, I can't rest... I can't rest... because it's worse, much worse, much worse...” (Eva.54.1180-1187)

Interestingly, while Helena stayed still, Eva pushed herself until what she perceived to be her limits. Therefore, although they continued doing some of their tasks, their lives seemed to be controlled by NSCLBP. There seemed to be an underlying frustration and sense of hopelessness in their accounts, since they perceived to have no control over their lives. There was also an underlying idea they would not be able to have this control ever. For example, in the previous excerpt Eva claimed that she had reached her limit after doing a task. She appeared to present this as a fact and did not seem to consider the possibility of any changes to this situation, as this was perceived as out of her control.

On the other hand, in order to overcome NSCLBP, some participants seemed to be actively engaged in overcoming pain. For example, Rita and Marília exemplified these responses. They divided a demanding task into smaller and easier tasks, or reconfigured their tasks.

“I do everything as normal! It’s just that for example, sometimes, instead of doing it all in one go... For example, I’m peeling potatoes (...) It starts hurting more, so I go and have a glass of water, or go to the toilet, or so, I always find a way... (...) When the pain gets stronger I take a break! I might take 2 or 3 minutes longer to do things, but I’ve never missed my job, I’ve never missed a working day, I’ve always gone to work as usual! I’m just a little limited...” (Rita.25.532-543)

“When I started having pain... I started feeling limited in doing some tasks, right? For example, standing up for long periods of time... we got a stool so I could have a seat... so, I could work sitting down... (...) And, when I wasn’t able to stand... I would work sitting down...” (Marília.30.638-646)

Rather than react to pain, like Helena, Rita seemed to try to prevent its increase and rather than ignore pain, like Eva, she seemed to focus on finding the best strategies to keep doing some activities. Although Rita seemed to follow her mother’s example - work hard and ignore pain - she was also trying to go against it in order to make her life longer than her mother’s.

Similarly, Marília seemed to have reconfigured her everyday life in order to overcome her NSCLBP. Contrary to Helena and Eva, Rita and Marília seemed to perceive themselves as having some capacity to deal with NSCLBP, while still recognising its negative impact on their lives.

“The things need to be done... so I do them slowly... I clean more slowly... vacuum more slowly... and keep doing everything... we need to deal with pain... Even when my son was little... to carry him... I needed to do that...”
(Marília.31.661-666)

Although Rita and Marília reported having slowed down the performance of their everyday tasks, they seemed to perceive themselves as able to deal with obstacles inherent to their disorder. Rather than stay still or push their limits, they appeared to believe they were able to move forward with their everyday lives. Contrary to Helena and Eva, Marília’s phrase “the things need to be done... so I do them slowly...” seemed to be indicative of her perception of being able to have some control over her NSCLBP. Indeed, she reduced the speed of her performance and this allowed her to control pain and keep doing all the tasks she needed to do.

Regardless of the different perceptions of the ability to deal with NSCLBP on everyday life, all participants compared their past and current physical performances, emphasising a progressive decline. Thus, although reporting the uncertainty of the course of their NSCLBP, all admitted the possibility that it would progressively worsen.

“This... This won’t get better... day after day... pain is always with me, a dull pain... I don’t believe that it’ll get better” (Alice.51.1102-1104)

“Usually when you have a health problem you go to a doctor to help you, right? When your doctor says that there is nothing he can do... nothing... just pills and nothing more... You have to convince yourself that it’s going to continue like this... I think so, I don’t know!” (Laura.9.195-199)

Although the possible increase of pain worried participants, it seemed to be the loss of autonomy that disturbed them the most when they projected their life in the future.

“I see myself in the future... Maybe using a wheelchair... because day after day, well it isn't day after day, it's year after year... I'm getting worse... worse... and with the passing of time I'll have more pain, for sure. (...) I believe that one day... I'm not sure about the wheelchair... but I'm sure that I'll be disabled... at least in my ability to walk... for sure” (Helena.38.816-824)

It is interesting to note that the anticipated disabling course of NSCLBP seemed to be presented in a fatalistic tone. Contrary to the previous examples, Marília considered the progression of NSCLBP as dependent on her ability to deal with it. In the following excerpt, she seemed to be confident in her ability to do so.

“Well I don't know... I don't know! But I know how to deal with pain, so... It's like when we go through menopause, right? I'm already going through menopause and I'm dealing quite well with it... I know that I have to feel the hot flashes... but, I put things behind me... Ow these hot flashes! No, I'm not having therapy, like many people, I'm not having therapy! Even the doctor agreed with that... And, the pain is the same... If I'm in pain, I try to deal with it... Or I take pills... if it doesn't work, I go to the doctor. I can't do anything more. I think so... right?” (Marília.49.1075-1086)

Thus, in the context of a disruptive experience, the participants' perceived ability to deal with NSCLBP appeared to have some influence on its impact on their current everyday life, as well as their expected future everyday life. Alongside the impact of NSCLBP, the need to deal with unpredictability and overcome their disorder led the participants to engage in a search for meaning.

6.4.2. Theme 2: Searching for the meaning of NSCLBP

The participants` meaning making of NSCLBP and desire to understand it were explored in this theme. The participants` explanations for NSCLBP as well as their usage of other people`s explanations were also examined. Additionally, the apparent relationship between the reported needs for understanding NSCLBP and controlling it were highlighted. This theme was formed by three sub-themes that are represented in the figure below.

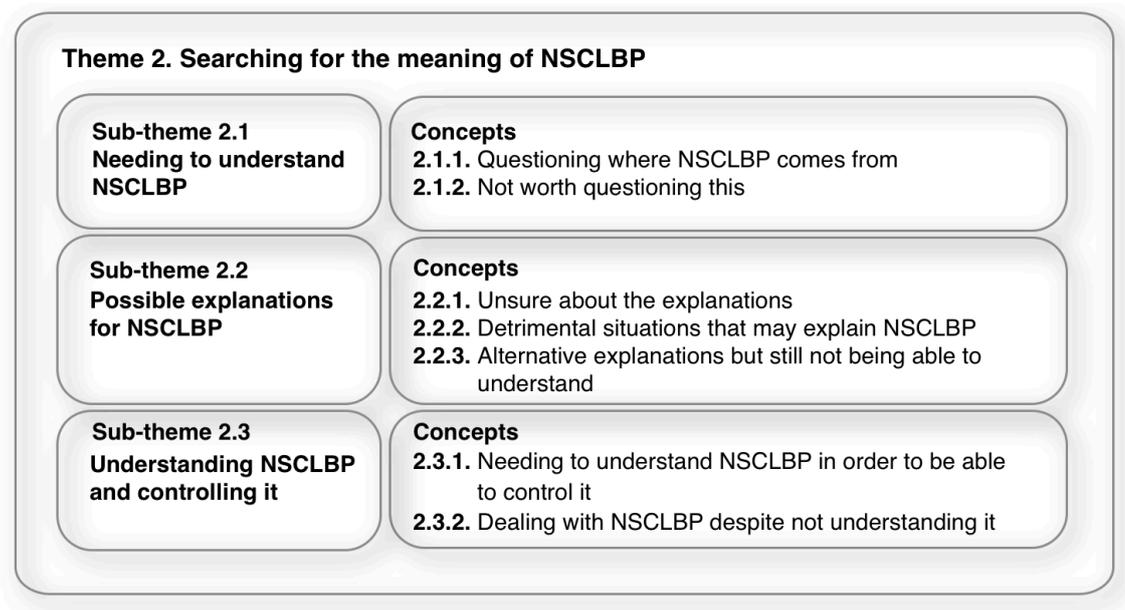


Figure 5 – Overview of the sub-themes and concepts included in the second theme.

Sub-Theme 2.1. Needing to understand NSCLBP

The majority of this study`s participants shared the need to understand why they have had NSCLBP. Throughout the interviews they frequently emphasised the lack of explanation for their experience and their search for meaning. However, the importance of understanding NSCLBP and efforts made to do so, were seemingly quite different depending on the participant. This sub-theme reflected these differences and was organised into two central concepts: questioning where NSCLBP comes from; and, not worth questioning this (figure 5).

Concept 2.1.1. Questioning where NSCLBP comes from

Some participants seemed to be focused on developing an understanding of NSCLBP to help them clarify its meaning. For example, Eva demonstrated this search for explanations by relentlessly making an effort to justify her NSCLBP. Central to her account of making sense of pain, was her constant attempt to identify which situations in her everyday life were responsible for it.

“I don’t know if it happens because I move my leg more... if it’s because I move it... I can’t explain this... it also happens when I walk on the pavement... it’s so flat... sometimes I look back just to see where I put my foot... why was it so painful? Because, usually it’s slightly uneven... or sometimes it happens when I go down the stairs... or just walking (...) But it also might happen when I’m sitting down and I’m not in pain... and a slight movement is enough to cause me pain... very slight, sometimes I don’t feel that I’m moving at all... so slight, it’s not even visible... and the pain comes... very slight movements... I mean, I can’t find a specific situation...” (Eva.12.243-264)

The absence of a clear relationship between NSCLBP and its possible causes left Eva with a range of unanswered questions about pain. Eva’s experience was also echoed by Laura who doubted that some of her questions might ever be answered.

“The question is always the same: what is this [NSCLBP]? What can I do? These are my doubts! These have been my doubts for so long... And I’m not sure that I’ll have answers... These doubts will be with me, at least until I have a concrete answer... I think it’ll be like this...” (Laura.42.908-913)

In a framework of a long lasting disorder, such as happened with all the participants, the lack of answers seemed to be responsible for some participants’ struggle to understand pain. Besides Eva and Laura, Helena also

demonstrated a sense of struggle regarding the lack of understanding about NSCLBP.

“Because I don’t know where this pain comes from... Maybe, it started like every kind of pain... But when you cut your finger, you know that your pain comes from this, right? When you fall and sprain your ankle, you know that your pain comes from this. But this pain, I don’t know. I don’t know where it comes from!” (Helena.50.1097-1102)

The previous excerpts suggested that the struggle regarding the lack of understanding of NSCLBP seemed to take part on these participants’ lives regardless of pain duration. For example, it was reported by Eva, who had experienced NSCLBP since “she was very young”, Helena, who had had NSCLBP in the previous fifteen years and also by Laura, who had had pain in the previous four years. Thus, the struggle regarding the lack of understanding of NSCLBP seemed to be a common topic in these participants’ experiences of having NSCLBP. Since this seemed to have a considerable impact on these participants’ lives, it was important to explore the participants’ thoughts regarding the strategies to deal with this struggle.

Fernanda’s account shed some light on the possible mechanisms to relieve this struggle. For her, it appeared that when someone had a problem, it was important to understand its cause and what could be done to solve it. In the following excerpt, she used her job as a metaphor to explain the importance of understanding NSCLBP. As a teacher working with special needs children, she was supposed to understand why they were not learning in order to apply appropriate strategies. Accordingly, in her perspective, a reason for her NSCLBP should be identified in order to relieve it.

“I think it's like this: when we have a problem, I think we should explore it in depth, to know why it happens, how we can fight it... because this is what we do at school... we try, at least, to help the kids... we try to find out why they do not learn, and if they do not learn in a specific way, we try to find strategies for them to learn in another. Here in this case, I can’t go

along with not knowing... to not having a solution for this situation [talking about her pain], do you understand?" (Fernanda.22.465-475)

There seemed to be an underlying idea that understanding the origin of NSCLBP would be fundamental to abolish it. This might justify some participants' investment in trying to understand their NSCLBP. Thus, accepting the lack of understanding seemed to be difficult, as it appeared to mean accepting the absence of a solution.

Concept 2.1.2. Not worth questioning this

While some participants struggled with the lack of understanding of NSCLBP, others seemed to have accommodated the idea that they would not have a proper understanding of it. They described NSCLBP as something normal that did not require questioning and tended to devote little time in their interviews exploring this topic. Alice and Marília reported that NSCLBP simply appeared in their life and demonstrated they were unwilling to find an explanation for it. There seemed to be an apparent acceptance or resignation regarding this subject.

"Yeah, it's not so easy to understand! It's like I usually say, let's keep going and we'll see... what we can do... where we can get to... and how..." (Alice.38.824-825)

"Yesterday I was in pain... but it has been a while since the last time this happened! But why did that pain appear? I don't know... I've got no idea... I've got no idea... if it happened when I was sleeping... or not... It's like a bruise... It just appears... With no reason... I don't know where it comes from... it comes from somewhere, but... (...) But I don't worry... I just leave it..." (Marília.51.1106-1124)

Irrespective of the perspective towards understanding NSCLBP previously described, at first none of the participants' accounts were suggestive of a clear understanding as to exactly why they have had pain. However, when the

researcher further explored how they understood and made sense of NSCLBP, all of them formulated an explanation of some sort.

Sub-Theme 2.2. Possible explanations for NSCLBP

The participants' explanations for NSCLBP were underpinned by three main concepts: unsure about the explanations; detrimental situations that may explain NSCLBP; and, alternative explanations but still not being able to understand (figure 5).

Concept 2.2.1. Unsure about the explanations

The participants emphasised their difficulties in formulating explanations that could help them to make sense of their NSCLBP. They tended to present these with caution, highlighting that they had no concrete ideas. This apparent lack of confidence may be related to the participants' uncertainty regarding the adequacy of their explanations.

Eva demonstrated an underlying rejection associated to the hypotheses she formulated when explaining NSCLBP. She considered several hypotheses for her NSCLBP onset but was unable to confirm any of them, which may contribute to the aforementioned sense of struggle (concept 2.1.1).

“I don't know if it's because of the mattress, because I've changed my mattress several times! I have new mattresses at home... You start feeling down... you start thinking that it's because of your mattress, you start thinking it's the chair you use, you start thinking it's because of the sofa, you start thinking that it's because of everything and you end up not knowing...” (Eva.6.109-119).

Furthermore, despite João and Marília's apparent acceptance of their own explanatory ideas about NSCLBP, they were unsure about their adequacy.

“Probably, there's a muscle injury... or... I don't know... kind of a hernia or something like that... and it causes pain on several occasions... it's

probably that... I don't know..." (João.31.673-677)

"Is it psychological? A person takes a pill and the pain lessens after a while... it stops... Or is it an infection... and the pill will help... I can't explain it! I don't know!" (Marília.21.450-454)

Interestingly, while some participants demonstrated the need to get confirmation from someone more knowledgeable and thus rejected their own ideas, others recognised that their ideas were possibly wrong, but seemed to accept them. Nevertheless, common to all participants' accounts was an apparent uncertainty about their own explanations for NSCLBP.

Concept 2.2.2. Detrimental situations that may explain NSCLBP

Seemingly, the participants' explanatory ideas about NSCLBP were mostly rooted in the physical origin of pain, which may reflect their use of a physical mind-set in making sense of NSCLBP.

In this framework, NSCLBP was explained by situations or factors that were perceived by participants as out of their control. Thus, the most common explanation used by the participants for NSCLBP was their jobs. They all spent considerable time in their interviews demonstrating how detrimental their professional activity had been to their back. For example, Marília revisited the idea of detrimental jobs several times, regarding both previously held positions (in printing companies) and her job at the time of the interview (cleaner).

"Yes, pain has appeared. It was not for a specific reason... Like I did something and I had pain as a consequence... no! I think it's related to improper posture, from years of working... Long periods sitting... standing... I think so..." (Marília.36.770-774)

Rita also emphasised the relationship between her jobs and NSCLBP. She justified the presence of NSCLBP in her life with the physically demanding work she did in the fields after her mother's death. She also related her job in clothing factories to her NSCLBP. When recalling that period of her life, she described

herself as an old woman with a hunchback, which was caused by the pain from being in the assembly line for several hours. The use of this metaphor seemed to illustrate both how painful her job was and how detrimental it was to her back.

“Then I came from the north and went to work in a clothing factory... I worked there for many years, many years... Maybe 7 or 8... You`re in the same position all day... While sitting at the machine, you only move your feet, one to lift the presser and the other to sew, isn`t it? And you spend the whole day in that position... And when I got up, at that time, I used to feel as much pain as I do now... Because when I was getting up from the chair I was like an old woman with a hunchback from the pain of being 4 hours in that position!” (Rita.7.142-152)

These participants` professional activities seemed to include jobs that were physically demanding and jobs that involved being seated for long periods. All were recalled as detrimental to their backs and thus identified as a possible explanation for NSCLBP.

Furthermore, some of the participants identified other possible reasons to justify and explain their NSCLBP. Regardless of these reasons, the need to present a physical explanation remained. For example, Eva hypothesised that her NSCLBP was related to a car accident she had when she was eleven. There was a recurrent association between the car accident, a seemingly traumatic occurrence in her life, and pain during her interview.

“When I was eleven, I had a car accident and broke my leg, pelvis and jaw... Since then, I`ve had problems here in my pelvis [pointing to pelvis and low back]. (...) but as the time has passed... the years have passed... I mean, the pain has become more frequent and... in the last few years... In the last few years it has appeared on a daily basis... daily basis... In the last three years it has appeared on a daily basis...” (Eva.2.40-54)

Marília also illustrated the tendency to offer an explanation for NSCLBP, which was based on the detrimental effect of falls on her back.

“And then the falls... Once, I fell while I was climbing the stairs... This was very painful... I had to ice it, as much as I could and put up with pain... that’s all I could do! Ow, and take pills... of course there was an inflammation... there was an inflammation on my bone... Was it? Or wasn’t it? But, I think so (...) The treatment stopped the pain... but now and then... it’s here... it doesn’t have a cure... and when I spend some time sitting down, it hurts! But, I don’t pay it too much attention... this is an inflammation I have here...” (Marília.34.745-755)

João’s account also echoed the previously mentioned tendency to offer a physical explanation for NSCLBP. He reviewed several factors that could explain it: a motorbike accident several years ago, also his jobs, or even a fall when he was a child. Since João could not identify a specific situation that was responsible for his NSCLBP, he tended to emphasise the idea that there was a sum of situations that contributed to its development. Implicit in his explanation were both the detrimental effects of these situations and their apparent inevitability.

“For me there is... There is a sum of several situations that have happened... that are responsible for my pain... I don’t... I can’t identify the precise moment – look from this date on... because of this, it happened... I started having this pain. No, because I had pain... then it disappeared... I don’t know... then it became more.... chronic... I don’t know maybe there were some situations... acute situations that led me to a more chronic situation... I don’t know.... I can’t help you understand this... I have no idea...” (João.16.336-348)

Furthermore, ageing also emerged as one of the most common reasons to justify NSCLBP. The participants seemed to relate ageing to body deterioration and pain. Although their medical tests did not appear to reveal any specific problems, some seemed to view their NSCLBP as a consequence of suspected herniated discs that resulted from ageing. Fernanda compared herself to her peers, who also had back pain, in order to provide evidence for this explanation.

“No... I mean, everyone... everyone says “you get older, everyone has hernias and we drive a lot... maybe this is a hernia”... I mean... I didn’t relate this pain with any occurrence... a fall, or something like that, no! I didn’t relate it to anything in particular!” (Fernanda.4.85-90)

The immediate explanations provided by all participants seemed to be rooted in the physical origin of pain. Indeed, they seemed to use a physical mind-set in making sense of NSLCBP that may be related to cultural aspects. Nevertheless, despite participants’ conviction of a specific problem in their back, the perceived incoherence of their own explanations led them to consider other factors to justify NSCLBP. It is interesting to note that when participants explored all plausible reasons and, most importantly, when they became aware of the inconsistencies within them, they started proposing alternative explanations.

Concept 2.2.3. Alternative explanations but still not being able to understand

Some participants provided explanations that were focused on the possible psychological nature of their NSCLBP. These explanations tended to come later in the majority of the interviews and appeared to be more difficult to discuss, as participants seemed to perceive the lack of physical evidence as possibly questioning the reality of their pain. For example, some participants discussed a connection between NSCLBP and anxiety, by identifying stressful life events that had triggered pain.

“When I spend some time sewing... (...) It hurts if I spend more time sitting down... (...) But when I’m in the coffee shop, it doesn’t hurt! Is it because I’m moving my leg? Is it because I’m working with the machine? Because you’re working under pressure, right? There is no one putting this pressure on, there is no boss! But, I know that I have to give an item of clothing to a client. And, I want to finish work, I’m under pressure... This makes you work with some anxiety and this may cause pain... Does it? Doesn’t it? I don’t know!” (Marília.23.503-521)

The participants tended to present their alternative explanations as hypotheses, about which they demonstrated some hesitance. Marília's words in the end of the previous excerpt ("Does it? Doesn't it? I don't know") may reinforce this idea. Indeed, the participants did not seem confident about the rigour of these explanations, since they were still looking for an explanation that could help them dealing with the aforementioned struggle (sub-theme 2.1.).

On the other hand, João emphasised that staying on the sofa at weekends was also responsible for his pain:

"In the winter sometimes... there are those moments of acute laziness, when you don't want to do anything... You move from the sofa to the chair and from the chair to the bed... It breaks my back... The absence of movement..." (João.26.556-559)

The previous excerpts suggest that NSCLBP appeared to be triggered by physically demanding activities, stressful situations as well as by the absence of these circumstances. Thus, the absence of coherent patterns and apparent unpredictability seemed to be the basis of participants' difficulties in understanding and making sense of their NSCLBP. Fernanda's account reinforced this idea.

"I did nothing to start having pain! Nothing! I was fine! I would have a normal night! I'm not saying... It wasn't related to walking... to exercise... I mean physical exercise at the gym... Because I used to go to the gym... It had nothing to do with that! Because I did several experiments: not going to the gym, going to the gym that day, not going on that day but going on the day before... I did several experiments but it was not related to anything... I was fine at night, I would watch TV on my couch... go to bed... perfectly! On the next day, I could barely get up! And on some days, I wasn't able to get up! I missed work! I couldn't go!" (Fernanda.15.315-329)

Despite presenting a range of hypotheses, the participants emphasised that they could not explain why they had NSCLBP. In addition, their explanations seemed to be indicative of an underlying conflict between a physical and a psychological mind-set in understanding pain. This conflict may be related with the participants` interactions with health professionals and their possible biomedical approaches (further explored in theme 3).

Although the previous paragraphs were focused on the individual sense making of NSCLBP, it is important to consider that this process also appeared to be influenced by their interactions with other people. More specifically, some participants seemed to accept other people`s explanations for their NSCLBP, while others expressed rejection or indifference to other`s perspectives regarding their NSCLBP. For example, Alice frequently used the expression “people say it`s because of...” (Alice.13.286) to explain why she had NSCLBP. Despite adopting other people`s ideas she was still confused regarding this.

“Well, I ask myself about this [why she had NSCLBP]. Sometimes I ask myself about this. Because some days I go to bed at night and I feel fine... and when I wake up... it`s like I`ve been working the whole night... I don`t know! I haven`t reached a conclusion... people say it`s because of the weather but I don`t know anymore...” (Alice.13.283-289)

When the participants` explored their hypotheses to explain NSCLBP, there were some similar points such as jobs, ageing and genetics, which may reflect the impact of socially constructed ideas in making sense of NSCLBP. Furthermore, the attention they appeared to give other people`s explanations seemed to reinforce their need to understand and make sense of their NSCLBP.

Sub-Theme 2.3. Understanding NSCLBP and controlling it

The previously explored participants` engagement in a quest to understand the origin of their NSCLBP (sub-themes 2.1 and 2.2), may be related to some participants` need to control pain. This sub-theme explored this apparent relationship between understanding and controlling NSCLBP. It was organised

into two main concepts: needing to understand NSCLBP in order to be able to control it; and, dealing with NSCLBP despite not understanding it (figure 5).

Concept 2.3.1. Needing to understand NSCLBP in order to be able to control it

The participants, who appeared to invest in understanding NSCLBP (sub-theme 2.1.), struggled with its apparent unpredictability (sub-theme 1.2.) and seemed to have a stronger sense of lack of control. This was highlighted by Eva, whose questions about the origin of NSCLBP seemed to reveal her need to control it.

“What have I got inside my body? Is it in my bones? Is it in my muscles? Is it the muscle stuck on the bone? Is it associated with the car accident I had? Or is this a new problem? What can I do? What can I do to get some pain relief? What should I do? Should I do gymnastics? Physiotherapy? Walk? Sit? (...) I do not understand because I do not know what is causing my pain and why it started. I only know that it disturbs me, every single day. That`s it! And, honestly I cannot understand it!” (Eva.23.491-514)

For participants with experiences similar to Eva, understanding the origin of NSCLBP seemed to be the only alternative to controlling it. In the following excerpts, Helena emphasised that understanding her NSCLBP would help her to deal with it.

“Understanding pain would possibly help me feel better... Because I would know what it is... That pain comes from there, from the problem I have there... And, by knowing this I would be able to deal with it... Or, completely forget everything... I don`t have any problems... and that`s that!” (Helena.49.1071-1077)

Thus, in the context of the aforementioned quest for understanding and retaining control, finding meaning and learning how to deal with the unpredictability of NSCLBP seemed to represent major challenges for these participants. In this context, the participants demonstrated that the most disturbing aspects regarding the experience of having NSCLBP seemed not

only to be their lack of understanding but also, and perhaps more importantly, their lack of pain control.

This finding drew attention to some participants' perceptions of a relationship between understanding NSCLBP and controlling it. Nevertheless, it could be questioned if the provision of an explanation for NSCLBP would necessarily ensure the participants' development of a sense of control over their disorder.

Concept 2.3.2. Dealing with NSCLBP despite not understanding it

Some participants appeared comfortable with their capacity to control NSCLBP. João and Rita's accounts demonstrated this idea – throughout their interviews they were both concentrated on describing how they controlled pain, giving the impression that understanding pain was not a pre-requisite to control it.

“If I walk, it hurts but not as much as when I get up... (...) Because when someone's walking, I don't know if it's the blood circulating, if... It doesn't hurt so much... It's the same in the morning... (...) I had some tests done, they didn't show anything, it's not worth doing any more tests! That's why I think that when the arms are more relaxed, there isn't so much blood flow... Then I start moving, it doesn't mean it doesn't hurt a bit... but there are some days it hurts and others it doesn't. But I think that not moving around so much is worse...” (Rita.41.902-919)

“So, there are little... strategies that I need to use to prevent pain, do you understand? Because, if I don't do this, I know... I know I'll have pain... Obviously, using these strategies I can manage, more or less... the pain... But this pain exists... No, this is not what I want to say... The problem is here... if I don't do anything to overcome it, I'll have pain!” (João.27.582-591)

Rita and João described examples illustrating that they seemed to feel capable of controlling their NSCLBP without necessarily understanding it. Interestingly, some participants seemed to redirect their energy from finding an explanation towards finding ways of living with NSCLBP.

“It`s like I told you... I deal with my pain quite well... I do everything... I do... If I don`t do it today, I`ll do it tomorrow. For example, if I need to clean my house... I`m not going to clean everything at once, starting with the living room... then the kitchen... No, I clean one room at a time... sometimes I`m in pain, right? If I need to do anything, I manage things like this: I`ll do this, rather than that, because it`s easier and then tomorrow, if I feel better, I`ll do that because it`s heavier... You have to know how to deal with pain... At least, for me it works, right?” (Marília.32.699-708)

The need to control NSCLBP and its impact on everyday life seemed to be reported by all this study`s participants. The participants who invested in the quest of understanding of their disorder (sub-theme 2.1.), tended to perceive themselves as unable to overcome NSCLBP. Whilst the participants, for whom the understanding of NSCLBP was not a priority (sub-theme 2.1.), tended to perceive themselves as able to deal with it. Thus, while some appeared to concentrate on finding an explanation for their NSCLBP, others seemed to be able to live with NSCLBP and control it, even in the absence of concrete explanations.

Nevertheless, since the participants found it difficult to make sense of their NSCLBP, they seemed to direct their attention towards the health professionals in order to obtain clarification.

6.4.3. Theme 3: Clinical encounters that perpetuate the lack of understanding about NSCLBP

In this theme the clinical encounters were highlighted, particularly with respect to their contribution in maintaining the lack of understanding about NSCLBP. The participants` expectations of being given the ultimate explanation for NSCLBP were explored. Moreover, the participants` unmet expectations and their possible contribution to the development of a querying attitude were also examined. Additionally, the participants` meaning making of the health professionals` explanations was discussed, with particular emphasis on the lack of a specific diagnosis. The therapeutic relationship and the participants` perceptions regarding the consecutively unsuccessful health professionals`

approaches were also highlighted. This theme was formed by four sub-themes that are represented in the figure below.

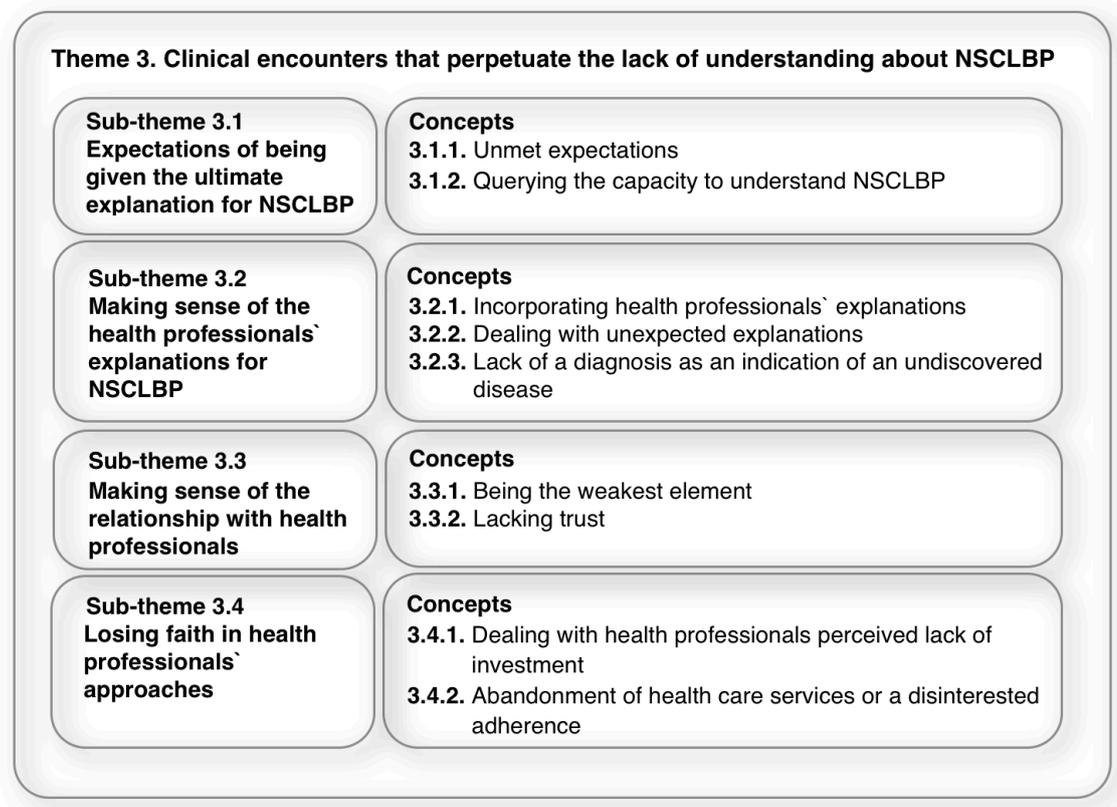


Figure 6 – Overview of the sub-themes and concepts included in the third theme.

Sub-theme 3.1. Expectations of being given the ultimate explanation for NSCLBP

The description of encounters with health professionals frequently emerged throughout the majority of the interviews. The participants' expectations of being given the ultimate explanation for their NSCLBP was one of the most commonly explored topics. The level of importance attached to the expected explanation suggested that some participants would discard or substitute any previous explanations (sub-theme 2.2). This sub-theme was organised into two concepts: unmet expectations; and, querying the capacity to understand NSCLBP (figure 6).

Concept 3.1.1. Unmet expectations

Some participants seemed to consider the physician to be the only person who could provide a legitimate explanation for their NSCLBP and they seemed to persistently search for this explanation. Others recognised that an explanation

might not be offered and did not look for it, or simply accepted the explanation given despite not fully understanding it. Eva demonstrated her persistent quest for physicians' explanations, while Alice revealed an underlying acceptance of their lack of explanations.

“Do I have a fracture on my hip and my muscle is trapped there? And, because of this, I'm in pain while moving? But, where is this fissure? And, where is my muscle trapped? Where? Where is it trapped? Because we can imagine this in our back, but here... Here, I can't even imagine... do you understand what I'm saying? Because I imagine this is a smooth bone, right? If it is smooth, how can it trap anything? Where does the muscle that gets trapped here come from? One day, when I've got time... I'm going to go from physician to physician...” (Eva.68.1481-1494)

“I don't know! We go to the physician and it's always the same “the vacuum doesn't help, the mop doesn't help” and that's that...” (Alice.4.83-86)

Although the participants reported several health appointments, they emphasised the absence of physicians' explanations about their NSCLBP. Helena's experience supports this idea:

“They don't say anything! That's that! They just say I have to put up with the pain... do some physiotherapy... and that's that (...) I haven't done any more physiotherapy because, honestly... I go to the physicians and they always say the same thing...” (Helena.8.166-171)

When this topic was further explored with other participants it became apparent that the physicians had provided some explanations but the content and delivery did not meet the participants' expectations. Thus, the health professionals' provision of information *per se* seemed to be perceived as insufficient, when the participants' expectations were not considered. Fernanda

and Laura indicated a lack of satisfaction with the answers given by their physicians.

"I've already asked! Actually, I always ask everything! I try to understand everything! It was supposed to be a hernia... known as bone spurs... (...) He says "it's about ageing, ageing..." and the conversation ends there... I was never given an explanation... just "don't worry, leave it... this is normal!" (Fernanda.10.217-225)

"But, I don't think it is related to it... I don't know if it is related to it, or not... But I believe it isn't... but I'm not a physician... But, I don't understand how he can make this association... that my pain increased because of this situation... without any complementary tests... I don't know! (...) He said, "it's all about this"... This was what he said... "It's all about this... everything is connected..." And I was upset and didn't want to continue talking about it and just left... the appointment finished and that's that..." (Laura.26.553-564)

Similarly, Eva expressed this lack of satisfaction regarding the explanation she was given by her physician. She tried to confirm that her NSCLBP was the result of a car accident she had had when she was eleven, however she was apparently given a vague hypothesis.

"My pain? Even I do not understand this pain, because... First of all, I don't know why I have this pain... I relate it to... and a physician also confirmed this... effectively... Because last year, I was... I was... totally down... this time of the year, autumn, winter... I went [to a medical appointment] (...) I started talking about my accident and that I had pain and that this pain was probably related to the accident, but I was not sure... Meanwhile I had an x-ray and some stuff and I was told that it was probably related to the car accident I had..." (Eva.21.460-478)

The previous excerpts also appear to reinforce the previously presented physical mind-set for understanding NSCLBP (theme 2), as the participants reinforced their expectations of being informed about the physical cause for their disorder. Accordingly, the lack of explanations that focused on a specific physical cause for NSCLBP seemed to prompt participants' negative reactions. More specifically, the experience of successively unmet expectations seemed to prompt participants' reactions to health professionals that appeared to include anger, exasperation, disappointment and detachment. For example, Eva's previous excerpt suggested an underlying sense of anger towards her physician's approach because he tended to provide her with confusing and evasive explanations for her NSCLBP. She seemed to blame him for her lack of understanding. Similarly, Laura demonstrated an underlying sense of exasperation, as presented in the following excerpt:

“Yes, I'm angry! I mean, it's not angry, it's not angry! It's like: I go to the GP and I already know that... I go, with the idea that... almost sure that I'll come back knowing the same... Am I making myself clear? (Laura.28.600-604)

Some participants also expressed disappointment. They seemed to consider that their problem was not suitably analysed and consequently the answers to their questions regarding the origin of NSCLBP could not be provided.

“I feel disappointed. I feel disappointed because they don't analyse our problem in depth... Because if we complain about pain... (...) it's just “do the physiotherapy, you're going to get better and that's that”... It's like this! They don't add anything more! I think... we should have more support because this pain is difficult to deal with...” (Helena.9.183-191)

Furthermore, some participants demonstrated an underlying sense of detachment regarding the physicians' explanations. For example, João's contact with health professionals was restricted to routine appointments, with no

specific mention of NSCLBP. He did not seem to believe that the GP added anything relevant to what he already knew.

“The GP is very... I mean my GP says “oh, we already know your problems.... this... this is already familiar”. I mean she does not add anything... I mean... She says I should do exercise, pay attention to my diet and all of that...” (João.36.775-781)

These findings demonstrated that despite the participants` common need to receive an explanation for NSCLBP, they expressed different expectations and reactions towards the health professionals` provision of information. Thus, the findings were also indicative of the participants` needs to receive tailored information regarding their NSCLBP.

Concept 3.1.2. Querying the capacity to understand NSCLBP

Some of this study`s participants, particularly those who expressed anger, exasperation and disappointment regarding health professionals explanations for their NSCLBP, tended to query the health professionals` capacity to understand their disorder. Accordingly, the physicians` perceived incompetence was proposed as a possible reason for the lack of clear explanations about the cause of participants` NSCLBP.

This seemed to produce a vicious cycle, in which some participants were still looking for a physician who would finally give them the ultimate and expected explanation. For example, Laura explored this idea throughout her account: she was planning to see a specialist for an adequate explanation for her NSCLBP, as the explanation the GP provided did not meet her expectations.

“When I can financially, I`m going to... I`m going to look for one and ask where I should go... what is the best medical speciality... when I can financially... who is the specialist I should see... to give me a “solution”...maybe “solution” isn`t the best word... It may be a “solution”, or not... But, at least to find someone to tell me “you`ve got this problem... or... this is pain, you have to live with this, you should do this or that...”

Either there is treatment or there isn't ... But at least... Am I making myself clear? I think the GP isn't well informed about this problem... of back pain..." (Laura.28.609-624)

On the other hand, some participants, especially those who accepted the absence of concrete explanations from health professionals, did not question the professionals' knowledge and assumed they knew the exact reasons for their NSCLBP. In this sense, it was the participants who perceived themselves to be unable to understand the explanations provided by the health professionals.

"Well, I don't know! The physicians don't explain it. I read the CAT-scan report, but I can't understand... For example, the CAT-scan I did... I've got back pain and I've got no idea what it is! They are the ones who know! The physicians... (...) It's like this... they may... The way they speak... people don't understand what the problem is. Where does this pain come from?" (Marília.26.557-565)

The previously presented expectations regarding health professionals' explanations about NSCLBP suggest that this study's participants attributed different levels of importance to these explanations. However, despite the different levels of expectations demonstrated, they all seemed to have been influenced in some way by health professionals' explanations or absence of them.

Sub-theme 3.2. Making sense of the health professionals' explanations for NSCLBP

When the encounters with health professionals were further explored, it became apparent that the participants' understanding and meaning making of NSCLBP reflected the impact of the health professionals. This sub-theme discussed the participants' meaning making of the health professionals' explanations for NSCLBP and was organised into three key concepts: incorporating health

professionals` explanations; dealing with unexpected explanations; and, lack of a diagnosis as an indication of an undiscovered disease (figure 6).

Concept 3.2.1. Incorporating health professionals` explanations

One of the dominant topics in the participants` accounts was the health professionals` explanation for NSCLBP. For example, João thoroughly explored the idea of a fragile spine that needed to be protected. This idea seemed to be a consequence of an appointment he had had with a physician because of his back pain when he was twenty. When the physician looked at the X-ray of his back, he told him it looked like that of a sixty-year-old man. This episode, which had occurred more than twenty years ago, seemed to have had a major influence on the way he made sense of his NSCLBP. João has used the physician`s words to justify pain all his life, as demonstrated in the following excerpts:

“When I was twenty I had my first X-ray of my spine... and went to the GP because of my back pain... And the GP said... exactly... At that time... These were his words “You have the spine of a sixty-year-old man”... or something like that... So, at that age... Those were not very encouraging words, right? Now, I`m forty-seven, I imagine I have the spine of ninety-year-old man or something like that...” (João.32.701-707)

João recognised that these were not very encouraging words, but accepted them as the truth and did not ask for a second opinion. Consequently, there was nothing to do about his NSCLBP, but protect his back. This idea is supported in the following excerpt:

“I don`t keep thinking about it... It happened, ok... you deal with it... it doesn`t matter anymore, it`s over, I mean... I don`t keep thinking “poor me...” So, imagine someone in their twenties whose doctor says “Oh, you`ve... you`ve got the spine of a sixty-year-old man...” Probably a lot of people would have got depressed, started taking pills... some people would have committed suicide... probably a lot of people would have done

that... but too bad... what can I do? But, I didn't look for a specific job... my life took a different path... and I had to follow it... and keep living the best I can..." (João.52.1145-1164)

Fernanda also reproduced her GP's words to confirm her idea that NSCLBP was caused by a herniated disc. Those words seemed to calm her down, as she felt relieved for not needing surgery.

"The doctor says I have to live with this pain, there is no reason to have surgery because it is not a hernia worth operating on... and when I have more severe pain, I should take a pain killer..." (Fernanda.8.156-161)

Rita also demonstrated to have accepted the physicians' explanations, despite these being perceived as vague or ambiguous:

"It was curved [the spine] because... They said it must have been from the positions, the work I used to do and all that... They said the spine was too curved for my age. Or from the pregnancies, they also mentioned the pregnancies... As I tend to be fat, I get very fat with pregnancies" (Rita.15.314-319)

Accordingly, health professionals seemed to be responsible for the common idea that NSCLBP was related to spine deformities caused by physically detrimental activities. Similar to João and Rita, Marília also recalled seeing a physiotherapist over 20 years ago who informed her that her back was curved and asked what she did professionally to cause such damage.

"The first time I did physiotherapy, he told me I had a space, 1 cm, in my spine, in my vertebrae, right? What was I doing in my life to have such a curved spine? And, I explained what my job was... "I'm always sitting down, sometimes I stand up, go the window, have a snack... but most of the time I'm sitting down, I'm always in the same position" (Marília.5.105-113)

The nature of the explanation provided seemed to determine the participants' acknowledgment and assimilation: the explanations that met the previously discussed participants' mind-set for understanding NSCLBP (sub-theme 2.2) tended to be well accepted, although not necessarily understood.

Concept 3.2.2. Dealing with unexpected explanations

Some participants emphasised that the explanations they had been given did not make sense. For example, Laura's GP led her to believe that psychological issues could explain her NSCLBP. Laura perceived that the GP associated the beginning of NSCLBP to a distressing period of her life: it began when her older son moved to another city causing her to feel depressed. Although Laura recognised that both episodes happened consecutively, she found the GP's association between them strange and difficult to understand. Despite admitting that she had felt miserable, she emphasised that she was not depressed at the time of the interview and her NSCLBP persisted. In the following excerpt, she highlighted the lack of logic of the GP's explanation:

“When my sons went to university I felt very down... I felt really down... and the GP told me my pain was possibly caused by anxiety... And I thought “anxiety and back pain, what's this?” I didn't connect the two situations... But I was in fact, I was weakened... And, I had more difficulty doing my tasks because I was weaker and fragile... and had to push myself... Maybe it was that... I didn't do any physically demanding tasks... (...) But then, that phase went and the pain continued... it didn't stop... But, I didn't connect the two situations... The GP told me I needed to react and all that stuff... But, I didn't connect the two situations and just asked myself “back pain and anxiety, what's that?” I don't look at things that way, but they're the physicians...” (Laura.10.209-242)

Helena also demonstrated the confusing impact the physician's explanation had and the lack of sense it made. Like Laura, she was also induced into considering the psychological nature of her pain, which seemed to increase her struggle in understanding NSCLBP and even question its veracity.

“I don’t know if it comes from my mind, as he said...or not... but no, I don’t think this comes from the mind, because we feel this pain, right? We feel this pain, so it’s not our imagination...” (Helena.23.489-492)

It is interesting to note that these examples seemed to conflict with the participants’ mind-set for understanding NSCLBP discussed in the second theme (sub-theme 2.2). Seemingly, the participants had difficulty in dealing with the differences between their own and health professionals’ explanations for NSCLBP. This not only seemed to increase the participants’ sense of struggle, but also prompted the previously mentioned continuing quest for meaning (theme 2).

Concept 3.2.3. Lack of a diagnosis as an indication of an undiscovered disease

The lack of a specific diagnosis seemed to reinforce the aforementioned struggle and quest for meaning (sub-themes 2.1, 2.2 and 3.1). Some of this study’s participants strive for diagnosis, since specific and coherent information regarding their NSCLBP was not given, or when provided, did not make sense to them. Eva’s experience supports this:

“Once, I was told that this is kind of osteophytes... kind of? I don’t know what this means... I know what’s the meaning of osteophytes... you can read about this, you know what it is. But “kind of”... I don’t know what “kind of” is... I don’t know if this “kind of” can be treated, if it can get better... and that’s it...” (Eva.11.227-234)

Laura emphasised her difficulty in dealing with the uncertainty caused by the lack of a specific diagnosis, indicating that having a diagnosis would be more important than having pain relief.

“It’s difficult not knowing the reason! If I went to the doctor and he said you’ve got arthritis or something like that... or something like that... ok, fine! Maybe pain wouldn’t just disappear because of knowing... but maybe, it would be important to understand... Who knows? In fact, pain

won't just stop because of knowing, I think so... just because of knowing, right? If there is no treatment, if there is no specific treatment for this pain... just knowing why, won't stop it... but I think that, at least psychologically... We... I don't know, but having this information can be healing... but I don't know!" (Laura.42.916-930)

Besides the distressing effect of this situation, the lack of a concrete definition for their problem also induced participants into imagining alternative justifications, mostly associated with the possibility of having an undiscovered disease. This idea was highlighted in several accounts, however Laura was the participant who presented it more clearly.

"Now, I have nothing! Isn't it? Concretely, I haven't got any problems in my back. (...) No one has said, "you've got this"... And this makes me think, and I think everyone would think the same... What is my problem? What is my problem? If... I must have something wrong because my pain is here! But, what is it? And that's why I say I can't understand! I have pain and my physician says it is nothing... nothing... (...) What if I have a serious problem? Because this pain is here, every single day. It is not a strong pain, it is a dull pain... But it is always here, always, always..." (Laura.13.263-284)

For Laura, the physician's insistence that her back was fine also reinforced that there could be a serious problem in her back, which seemed to trigger a vicious cycle that increased the need for a diagnosis. Moreover, the importance of having this diagnosis seemed to be related to the participants' belief that without having a cause for their NSCLBP, it would not be possible to determine the best treatment.

In this context, it appeared that the various explanations provided in the consecutive appointments with health professionals increased their difficulty in understanding and making sense of NSCLBP. The discrepancy between the health professionals' explanations and the way the participants interpreted

NSCLBP seemed to be responsible for the latter's struggle to understand the former's point of view. Furthermore, some of this study's participants seemed to hold health professionals accountable for their lack of understanding about NSCLBP.

Sub-theme 3.3. Making sense of the relationship with health professionals

Further analysis of the aforementioned unexpected explanations prompted the emergence of the therapeutic relationship as a central element in the process of understanding and making sense of NSCLBP. Some participants connected their lack of understanding of NSCLBP directly to the therapeutic relationship, however most indicated a range of aspects that suggested its influence. This sub-theme explored this influence and was formed of two key concepts: being the weakest element; and, lacking trust (figure 6).

Concept 3.3.1. Being the weakest element

The participants seemed to have an underlying expectation of asymmetry in the therapeutic relationship, which was presented throughout the interviews. The distribution of power in the therapeutic relationship seemed to be unequal, with the participants believing they had less power to make decisions about their health. These decisions may include the medical tests prescribed, the type of treatment selected as well as the information provided. Some participants seemed to accept this asymmetry and demonstrate conformity.

“Well... I think that... I don't know [explain NSCLBP]... The physician is the person who knows this [explain NSCLBP], as a physician she might know, right? Because, the first time... I had a space in my back... But I've never... she said I had a space in my back... did it get better in the meantime?” (Marília.15.318-3222)

In this context, health professionals were apparently seen as unquestionable authorities, who had important medical knowledge. The use of unclear and incomprehensible medical terminology reinforced the health professionals`

power, as it appeared to confirm the participants' underlying sense that physicians had more valuable knowledge about pain.

Interestingly, the underlying sense of the health professionals' authority seemed to prompt some vulnerability and lack of control among the participants, leading the latter to a continuing dependency on the former's decisions. Alice's question at the end of the following excerpt may support this idea.

“She [the GP] said – this is all connected to your back. That's her answer and that's that... I've already told her my father has an iron bar [prosthetic implant]... I laugh because she says – Because your father had one, you think you will too. But sometimes, it's like the bone is separating... it's here in my right side... I mean... this leg... Well... If I need... When I'm bad... I'll go back there... What can I do? (Alice.27.571-579)

In this context, the participants seemed to feel discouraged about asking questions and exposing their fears and expectations. The majority of the participants from this study seemed to take physicians' decisions without question, despite stating they did not understand them.

“They don't say anything to me... The physician said “it's the same thing, you're going to do physiotherapy...” but they don't explain... where this pain is coming from... if it's an infection or not... – Researcher: Have you ever asked any questions about this? – No... It must... I think that... No, actually I didn't ask... if it's an infection or not...” (Marília.14.296-301)

The previous excerpts appeared to be indicative of the participants' perceptions of themselves as the weakest element of the therapeutic relationship. They appeared to view themselves as someone who could not understand or manage their disorder, and the health professional as someone who was supposed to know about it and make the best decisions.

For example, in the previous excerpt, Marília demonstrated that she had never asked her physician about what the problem in her back was. The analysis of both Marília's excerpts provided in this section, may shed some light on why

she did not ask that question. Indeed, this could be related to her perception of not being capable of understanding the physician's words or being disempowered to make decisions regarding treatment, as she demonstrated conformity with an apparent asymmetry of power in the therapeutic relationship.

Concept 3.3.2. Lacking trust

Despite the participants' apparent acceptance of the health professionals' position of authority in the therapeutic relationship, they critiqued these professionals for not listening to their problems. This was evident, for example, in Alice's and Laura's accounts. Alice reproduced her GP's words emphasising the expression "get on with your life" (Alice.4.86), which she believed illustrated an apparent disregard. Laura also perceived this disregard, using an ironic tone to suggest that this attitude prevented health professionals from understanding patients' real problems and needs.

"I don't know! We go to the physician and it's always the same (...) - when it hurts, take these pills and get on with your life..." (Alice.4.83-86)

"It's all in a rush... That's what I feel. They don't pay attention. I think that... Or maybe... Just from us talking, they already know what's happening... (ironic tone) That's what I think... because... they don't pay that much attention... they don't spend time listening to... (...) They might understand from just a few words I say... or they don't have a single clue, and that's what I think that happens." (Laura.22.472-485)

Eva stated that patients needed to be able to summarise and select the main points of their pain story in order to be able to communicate with the health professionals, emphasising physicians' apparent disregard.

"No... No... No, I've never asked... No, because the physicians don't have time to listen to us! We arrive and say "I'm in pain, here"... We've a couple of minutes to say everything... briefly... very quickly, right? Pick the most important things... And, then they also spend a couple of minutes

saying something like “ok mam, I think so...” It’s like this, right? That’s what happens with everybody! I don’t think it’s just with me. I think that it’s the same for all the Portuguese. I believe that in foreign countries... things are different... Actually I’m sure that things are different because I’ve had that experience in a foreign country... I know it’s different... they pay attention to the patients. No... The stuff I’m telling you... it’s the first time I’m telling anyone this. That’s the truth! I can’t tell anyone this!” (Eva.27.590-605)

Helena emphasised that she did not feel believed or respected. She described one of her appointments, emphasising that she was “shocked” (Helena.3.57) when the GP started laughing and insinuating that she was exaggerating because there were no reasons for such strong pain. She perceived to be disbelieved and felt accused of imagining her pain.

“I... I remember that... fifteen years ago, when I was younger... I went to a physiotherapist... a physician... and when I complained about knee pain... I had a really strong pain in my knee, really strong... I went to the appointment and said that I had a strong pain in my knee and had no idea what was causing it... He just started laughing... and I... I was... really shocked... The physician... I mean, I was complaining about pain and he was looking like... doubtful! He said – Oh you’re so young... and all that stuff.... He might have said that to motivate me, or something like that... But, the way he said it... the way he said it... he just didn’t believe me.” (Helena.3.50-63).

Similar to Helena, Fernanda reported physicians laughing at her comments about NSCLBP. However, Fernanda did not think they doubted or teased her; she thought the majority of the health professionals were not available to listen and talk to their patients about their pain, and minimised the importance of their problems.

“I’d like to understand, but most of the time they don’t explain it to me and begin to laugh... “Oh don’t worry about it! Oh, I also have pain and whatever...” I have to accept it!” (Fernada.25.528-532)

This underlying perception of lack of respect, stemming from either disbelief or the minimisation of the participants’ complaints, seemed to prevent the participants’ development of a trusting therapeutic relationship. This was highlighted, for example, by Alice and Laura, in the following excerpts.

“I pay attention... of course when we’re in pain... We need to go to the physician... we need to trust them a little, somehow... But, nowadays... I don’t think I trust them anymore... They told us to do this and that... and we... I used to do what she told me and that’s that...” (Alice.50.1086-1091)

“At the end of the day, I don’t trust him... Maybe, I can be blunt... I don’t trust in what... my physician says... And I think that... To trust our physicians helps us because... But, to trust them... they need to give us reasons to trust them... by proving that they understood us... that they really looked at the problem and found we have this and that... They need to have this information so they can help us to understand... I don’t think that he [the GP] has to... I don’t know...” (Laura.29.625-633)

The reported lack of trust in health professionals may contribute to the previously mentioned quest for meaning (sub-themes 2.1 and 2.2).

In this context, whether the asymmetric therapeutic relationship was accepted or critiqued, it seemed to have a contribution in perpetuating the participants’ lack of understanding about their NSCLBP. On the one hand, those who accepted this asymmetry tended to feel discouraged from sharing their questions, fears and expectations. On the other hand, those who critiqued this asymmetry, identified issues such as the lack of attention, respect and recognition from health professionals as barriers for their understanding about NSCLBP.

Sub-theme 3.4. Losing faith in health professionals` approaches

The encounters with health professionals were discussed by all the participants; the majority demonstrating discontent with the health professionals` approaches. The aforementioned perceived absence of a careful analysis of the participants` complaints (sub-theme 3.2) as well as the perceived disregard of their real needs (sub-theme 3.3) seemed to be the most important reasons for their discontent. They directly related these aspects to the lack of success of the treatments prescribed.

This sub-theme explored the participants` loss of faith in health professionals` approaches and was organised into two central concepts: dealing with health professionals perceived lack of investment; and, abandonment of health care services or a disinterested adherence (figure 6).

Concept 3.4.1. Dealing with health professionals perceived lack of investment

Although the majority of the participants visited several physicians, their NSCLBP did not subside. Thus, they seemed to believe that their complaints about pain were not well analysed or managed.

"There are doctors and doctors! Most of the time they aren`t available... or because they take it lightly... and I... let it go... that`s why I say ... I'll have to live with this pain! And hope... that I won`t get... won`t get any worse!"
(Fernanda.24.517-523)

The participants presented arguments, such as the prescribed diagnostic tests, to justify the perceived lack of investment from health professionals. More specifically, they seemed to consider the X-ray as a basic and insufficient test and believed that they deserved a more detailed examination. Interestingly, they seemed to take the prescription of medical tests as a means of interpreting the value physicians attributed to their NSCLBP - the more detailed the test, the more attention and respect for their complaints.

“I think they should invest more, even do some complementary tests. But, they don't! It's just a simple X-ray, or sometimes a CAT-scan...”
(Helena.9.185-187)

Moreover, the repetition of unsuccessful treatments also led the participants to hypothesise that their physicians were not invested in solving their problems. Medication seemed to be the most common type of treatment prescribed, which was seen by the participants as useless and even detrimental to their health, leading some to avoid it. Furthermore, physiotherapy was also presented as a frequent treatment option and was also perceived as ineffective. Helena and Eva support these ideas.

“There we are with the routine [medical appointments], they listen... look at the records... and tell you to keep doing the same treatment... There is no new treatment... Just that, just that, just that... there are no new treatments! I personally don't feel any positive results from my treatments, because it's always the same... just that... paraffin... the hot packs... massages, sometimes with their hands, sometimes with electronic devices... They asked me why don't you have surgery? Why don't you try it? – It's risky! It's risky! A physician told me – you could have surgery, but you're too young to have surgery – So, I don't want it. I put up with the pain, I put up with the pain! And that's what I've been doing... putting up with the pain...” (Helena.24.520-535)

“Why didn't he prescribe other treatments, I might have got better... Something other than physiotherapy... Because physiotherapy... you feel better during that time... and everyone I talk to says the same... Physiotherapy only helps you while you're having the sessions... At least in my experience... it's just when you're doing it...” (Helena.22.481-488)

The reported similarities between their own and other people's treatment, reinforced the perceived lack of investment in understanding patients' problems

and needs and in prescribing individualised treatment. Fernanda emphasised her concerns regarding the lack of individual tailored treatment.

“I think the treatment they prescribed is the same as for the person next to me with a headache for example... I mean... Because I went to the hospital several times... those three times... and the treatment was always the same... I even asked the nurse “But why? Why are you giving me this? – Because it will ease your pain! – Ease? But I don’t want pain relief! I want to be pain free so I won’t need to come back!” (Fernanda.25.539-549)

The previous excerpts seemed to be indicative of a lack of alignment between both the participants’ and health professionals’ perspectives regarding health care. This appeared to promote the maintenance of unsuccessful treatments as well as the perpetuation of the participants’ lack of understanding and capacity to deal with their disorder.

Concept 3.4.2. Abandonment of health care services or a disinterested adherence

The successive unsuccessful treatments and the perceived lack of investment from health professionals led to participants abandoning health care services. They seemed to adopt several reactions, ranging from the definite abandonment of health care services to those following health professionals’ recommendations without particular interest or strict compliance. Helena explicitly demonstrated her definite abandonment.

“No... That support... I’ve already given it up... As I told you, it’s been four years since I’ve done anything like this... no physiotherapy... nothing...” (Helena.10.217-219)

Marília demonstrated how she tried to follow the health professionals’ recommendations, despite her difficulties in understanding their words.

“And then... the way they say... that I should contract the tran... transve... [transversus]... isn't it? So, even while I'm working, I do it. I can't do it when I need to pee, like they told me... That, I can't do... But, apart from this, I do it... when I'm walking, sweeping, hovering... I'm doing this [contracting the transversus] because of my pain... She said it helps to prevent pain.” (Marília.28.611-618)

João's excerpt suggests that although he followed his GP's recommendations, he did so without strict adherence as he preferred to use strategies that the GP considered detrimental to his back.

“I picked up my bike and started cycling even though my GP had told me that cycling would be detrimental to my back... But I thought, in my case, I feel really good when I'm cycling. So... I just avoid running... I don't think it's good for me because of the weight, the impact of when... when we're running, right? (João.11.221-228)

Furthermore, there seemed to be an underlying sense of criticism in the participants' analysis of health professionals' approaches. Although this study's participants demonstrated an underlying passiveness throughout their accounts, (as they expected health professionals to provide an explanation for their NSCLBP and to make all decisions regarding its management), some affirmed that information on how to deal with NSCLBP would be more useful than the standard medication or the common standardised physiotherapy sessions. Seemingly, some participants were not only misinformed about their NSCLBP, but also about the strategies they could use to deal with it. Helena emphasised the need to be informed about strategies to manage NSCLBP:

“... If we were prepared to deal with this [pain], with this stuff... It might happen, right? It might happen... this pain... and if we had knowledge about how to deal with it... It would be - I'm going to feel pain... so I need to do this to avoid it... - It would be better... [to have this knowledge],

right? Rather than having the usual ten sessions of physiotherapy...”
 (Helena.9.196-203)

The previous excerpt seemed to reinforce the Helena`s need to have individual rather than generic treatments.

Additionally, since the contact with health professionals did not seem to meet the participants` expectations, they tried to obtain support from their immediate social network.

6.4.4. Theme 4: Reshaping social interactions according to the meaning of NSCLBP

In this theme, the contribution of the meaning making of NSCLBP in reshaping the participants` social interactions was articulated. The participants` need to legitimise and validate their NSCLBP was highlighted. Additionally, the participants` reactions to the unsuccessful attempts in achieving recognition for their disorder were examined. Lastly, the relationships established by the participants were examined, particularly in what concerns the interplay between their needs and other people`s. This theme was formed by three sub-themes that are represented in the figure below.

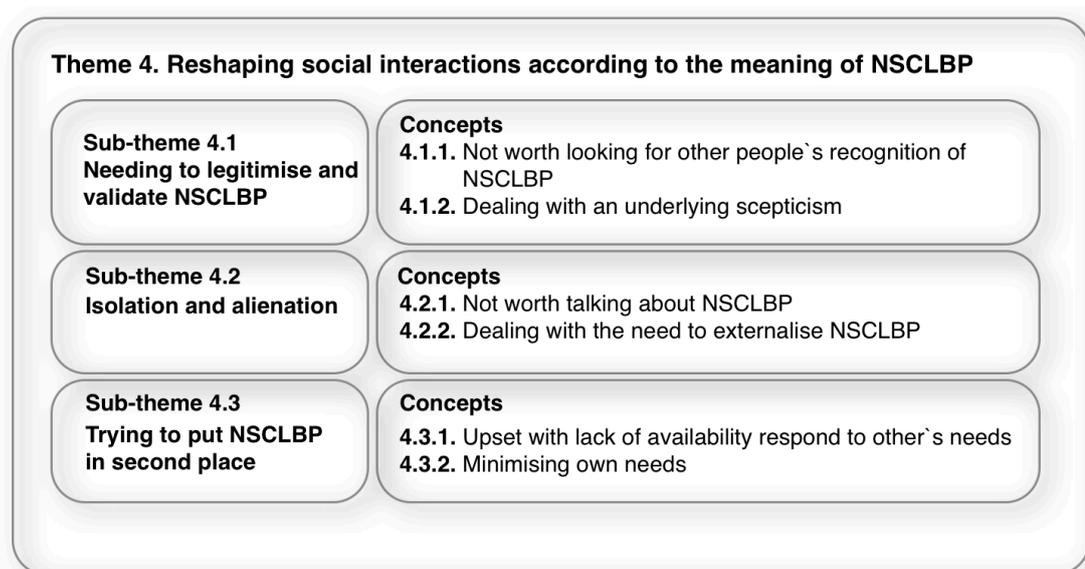


Figure 7 – Overview of the sub-themes and concepts included in the fourth theme.

Sub-theme 4.1. Needing to legitimise and validate NSCLBP

When trying to understand and make sense of NSCLBP, this study's participants seemed to consider their explanations as well as the health professionals' as unsatisfactory. Accordingly, some engaged in a search for meaning, where the quest for NSCLBP legitimation seemed to attain significant relevance. In this process, the participants appeared to concentrate on their immediate social networks as if they were trying to obtain the validation that they had not received from the health professionals. This sub-theme explored the participants' need to legitimise and validate NSCLBP and was organised into two central concepts: not worth looking for other people's recognition of NSCLBP; and, dealing with an underlying scepticism (figure 7).

4.1.1. Not worth looking for other people's recognition of NSCLBP

All participants discussed the need to have other people's recognition of their NSCLBP. However, they seemed to perceive that the absence of other people's experience of NSCLBP made it impossible for them to understand it. The following excerpts from João and Eva introduce this idea.

“Yes, I think so... at least my nuclear family... my nuclear family... and my parents and people who know me... they know that... It's well known... They know I have a problem and of course they understand... Actually, they might not understand... not understand the pain intensity or the impact of pain... this they don't understand.... they can't understand because they've never had this pain... they can't understand, right? But they know that I'm in pain... and that this pain affects me and prevents me from doing some tasks... yes, of course... they're aware of this...”
(João.58.1256-1267)

“Ow, not at all! People don't understand! People don't understand! (...) No! People don't understand at all! (...) No! And they... they don't understand! I can guarantee you that they don't understand!” (Eva.17.354-372)

In these excerpts, the word “understand” seemed to be used to mean “empathise”, as if the participants were highlighting both the lack of other people’s capacity to understand their disorder and to vicariously experience it. In coherence with this idea, Alice emphasised that the only person who had an empathic understanding of her experience was her mother, who also had chronic pain. She described one of their usual phone calls, which seemed to demonstrate that they focused their conversation on pain: they shared experiences related to their pain and finished by encouraging each other to accept it.

“My mother is the closest person to me. We usually call each other... Yesterday she called me to ask about us [Alice’s family] and I answered “I’ve just got home (it was 9:30 a.m.)... I’ve just arrived and I’m exhausted... in pain...” (...) She told me she had been olive-picking, but she had done this standing up... because she can’t work on her knees... because her knee is swollen... it looks like... Well... it’s like she said in that phone call “we need to keep dealing with our pain...” What more did she say? She just said, “We all have to accept our destiny...” And sometimes she says to me, “I really know what living with this pain is”. Because she also has problems... arthritis and other problems... So, when the weather changes she calls me... to ask me “look, aren’t you in pain here or there? Because I’m in such a bad day”...” (Alice.41.893-924)

Seemingly, pain was seen as an innate part of life, part of destiny and something Alice and her mother had to live with it. They seemed to perceive that there was nothing they could do about it, but share their acceptance. This excerpt reveals a mutual understanding between mother and daughter, which was seemingly due to the shared experience of having chronic pain and not necessarily by being a relative. Alice seemed to feel better after these phone calls as she had found resonance with someone who experienced the same problems and needs.

Fernanda also reported that finding someone with a similar experience seemed to help her to deal with NSCLBP in a more positive way. She talked to a colleague, who also suffered from NSCLBP, about the difficulties and limitations they had in common. She seemed to be encouraged by the possibility of communicating her experience.

“The only thing is “ow you also feel like this? Me too! This is good! I mean... sorry, but...” At least I have some comfort knowing that I`m not the only one... And we end up laughing because, what else can we do? The physicians don`t give us any solutions! We thank God we don`t need to have surgery! And let it go! We keep living like this!” (Fernanda.13.272-279)

Both episodes described seem to have been highly valued by the participants, as they helped them to make sense and deal with NSCLBP. However, episodes of such connectedness rarely emerged in the participants` interviews. The participants seemed to be convinced that with the exception of the few people experiencing chronic pain they knew, other people could not have an empathic understanding of their experience of NSCLBP and, thus could not recognised its legitimacy and validity.

The chronic nature of NSCLBP seemed to be perceived as a barrier to understanding it by those who had never experienced it. Eva explored this idea, highlighting that people can identify with an occasional pain, however, chronic pain, such as her own, could not be empathically understood.

“No! They don`t understand! They don`t understand what constant pain is! Maybe they can understand if someone says “my belly hurts today”. Ok, yes, this is acceptable because it`s today... because it`s today... I can make a tea... and it`ll get better... it`ll get better... it`ll go away... But, that kind of pain that someone complains about... or makes that sign or gesture that shows that they`re in pain [talking about constant pain]... I

mean... people can't understand... and they get bored... that's the way it is!" (Eva.18.389-399)

Furthermore, the lack of visible signs of NSCLBP was also perceived as a barrier to other people's empathic understanding of the participants' experience.

"This gives me the impression that some people don't believe in my pain... Others... I don't know... I don't know... (...) They don't know this pain... and when someone doesn't have this pain... they can't believe it... They just believe someone is sick when they are bedridden. There is a popular saying... something like "the upright diseases are not believed!" The upright diseases – if someone is walking and going about their life... They don't believe in our pain... they just believe it if someone is bedridden... That's it!" (Helena.26.566-590)

Thus, an apparent conflict between accepting other people's absence of empathic understanding and the participants' need to make NSCLBP understandable and valid seemed to emerge in some participants' accounts. This apparent conflict appeared to prompt an underlying frustration and perceived lack of support in dealing with their disorder. In the following excerpt, Eva emphasised that "no one can understand" (EVA.56.1227), as she perceived to have no support in dealing with her NSCLBP. In order to reinforce this idea, she also expressed a desire for a way to communicate pain intensity to others, as this would make it possible to obtain other people's support in dealing with her disorder.

"No one can understand! Sometimes I say that I would like to have a sticker... Where you have pain you should have something... I can even imagine a kind of sticker which would be like... a white sticker in that area would mean "absence of pain"... the light orange would mean a soft pain... the dark orange would be a stronger pain... and then the red... the last one.... Sometimes I would like to pick up that sticker and put it in my

body, so people could see my pain... It seems silly... (...) It is not visible [pain]! I can't show anyone the pain I have... today I have pain, it's like this! (...) And people can't see... we can't see what we do not know..." (Eva.56.1227-1260)

Concept 4.1.2. Dealing with an underlying scepticism

Some participants perceived that the absence of the aforementioned empathic understanding meant that other people were sceptical and could not recognise the impact of NSCLBP. This was possibly responsible for their reported lack of support in dealing with the disorder.

"If it's pain that appears today and then goes away... Well, I think people can give it some attention! But if it's that pain that someone's been complaining about for years, plain and simple it doesn't count... it doesn't count! That's what I think!" (Eva.20.431-437)

Although some participants seemed to expect and accept this lack of empathic understanding, others repeatedly expressed their concerns about it. The former did not explore other people's reactions in their accounts in detail, suggesting that they did not attach importance to this. The latter identified a range of issues related to their interactions with other people, such as having their NSCLBP disbelieved, mocked or pitied. Interestingly, what was supposed to be a quest for legitimising and validating NSCLBP through their interaction with their social networks seemed to have an unexpected result, as they perceived that their NSCLBP was called into question.

Alice and Helena appeared to be negatively affected by their colleagues' comments regarding their NSCLBP. They reported being teased because they were seen as someone who was constantly complaining about pain.

"I believe that my mum understands, because she is also in pain. But other people I'm not sure... They make jokes about me... because of my pain.

Sometimes I say that they tease me because I`m always complaining about pain. Almost every day...” (Alice.44.949-954)

“I`ve had some situations... I think they`re teasing me, they`re teasing me... when someone says “Ow, I can`t...” or “I`m in pain...” or “I`ve got something here”... I think... they`re teasing me, right? I think they... There are people that seem to be teasing me about my pain... It`s like this... (...) And sometimes when I`m getting things off my chest with particular people... I believe they`re teasing us... it`s probable... “She has a pretty face, looks good and complains about pain and complains about this and that”. Yes...” (Helena.27.572-594)

Helena seemed to indicate how intensively and aggressively she perceived her colleagues` comments to be. Despite rationalising that she should not give these comments importance, as she still needed to keep working with these people, she perceived herself unable to avoid their detrimental effect.

Interestingly, when given support, Helena felt upset. For example, when older women from her neighbourhood tried to help her carry her bags, she felt grateful but pitied. This seemingly generated an internal conflict, where she felt upset by other people and by the impact of NSCLBP in her life.

“I feel upset when they make jokes... that joking feeling... when I`m complaining about my pain... but I also feel upset when I complain and people realise that I can`t carry a bag full of groceries and help me... I have principles, of course I`m grateful... Sometimes I say that I`m fine... because I`m a nice person... I`m sometimes grateful because I`m feeling so bad... (...) I feel upset because I`m a young person and I can`t carry a bag full of groceries but I also feel upset when they don`t believe my pain... I don`t know... I can`t explain it... I don`t know” (Helena.32.681-721)

Accordingly, the participants' apparent quest for legitimising and validating their NSCLBP through interaction with their social network seemed to have an unexpected result for them, because this process eventually questioned the reality of their disorder. Other people's inability to vicariously experience the participants' experience of having NSCLBP disorder was perceived in several ways. For some it was an integral part of life and needed little explicit reference in their accounts, while for others it had an important role in their accounts and was perceived as an issue since it questioned the legitimacy and validity of NSCLBP.

Nevertheless, the participants' accounts suggested that their social networks appeared to contribute to their meaning making and overall experience of having NSCLBP disorder. The lack of understanding from other people not only seemed to prevent the participants from legitimising and validating their NSCLBP, but also had an impact on the way they interacted with other people.

Sub-theme 4.2. Isolation and alienation

As a consequence of the apparent social lack of legitimation of their disorder, some participants demonstrated an underlying sense of helplessness, which led to a progressive isolation and alienation from their social networks. This sub-theme explored these ideas and was organised into two central concepts: not worth talking about NSCLBP; and dealing with the need to externalise NSCLBP (figure 7).

Concept 4.2.1. Not worth talking about NSCLBP

The participants' accounts suggested that they were not used to sharing their experience of NSCLBP, since they reported difficulty in verbalising it. The following excerpt from Eva offered a preliminary indication of an underlying sense of isolation and alienation from people in general as she emphasised that she had never told anyone what she was verbalising in the interview.

“It's difficult to describe this pain. It's very difficult to talk about this pain! I never thought it would be so difficult! It's not easy, not at all! Because, we're talking about something that we can't see (...) I never thought it

would be so difficult to talk about pain. I've never spoken to anyone like this before... not to anyone!" (Eva.40.870-878)

Seemingly, Eva tried to divert attention from her NSCLBP when talking to other people. This occurred during her interview: she smiled, laughed and joked, and only talked about more difficult issues when the researcher encouraged her to do so. Like her, there were other participants who demonstrated difficulty in talking about their NSCLBP throughout the interviews, suggesting that they had progressively stopped doing it.

In a completely different manner, Helena demonstrated sadness and anger when reporting that she tried to live her life without externalizing pain since she perceived that some people implied she was pretending or exaggerating. Thus, her behaviour seemed to be motivated by an attempt to protect herself from judgmental and negative social reactions. Similar to Eva, Helena also seemed to avoid this subject in her interactions with other people.

"You have to put on a happy face because the people around us aren't responsible for our pain... we can't complain all the time... because if we complain, they say we're whiny ... that we're always whining... that we don't want to do anything... It can't be... we need to move forward... basically we need to live with this pain..." (Helena.7.142-149)

Thus, the participants perceived the verbalisation of their NSCLBP as useless as it did not seem to generate any supportive behaviour from other people. Eva demonstrated that she preferred to do tasks that would cause her pain, rather than admit her limitations to her work colleagues.

"It [pain] isn't always understood by other people... Because sometimes we don't have the courage to say "I'm in pain" or to admit, "that task causes me a lot of pain"... because you don't want to bother other people every time... and also since I know that they don't have to put up with me..." (Eva.16.344-351)

After years of trying to arouse empathy in other people, Eva seemed to relinquish and minimise her own pain. Laura also claimed to be tired of pain and had the perception of tiring other people, which caused her to avoid speaking about this subject. In the context of her account, the use of the word “tired” seemed to be indicative of the distressing experience of constantly facing negative reactions to her NSCLBP.

“I don’t know why I don’t speak... Maybe because it... I think that it’s something that happens every day and you bug others... it’s the same thing every day.... (...) And I think that I’m so tired of this pain that it seems that I’m tiring other people. So I avoid speaking about it... Besides, I don’t have too much to add... it’s always the same!” (Laura.41.891-902)

Regardless of their different personalities and the variety of situated social contexts illustrated in the aforementioned excerpts, this study’s participants attempted to avoid talking about their NSCLBP with other people and progressively limited their social interactions.

“I’ve stopped going to some places because of pain. (...) For example, I received an invitation to travel. New York! (...) People who don’t have this pain, can’t imagine... (...) So, I don’t go to some places because of my pain! Or, because I fear my pain...” (Eva.48.1043-1062)

Concept 4.2.2. Dealing with the need to externalise NSCLBP

Despite purposefully avoiding talking about their NSCLBP disorder with other people, the participants reported that in some circumstances they could not remain silent. Seemingly, there was an underlying need to express themselves despite anticipating that people would not understand or support them, and would possibly even judge them. There were moments when the participants perceived a possibility of being understood, however this led to a feeling of frustration and anger because ultimately this did not happen. Alice critiqued her almost automatic tendency to complain about pain - she realised that since people could not help her, it would be better to remain silent.

“I should keep my mouth shut... Sometimes I think about this... in my job... Why am I always complaining about pain? They can't do anything for me... But I can't control this... I arrive at my job, I take a seat and immediately I say - Ow”. (Alice.44.954-960)

Eva also regretted her verbalisations about NSCLBP, as other people could not understand them. However, these seemed to have an underlying aim of finding an empathic understanding, legitimisation or validation of NSCLBP as did Alice's. Eventually, Eva recognised the uselessness of complaining about pain and seemed to perceive that her pain was dismissed by others.

“Sometimes I regret complaining about pain and say to myself “You shouldn't have said this, you should shut up”... because this is boring... I think people get bored... People get bored when listening to that person... It's like I say... If you have an occasional pain and it gets resolved soon, they can pay some... some attention! But, when you've complained about pain for years, it just doesn't count. That's my opinion!” (Eva.20.425-437)

There seemed to be an underlying sense of contradiction regarding the participants' interactions with other people. On the one hand, the participants seemed to avoid contact with others, whereas on the other, they demonstrated the need to be listened to, as in several accounts they could not avoid expressing their pain. Isolation and alienation seemed to be related to a response to unsupportive contexts rather than to the participants' needs.

Sub-theme 4.3. Trying to put NSCLBP in second place

By placing their experience of having NSCLBP into their social contexts, participants revealed both the previously discussed underlying sense of alienation and isolation and an overall change in the way they related to their contexts. Some participants explicitly reported that NSCLBP reshaped their relationships, which seemed to lead them to put NSCLBP in second place. This sub-theme explored this reaction and was organised into two central concepts:

upset with lack of availability to respond to other`s needs; and, minimising own needs (figure 7).

Concept 4.3.1. Upset with lack of availability to respond to other`s needs

Seemingly, the participants blamed NSCLBP for their lack of availability to listen and respond to others` needs. For example, in the following excerpt Laura demonstrated the impact of NSCLBP in her motivation to connect with people in general, regardless of the proximity.

“It`s uncomfortable and at least in my case, if I`m uncomfortable I stop being able to handle anything or anyone. I`m really not (...) I don`t feel like! I don`t know! I don`t feel like, I can`t explain it! When I`m in more pain... I just want to... I don`t know... I don`t want to go out... I just want to stay at home... in my own space, in peace... because... at the end of the day, I can`t handle other people and I also don`t want to listen to anyone, to hear anything...” (Laura.33.721-735)

Eva corroborated Laura by emphasising that NSCLBP prevented her from having cordial and attentive relationships. In the following excerpt, she demonstrated that the strong intensity of NSCLBP required all her attention making it difficult for her to pay attention to other people.

“Because when someone is in pain... we can`t have the same... I speak for myself... I don`t have the same tolerance... When I`m in strong pain... stronger pain... and persistent... I don`t have the same tolerance... and this really upsets me because it affects my capacity to relate to other people on a daily basis... a lot... unfortunately! We could say that we can ignore pain and move forward, but it`s not that easy, it`s not that easy! I don`t think it`s that easy to ignore pain... like people say sometimes... At least some kinds of pain... not at all... not at all! (...) If I`m in strong pain I don`t have the same capacity to be... tolerant... I don`t!” (Eva.46.1009-1022)

Concept 4.3.2. Minimising own needs

The awareness of the powerful impact of NSCLBP on social interactions seemed to motivate some participants to concentrate on trying to minimise their needs and put these after others`, especially their relatives. In the following excerpts Laura and Marília demonstrated their priorities to be their sons, causing their NSCLBP to be in second place.

“At this moment, I can’t financially because my kids are both studying at university and that’s my priority. But if I could, I would go to a private doctor... to at least get a second opinion, but I can’t, it’s out of the question because it’s very expensive... and the kids` studies are my priority... and until their situation is unsolved... mine has to be in second place...” (Laura.23.503-512)

“If I need something... even my daughter... She is living in X, it’s close! She comes, but we have to understand that she has her own life. Even my stepdaughter... if I need something. If I wanted to, I could take the clothes in my car and she would iron them. But I don’t think it’s a good idea... to overload someone that has their own life... she has kids... it’s not worth it! I can do it so I don’t overload anyone” (Marília.40.862-869)

Marília`s generalisation at the end of this excerpt may suggest her tendency to minimise her own NSCLBP in order to avoid troubling other people, which was also reinforced in the following excerpt.

“Yesterday I was... My stepson told me “Marília you’re so pale today! What’s going on with you?” And I told him “Don’t even talk to me about it because I couldn’t sleep last night, but I don’t want your father to notice this... you know that he gets worried”. He asked “Why?”, “because you know that he is very careful with me – oh dear these pains won’t go away” (Marília.21.439-446)

While some participants were in a constant search of balancing their needs with other people`s, others seemed to focus all their attention on taking care of other people, and thereby neglecting their own needs. When contextualised into the previously mentioned notion of lack of legitimation, this neglect seemed to represent an attempt to avoid negative sanctions or to respond to others` implicit blame for participants` predicaments.

For example, Rita seemed to ignore her NSCLBP and focus on ensuring a comfortable life for her children. It appeared as if she was trying to compensate her children for what she had not had during her childhood and adolescence. She focused on being a good mother and preparing her children to be independent, as she believed she would die young, as had happened with her mother. Nevertheless, she had also started making plans to take care of her future grandchildren, if this did not occur. Thus, there seemed to be a permanent need to take care of others at the expense of her own needs. Interestingly, Rita did not mention her needs throughout the whole interview.

“Even in pain, I`d rather my children not do things, I don`t want them to ever have the pain that I have. With the backpacks and those things... Since it`s me who has the pain and me who gave birth to them, and me who has to raise them, it`s better that I bear those pains and that in a few years they turn out to be little men...” (Rita.64.1397-1404)

Additionally, Rita`s focus on taking care of others extended beyond her children, as she demonstrated the same tendency with her work colleagues.

“Because at work, I think everyone feels more pain than I do. Because one goes on sick leave one day, then the other goes on sick leave. Then another misses work... Some of those poor souls are sick! (...) so why should I complain? It`s not worth it! The one who is in the kitchen with me for example, I can`t carry weights, she can`t carry weights, neither of us can. I have to carry everything by myself... who else will? (Rita.42.924-937)

The participants` neglect of their specific needs seemed to emerge alongside their difficulty in verbalising their expectations of others. Simultaneously, it seemed to be difficult to manifest their needs within a context where their experience was not recognised and validated.

The interactions with their social networks (theme 4) and health professionals (theme 3) in a context of a permanent search for meaning (theme 2) seemed to lead the participants to engage in a deeper analysis of their sense of self.

6.4.5. Theme 5: Defining the self through the meaning of NSCLBP

The participants` definition of their sense of self through the meaning making of NSCLBP was examined in this theme. In this context, the participants` search for their own credibility was analysed. Their engagement in a deeper analysis of the sense of self as a consequence of their search for credibility was also examined, particularly the assimilation of the disorder into their sense of self. Also articulated were the comparisons from and to people not experiencing pain as well as their influence in the participants` meaning making of their sense of self. This theme was formed by two sub-themes that are represented in the figure below.

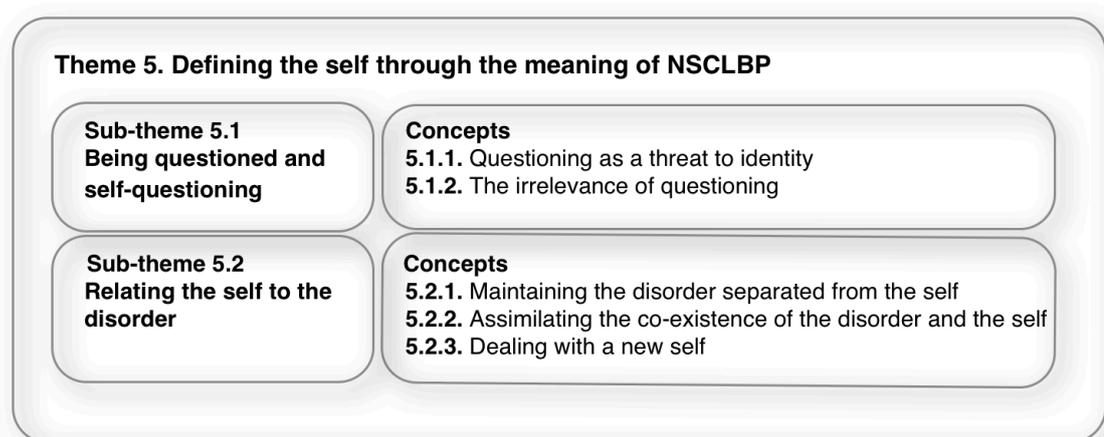


Figure 8 – Overview of the sub-themes and concepts included in the fifth theme.

Sub-theme 5.1. Being questioned and self-questioning

The absence of legitimation and validation for the participants` NSCLBP, particularly from relatives, friends, colleagues and health professionals, seemed

to precede an underlying questioning of credibility. More specifically, it was not only the credibility of NSCLBP that participants perceived to be questioned, but also, and possibly more importantly, their credibility as individuals experiencing pain. This sub-theme discussed how participants dealt with being questioned and most importantly with their own questions and was organised into two central concepts: questioning as a threat to identity; and, the irrelevance of questioning (figure 8).

Concept 5.1.1. Questioning as a threat to identity

All participants raised the question of the reality of their NSCLBP at some point in their accounts. However, it is important to note that this questioning had a distinct impact in the participants' accounts. Some participants thoroughly explored this topic and others sporadically mentioned it, as it did not seem to be perceived as relevant.

Those who thoroughly explored this topic throughout their accounts appeared to incorporate this question as a threat to their identity, as they needed to demonstrate their credibility. More specifically, they extended the previously explored need to legitimise NSCLBP (theme 4) into a quest for proving their credibility as individuals experiencing NSCLBP. Eva introduced this topic, highlighting herself and not her NSCLBP as being doubted.

“Right now I`m smiling, but there are many days when I don`t want to smile... and this is something that people don`t understand... The thing is, when we`re not as cheerful as usual... no one understands why. If you say that you`re in pain or you aren`t feeling too good... they don`t get it (...) I feel like people don`t believe me in these situations. Yes, I feel doubted. I do feel, doubted (...) I don`t feel much more than this, just this. I`ve learnt not to pay attention to a lot of things. You learn to value some things less... As you get older, or more experienced, you learn to value them less, but I feel doubted, for sure” (Eva.35.756-773)

Similarly, Helena also seemed to perceive the lack of other people`s recognition of her NSCLBP as a threat to her identity. However, while Eva reacted to this challenge by focusing on a way to prove her NSCLBP (sub-theme 2.2), Helena responded by questioning both her NSCLBP and her own credibility. She asked herself several questions and for a few moments during the interview she appeared to doubt herself. She considered the hypothesis that her NSCLBP may be a product of her imagination, however this hypothesis seemed to be difficult to accept as she quickly rejected this idea.

“Is it [pain] in my head...? If it... but no, it`s not in my head because I feel it. We feel this pain, it is not our imagination!” (Helena.23.489-492)

Given that Helena reported having no contact with anyone experiencing chronic pain, it is interesting to note the change from the singular “I feel” to the plural “We feel” in the previous excerpt. She was possibly trying to highlight what she perceived to share with other people experiencing NSCLBP as a way to reinforce her credibility.

Similarly, the lack of objective proof led Laura to doubt herself and question her sanity, despite emphasising the legitimacy and validity of her NSCLBP. This self-questioning seemed to be challenging as Laura changed the subject quickly, which was similar to Helena. This change of subject may indicate that this hypothesis was more difficult to accept than the previously discussed scepticism.

“... they [health professionals] say that carrying heavy objects should be avoided... not carrying heavy objects... so this [NSCLBP] is something that I relate to my job... if it isn`t... then I`ll keep saying what I`ve said before... one of these days I`m going to start thinking that I`m going crazy, right? If it isn`t related to my job, then where`s this pain coming from?” (Laura.23.496-501)

“I`m going to start thinking that I `m going crazy... Well, that`s not really the case because I think I`m a strong person in this way, but sometimes I ask myself, what if I`ve got something?” (Laura.13.275-278)

Although speculating about the possibility of having imagined her NSCLBP disorder, Laura used the phrase “I`m a strong person” to reject this idea. It is interesting to note that the hypothesis of imagining pain seemed to be perceived as an indicative of weakness, and thus as threat to their identity.

Possibly, as a reaction to this perceived threat, some participants felt the need to emphasise their strength and perseverance. For example, Marília exemplifies this:

“Meanwhile... I just kept going ... when I had pain I would usually go to the hospital... But it was more because of this pain back here (...) I would go to the hospital, if I had this pain for some time... I would have one of those injections for horses... It was good for that pain... but it probably wasn`t for other things...” (Marília.30.650-655)

It is interesting to note the Marília`s phrase “an injection for horses” in the previous excerpt seemed to reinforce her perception of being more resistant than the average person as she was able to bear a seemingly stronger treatment. Marília seemed to consider herself as stronger than most, as she perceived herself to be more resistant to pain.

Some participants compared themselves to other people, which seemed to prompt a sense of pride in their strength to bear pain and carry on with life. For example, Rita suggested that although she was not as smart or as beautiful as her younger sister, she perceived herself to be stronger. Her perception of being stronger seemed to be the basis of an underlying sense of self-sacrifice for other people (sub-theme 4.3).

“Actually I never had any problems, my sister who also worked there for many years... Until she... as she was weaker than me, maybe it was the

bones, I don't know... I know she was on sick leave for a long time because of a pain on the shoulder that prevented her from lifting the jackets..." (Rita.8.158-164)

Despite the participants' perception of being seen as weaker, the comparisons to other people seemed to prompt their perception of being stronger than average. The participants' emphasis on their capacity to bear pain may also be seen as an attempt to have some social recognition (theme 4). Indeed, the participants who perceived the aforementioned questioning as a threat to their identities were those who struggled with the lack of recognition, tended to withdraw from social interactions and avoided talking about their NSCLBP (theme 4).

Concept 5.1.2. The irrelevance of questioning

Although the majority of the participants hypothesised NSCLBP as a possible product of their imagination, some seemed not to acknowledge these questions, as they apparently perceived that their credibility as individuals experiencing NSCLBP was not in question. In the following excerpt, Fernanda reported that NSCLBP could be psychological. However, with the exception of the following quotations no other references to this topic were made, suggesting that this was vaguely purported and neither considered relevant nor a threat to her identity.

"But I know that I can't... sleep in my bed.... So, if I sleep on the couch with a heater close to me and with a blanket covering me... I can sleep perfectly... In my bed, I don't know if my leg gets cold, I've got no idea... I just know that the problem is here and I've got pain here... I really wake up.... I just don't know if this is psychological, I wake up in tears... At the weekend, the weather was warmer... there were some warmer days... and I didn't have this pain..." (Fernanda.3.57-68)

When compared to other participants, Fernanda's apparent absence of self-questioning may shed some light on the previously mentioned minimisation of own needs (sub-theme 4.3).

Regardless of the depth in which the participants explored the aforementioned questions, it seems that the experience of having NSCLBP disorder has some impact on the participants` identities. The participants seemingly started to become aware of this impact as they were making sense of the degree of their disorder`s presence in their identities.

Sub-theme 5.2. Relating the self to the disorder

When making sense of the degree of the disorder`s presence in their identities, it is important to consider the variability by which each participant made sense of this. While some explicitly explored it and expressed distress about the intrusion of NSCLBP into their sense of self, others merely alluded to it, suggesting an underlying acknowledgment of the assimilation of the disorder into the self. Furthermore, some participants seemed to explore these aspects further, emphasising the emergence of a new self as a consequence of the experience of having NSCLBP. This sub-theme was organised into three central concepts: maintaining the disorder separated from the self; assimilating the co-existence of the self and the disorder; and, dealing with a new self (figure 8).

Concept 5.2.1. Maintaining the disorder separated from the self

Some of the study`s participants seemed to struggle with an apparently perceived dichotomy between the disorder and the self. For example, Eva alluded to a separation between her NSCLBP and her self, as she seemingly perceived them as two distinct and independent identities.

“You’re asking if I can relate my pain to daily situations, right? I can’t do that! I can’t do that! Like something happens and I get worse... (...) I’ve never been able to do that! I’ve never been able to relate... Like, being nervous or... no! I’ve never been able to relate them! I can’t tell you anything about that!” (Eva.34.734-744)

It is interesting to note that her decision to introduce the idea of “being nervous” after such an open question may reveal the need to establish a separation between her identity and her disorder.

Additionally, the following excerpt may also support Eva`s attempt to separate NSCLBP from her sense of self - she seemed to force herself to ignore the pain in order to preserve her self (the one who was not in pain and was able to carry out everyday life activities).

“I never say “I can`t do this” or “I can`t do that”, I never say this because people would plain and simple think that I don`t want to do it! That`s reality, whether you like it or not, that`s reality!” (Eva.19.411-417)

Although Fernanda did not emphasise this separation between the self and the disorder, she seemed to struggle with an apparent intrusion of the disorder into the self. In the following excerpt, she rejected the possibility of being sick, as this was perceived as a consequence of having NSCLBP.

“It`s like this: I can`t be sick! Because nowadays, we can`t count on our kids like we used to count on our parents, right? While I was raising my child, I always had my mother in the background... but unfortunately she died! I don`t expect my son, who already has a daughter, to leave his job... To leave his job, his wife; they live in another city... to come here to support me... So, logically... I always believe that... I`ve always believed that I can`t be sick... So, I need to keep having a normal life. Some days are better, some days are worse, that`s it...” (Fernanda.11.230-242)

The further exploration of this idea revealed that Fernanda`s rejection of being sick was related to a motivation to preserve her autonomy, as she did not have a supportive network. Seemingly, her perseverance to keep working helped her to avoid this unwanted role.

Similar to Eva and Fernanda, João also seemed to keep NSCLBP separated from the self – he emphasised that he tended to minimise or even neglect pain in order to be able to run his business and accomplish his objectives. However, this response seemed to vary according to the contexts: when with his family,

he seemed to consider pain to be a reason to avoid or interrupt some activities. The following excerpts exemplify these two perspectives.

“I had this professional activity... with domestic appliances... I also installed satellite dishes, satellite dishes... and sometimes I had to pull the dishes... dishes that were two metres, thirty in diameter... very heavy things... and pull them up to the third or fourth floor... pull them with a rope... you need strength... and it`s not only upper body strength... we`re talking about this part [pointing to low back] right? And... it`s funny... I remember many times, when I was working with the drill... and I have a powerful drill... with big drill tips... they have to be really thick... sometimes I was perforating thick structures, like a wall of cement or something like that... and... that vibration... that vibration affected my back... my bones.... And at the end of the day I was in pain... I was aware that this task had affected me” (João.18.387-407)

“When they were babies just to hold them in my arms.... I had pain and I had to... it`s the same pain I have when I`m in the kitchen and need to carry something.... I have to leave the object immediately and sit down...” (João.55.1203-1208)

The previous excerpts suggested that the acceptance or rejection of the intrusion of the disorder into the self depended on the contexts. In his job, João`s description of this experience in his job suggested that he tried to preserve a clear separation between his self and his NSCLBP. He seemed to ignore or reject pain in order to maintain his job, which involved demanding physical tasks that were perceived as damaging for his back. It is interesting to note that this rejection appeared to be perceived as indicative of personal strength, as if it demonstrated João`s capacity to deal with the effects of NSCLBP. On the other hand, in a family context João did not appear to preserve this separation between the self and the disorder, as he seemed to accept that pain could have an impact on his family.

Concept 5.2.2. Assimilating the co-existence of the self and the disorder

Some participants appeared to have assimilated the co-existence of the self and the disorder. More specifically, their accounts seemed to indicate an underlying fusion of sorts, as if both were perceived as inseparable.

Alice`s account may be used as an example to highlight the aforementioned underlying fusion between the self and NSCLBP. She seemed to perceive herself as predisposed to having pain, as she had no recollections of being without pain. On the one hand, the foundation for this perception seemed to be connected to the long duration of NSCLBP. On the other hand, there seemed to be some personality traits that Alice perceived as responsible for her NSCLBP. In the following excerpts, she seemed to have difficulties in distinguishing between NSCLBP and her personality traits.

“I`m very nervous, very, very, very nervous... I don`t know how to control myself... Since I was I child, according to my mum... I`ve been... I already was... This hasn`t been easy... There are people with more serious problems than me, I can`t complain... But I`ve also had my problems...and maybe I don`t deal with them quite well, as well as I should... (...) Then I become “completely broken”... everything hurts... there is not a single part of me that doesn`t hurt... When I`m like this... the next day I`m “completely broken”, completely... I usually say that I`m hungover the next day” (Alice.29.622-668)

Alice related being “very nervous” to becoming “completely broken”, as they were two aspects of her personality that co-existed. Similarly, Rita seemed to acknowledge NSCLBP as an inseparable part of her identity. When she was prompted to recall her experience of having NSCLBP disorder, she started recounting her life story, beginning with what appeared to be the most significant episode – her mother`s death, when she was fourteen years old. It is interesting to note that she seemed to use her mother`s life story to make sense of her own and reflect on her sense of self - her mother bore pain until death and Rita seemed to be prepared to do the same.

“I don’t remember my mother saying: “Today I don’t feel any pain”. And... my mother is present every single day of my life! I cry a lot, I’m not happy... I’m happy with my children! I’m happy with my marriage but... there isn’t a single day I don’t remember my mother. And this thing with my mother has left a mark, it really has. I don’t like talking about my mother, because each time I do... and I always think that if my mother suffered so much with her husband, with her illness and got through it all until the day she passed away... I will too! And I have a lot of faith in my mother!” (Rita.51.1112-1117)

Following the example of her mother, Rita was focused on ensuring her family’s sustainability, possibly indicating that pain and, thus her self were not that important. Her mother’s story seemed to inspire her to do what needed to be done, despite the pain. Rita’s account seemed to demonstrate how this experience could be responsible for defining the self, through the development of a specific role – apparently in this case the role of martyr.

The participants who seemingly assimilated the co-existence of both the self and the disorder as inseparable identities appeared to be those who accepted the lack of concrete explanations for their NSCLBP (theme 2). Indeed, the aforementioned assimilation may be an important aspect to help participants dealing with the struggle to find explanations for their NSCLBP, as this assimilation could help them making sense of their disorder.

5.2.3. Dealing with a new self

Some participants seemed to relate the experience of having NSCLBP to the emergence of a new self. In the following excerpt Laura introduces this idea:

“I feel different! I like the same people, I like the stuff that I’ve always liked, but now... when the time comes... to do, or to speak, or to be with... I reach a point... I plan to do it, and I want to do it, but when the time comes I can’t... because... I don’t have the strength I’d like to have to help me deal with the pain... I don’t know...” (Laura.39.845-853)

Laura seemed to make sense of her self by establishing a comparison between an “old self” and a “new self”, where the experience of having NSCLBP seemed to have caused this distinction. Before having NSCLBP, she considered herself to be a positive person and strong enough to support everyone around her, but at the time of the interview she believed that she did not have enough strength to deal with her own problems. In the following excerpt, Laura demonstrated that her “old self” was sociable and enjoyed having family and friends at home, whereas the “new self” avoided contact with people and was isolated.

“It’s complicated because I can’t feel good! Good! I can’t feel good about my pain, not even to... I’ve always enjoyed having people around, my friends, family... But sometimes I’m not well... If I’m not well... If I’m not well because of this damn pain... This makes me feel uncomfortable... upset because of pain... I just want pain to go away because I’ve got things to do... but it’s disabling... this is complicated for me, I can’t be the person I used to be, I don’t know if you understand...” (Laura.37.794-805)

In Laura’s previous excerpt, she seemed to perceive that if the NSCLBP could be removed, she would recover her “old self”. The phrase “I can’t be the person I used to be” may indicate her preference for the “old self”, as it were “the real me”. Additionally, the need to systematically confirm the understanding of her words “I don’t know if you understand...”, may demonstrate her struggle to make sense and talk about such an abstract subject.

Contrary to Laura, Marília seemed to be investing in redefining a new self, which was still “the real me”. She discussed how she managed to adapt the tasks she considered central to her life to the pain, which seemed to help her in the reconstruction of her sense of self.

“It’s like I say... I deal with this quite well ... I continue doing everything... I do... If I can’t do it today, I’ll do it tomorrow, but I’ll do it. For example, if I have to clean the house... I don’t clean everything, the living-room, the kitchen... I do one thing at a time... sometimes I’m in pain, right? If I need

to do... I make a decision... I`m going to clean this rather than that... because it`s easier... and then, tomorrow, if I feel better, if I have less pain, I`ll do the more difficult tasks... People have to deal with it like this, at least I deal with it like this, right? (Marília.32.699-708)

Marília seemed to be concentrated on how she could move forward with the NSCLBP, take care of herself, share her difficulty with significant others and ask for help, if needed. Apparently, she was not looking for NSCLBP removal like Laura (who believed that pain removal would help her recover her “real me”), but was willing to find a way to help herself have a more comfortable life.

“The physiotherapist recommended swimming... (...) I came here for the physiotherapy. So, after the physiotherapy, I want to go swimming! I have to... because pain has been in my life for several years... so...” (Marília.3.48-56)

Additionally, the previous excerpt may be indicative of Marília`s development of new and deeper meanings of the relation between body and self. She seemed to have become able to think differently about pain and believed in her capacity to deal with NSCLBP.

Despite the variability in which participants make sense of the presence of NSCLBP into their sense of self, it is interesting to note that this meaning making seemed to be influenced by the recurrent comparisons from and to other people (theme 4).

6.5. Key findings: interrelations between themes

The Portuguese individuals` accounts of NSCLBP seemed to be indicative of the disruptive nature of this experience (theme 1). Indeed, the structures of their everyday life and the forms of knowledge that underpin these seemed to be changed as a consequence of NSCLBP. In particular, these participants seemed to be living a deferred life where they were focused on: (i) searching for

the meaning of NSCLBP (theme 2); (ii) searching for someone who could solve it (theme 3); (iii) trying to prove its legitimacy (theme 4); and, (iv) trying to prove their own credibility as individuals experiencing NSCLBP (theme 5).

The following figure represents the interrelation between the themes and sub-themes emerged in this study. The master table of themes, sub-themes and concepts can be found in appendix 21.

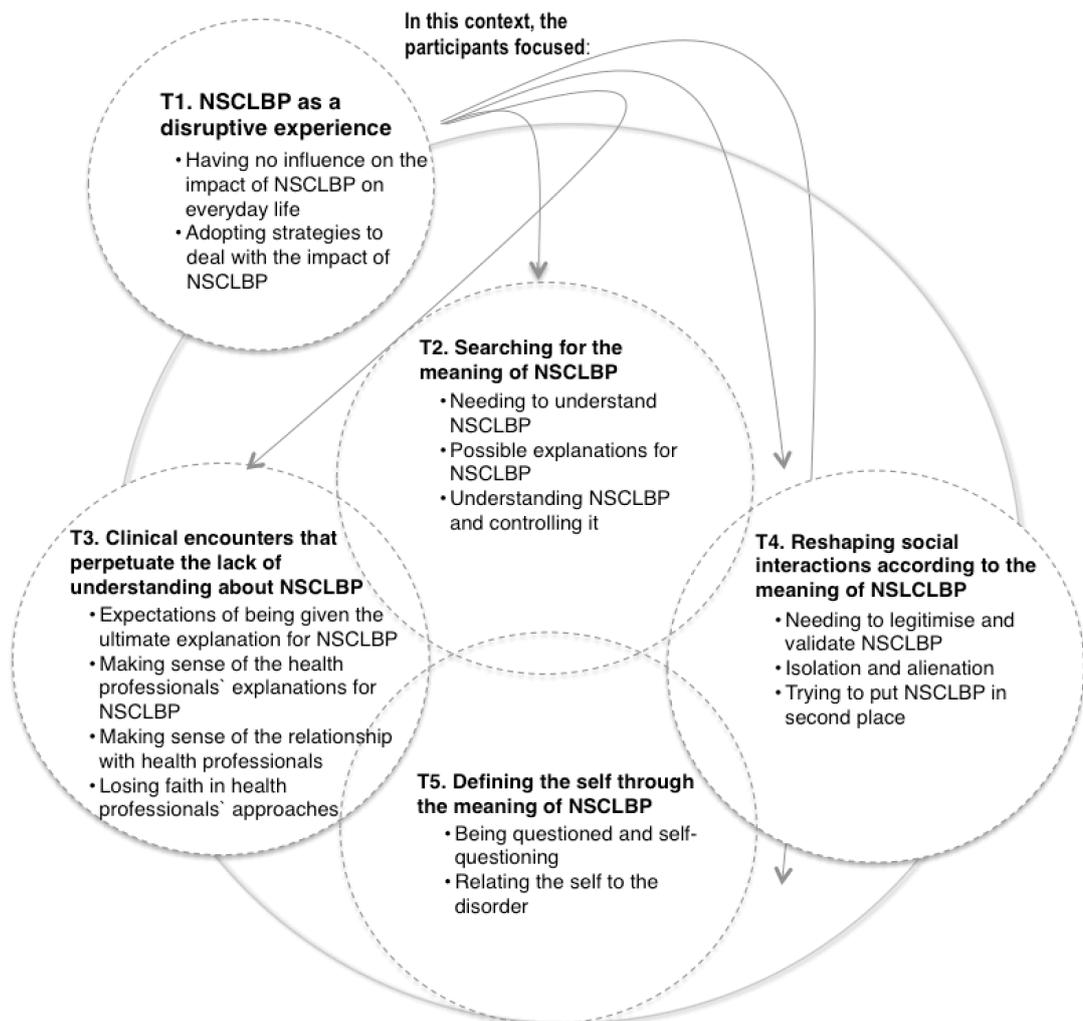


Figure 9 – Overview of the interrelation between the themes and sub-themes emerged in this study

This study's participants' lives appeared to revolve around their NSCLBP. They seemed to be trapped in a life dominated by pain, which was perceived to be out of their control. In this context, the perceived inability to have any influence

on the impact of NSCLBP on everyday life emerged as an important finding, which seemed to reveal an underlying fatalism, frequently related to the Portuguese culture. The participants perceived to have no choice but to restrict their life to what they considered to be mandatory tasks to ensure their family's sustainability. Despite the overall distressing and disabling impact of NSCLBP, the possibility of not being able to accomplish their perceived duties and obligations seemed to be the most disturbing. Irrespective of the perceived fatality inherent to the experience of NSCLBP, the participants adopted some strategies to deal with their disorder, which may reveal an underlying perseverance to overcome it. The participants' accounts suggested a commitment to face the obstacles related to NSCLBP, such as its unpredictability. Thus, the disruptive nature of the experience of Portuguese individuals with NSCLBP seemed to be characterised by a contextual dialectic relationship between both fatalism and perseverance.

In the context of a long lasting and disruptive experience, finding meaning for NSCLBP seemed to attain major relevance. While some participants struggled with the lack of understanding of NSCLBP, others seemed to have accommodated the idea that they would not have an adequate understanding of it. Irrespective of their perspective towards understanding NSCLBP, all participants formulated an explanation of some sort, of which they were unsure due to their perceived lack of knowledge. The majority of these explanations were rooted in their hypothesis of a physical origin for pain. However, the participants' perceived incoherence of their physical mind-set for explaining NSCLBP left room for a range of possible alternative explanations and subsequent unanswered questions, which seemed to increase their struggle to understand it. This search for meaning appeared to reveal an underlying need to control NSCLBP, since some participants viewed the understanding of the origin of their disorder as the only alternative to controlling it.

Clinical encounters between the participants and health professionals had an important role in the previously mentioned search for meaning. Rather than being helpful, as expected by the participants, the clinical encounters appeared

to perpetuate their lack of understanding about their disorder and perceived inability to control it. The participants' expectations of receiving a meaningful explanation for NSCLBP were successively unmet, as they were confronted with incomprehensible explanations. The discrepancy between the health professionals' explanations and the way the participants interpreted NSCLBP seemed to be responsible for the latter's struggle to understand the former's point of view. Thus, the participants questioned health professionals' competence and held them accountable for the persistence of their NSCLBP. In this context, the therapeutic relationship emerged as an element that seemed to contribute to the participants' struggle to understand and deal with NSCLBP. They demonstrated vulnerability, passivity and dependency on health professionals, however claimed not to be able to trust them and seemed to lose faith in health care services.

The lack of answers from health professionals regarding their NSCLBP led the current participants to engage in a continuous search for meaning within their social network, in which the quest for NSCLBP legitimation and validation attained significant relevance. However, rather than being an element of support, as expected by the current participants, social interactions seemed to become an issue as they called the reality of NSCLBP into question. After several unsuccessful attempts to arouse empathy from other people, all the participants tended to isolate themselves and focus interactions on their closest family, for whom they appeared to be willing to ignore their own needs.

Accordingly, other people's underlying scepticism regarding NSCLBP led the current participants to perceive their own credibility as being questioned. Seemingly, some engaged in a process of making sense of the perceived change of identity that occurred alongside their NSCLBP experience, while others merely ignored this and focused outwards. They dealt with an underlying altered sense of self in several ways, such as defending a clear separation between both the self and the NSCLBP, assimilating the co-existence of both or even accommodating the emergence of a new self. The latter response seemed to be related to an enhanced responsibility for self, which was possibly a key

element for regaining the control in life that was aspired by all participants. Finally, the comparisons to other people revealed a discrepancy in the way the current participants perceived themselves and the way in which they thought others perceived them. Despite their perception of being seen as weaker, the participants seemed to believe they were stronger than average, since they had to deal with more adversity in life. Enduring pain in silence appeared to be seen as a sign of personal strength.

6.6. Reflexive account

Reflections on my role as a researcher since the early stages of this study were quite important, as they allowed me to be more aware of my position regarding the phenomenon under investigation. Despite this, the data analysis was certainly the most challenging part of this research process.

I was aware that the time required to analyse data in sufficient and appropriate depth would be lengthy and I also knew that novice researchers frequently have difficulty in moving beyond a descriptive analysis. Given this, I tried to prepare myself the best I could for these challenges, by predicting that at least one third of the workload of this study would be devoted to data analysis. I also needed to develop a strategy that could help me to maintain the individuality of each interview and a clear pathway of my analysis, as I had to deal with a high volume of data (approximately twelve hours of audio-recording and 215 pages of transcriptions, which after adding my comments became 484 pages). Thus, considering the orientations from Smith et al. (2009a) previously presented in the fifth chapter, I developed my own strategy which included several procedures that helped me to maintain a rigorous and detailed approach to data analysis. Some of the procedures included were for example, an excel worksheet in order to preserve a registry of my decisions, the use of a colour system to facilitate the identification of themes, and the development of individual conceptual models in the NVivo 7 Research Software, among others. An example of the pathway including a detailed record of these procedures is presented in appendix 19.

As I repeated the same procedures for each interview, this was very time consuming. However, it attained major relevance because it helped me to engage with the data and reduce the initial volume of detail while maintaining the complexity. The knowledge about the methodological approach was fundamental in dealing with this complexity. For example, it helped me to engage with the previously presented hermeneutic circle, by permitting a motion between descriptive and interpretative stages. Indeed, the whole of each interview was transformed into a set of parts as I carried out the analysis, and then these parts were put together in another new whole. This new whole reflected a co-construction of meaning between both each participant and myself. The use of strategies such as abstraction and subsumption as suggested by Smith et al. (2009a) was also very helpful in looking for patterns and connections between emergent themes in each interview.

Regardless of the complexity inherent to the analysis of each individual interview, I considered that these strategies helped me to have a deeper understanding and interpretation of each participant's account. As a novice researcher, defining a pathway for the initial stages of analysis attained major relevance.

The most challenging stage of data analysis was the searching for patterns across the interviews, as I expected the final account to represent shared elements between the participants and the individuality of each one. However, at this stage, the complexity of the data had increased significantly because I was dealing with eight interviews simultaneously. Moreover, I was constantly challenged by the need to have a more interpretative approach to data.

Given that I was a novice researcher, I was being cautious and including organised procedures that could be discussed with the supervisory team. However, I realized that this would lead me to a highly descriptive final account. Therefore, to increase the level of interpretation required in an IPA study, I needed to address the complexity inherent to the participants' account. This required letting myself be guided by the participants' accounts, which helped me to "dig deeper". I had to deconstruct and reconstruct my assumptions about

these eight individuals' accounts, leading to new assumptions being incorporated into my framework, which helped me to expand horizons about the phenomenon under investigation.

This process was guided by the previously presented notion of hermeneutic circle. In the context of the researcher's reflection on data analysis, the "whole" was the researcher's on-going biography, while the "parts" were the encounters with each participant.

The acknowledgement of my previous preconceptions and expectations attained major relevance in this process. Indeed, as a consequence of my professional background as a physiotherapist, I believed that all individuals with NSCLBP would benefit from being provided with a detailed explanation on the neurophysiology of pain. Thus, I also expected that all individuals experiencing NSCLBP would consider this beneficial. Indeed, I was aware that I had tried to avoid asking closed questions about this in the interviews. Nevertheless, I realised that I was looking for this information when I started analysing the data. The awareness of this divergence between my expectations and the participants' accounts constituted an example of the aforementioned expansion of horizons. The new information from the participants was integrated in my interpretative framework and new knowledge was developed.

Additionally, I also conceived that health professionals should approach patients according to a biopsychosocial framework. From my perspective, this embraced several values such as respect for the patients' choices and individual needs. I realised that because of my strong beliefs on what health care should be, I would possibly be quite judgmental if my preconceptions were not reproduced in the examples of health encounters provided by participants. The awareness of my possible influence on the analysis of data concerning the clinical encounters, led me to put an emphasis on interpreting and reporting what seemed to be the most relevant information and to avoid being critical about it. Thus, my purpose as a researcher was to provide evidence from the participants' accounts for some of the problems they had explored in the clinical encounters, rather than critique the health professionals' approaches.

Furthermore, as a Portuguese individual, I also conceived Portuguese society as quite supportive. Thus, I expected that Portuguese individuals experiencing NSCLBP would have great support from relatives, friends and colleagues. Accordingly, at the initial stages of analysis it was quite important to realise that I was actually looking for participants` comments that could support my initial thoughts. Becoming aware of preconceptions throughout the analytic process helped me to add depth to my interpretation. Indeed, I gradually moved from a point where I (my preconceptions and expectations) was the focus to a point where the participants were the focus. The acknowledgment of my possible influence on the analysis helped me to attend to the participants` accounts of experiencing NSCLBP more closely.

It is important to consider that working simultaneously with two languages significantly increased the complexity of the analysis. A bi-lingual translator was essential to preserve the meaning in the translation from Portuguese to English.

6.7. Chapter summary

In this chapter, the findings from this study have been analysed. The analysis included detailed examination of the emerged themes, sub-themes and concepts. The next chapter is devoted to the discussion of this study`s findings.

Chapter 7: Discussion

In this chapter, the findings that emerged from this study are discussed. Firstly, the main findings are discussed in relation to relevant literature. This is followed by the critique of the methodological approach. Additionally, the study's contribution to knowledge is addressed. The implications for patients, clinical practice, health services and health professionals' education, are also discussed. Furthermore, suggestions for future research developing from this study are outlined. Finally, a reflexive account on the role of the researcher in the research process is presented, with particular emphasis on the discussion of this study's findings.

7.1. Discussion of findings

This is the first study that has been undertaken into the Portuguese individuals' experiences and perceptions of NSCLBP. The current findings' discussion intends to facilitate the conjecture of convergence and divergence from studies carried out in other contexts. The following sections aim to enable this process through the discussion of this study's findings with the existing research carried out in this area.

It is important to recall that five themes emerged from data analysis and provided an understanding of how Portuguese individuals' with NSCLBP tried to make sense of their condition. A decision was made to maintain a separation of the themes throughout this chapter as this was expected to promote the depth of the discussion. However, it is important to take into consideration that as presented in the sixth chapter, these themes should be viewed as interrelated parts of an extended account, where each part is essential to understand the whole. A higher visualisation of the emerged themes is frequently emphasised in the following sections. In this context, a higher visualisation is understood as a broader perspective of the data that may enable a relation to be established between specific parts of the analysis (e.g. one theme) and the whole (e.g. the extended account).

7.1.1. Theme 1: NSCLBP as a disruptive experience

In this theme, the scene for those that followed was set, since an overview of the underlying intrusion of NSCLBP in several dimensions of the participants' lives was provided. In this context, the current participants' perceptions of having no capacity to influence the course of NSCLBP in their life seemed to attain major relevance. Simultaneously, their apparent attempts to overcome NSCLBP were demonstrated through the use of specific strategies to deal with this disorder.

Sub-theme 1.1. Having no influence on the impact of NSCLBP on everyday life

In spite of the participants' emphases on the functional impact of NSCLBP, it seemed to extend beyond this and pervade several dimensions of their lives. The participants' accounts seemed to be representative of the chaos narrative suggested by Arthur Frank (1995) in his seminal book "The Wounded Story Teller". The plot of the chaos narratives includes a sequence of events that happen successively, where things are expected to worsen slowly. Thus, chaos is related to the absence of resolution. In this context, all efforts to stop an underlying collapse are useless, as the aforementioned events seem to be driven by forces that cannot be controlled (Frank, 1995; 2004). Frank (2004) drew attention to the value of voicing the chaos in narratives in clinical practice as it may help patients to hear previously unacknowledged aspects of their own accounts. Also important may be the idea of people being limited to representing their experiences according to the lack of structure their accounts make available (Frank, 2004). Arthur Frank's ideas may find some resonance with the current participants' accounts of NSCLBP, which were characterised by the absence of perceptible structure with no clear beginning or envisioned ending, or being influenced in any way by the participants' actions.

The current participants' seemingly chaotic experience provided the context for an underlying sense of disruptiveness. This could be likened to Bury's (1982) notion of biographical disruption that advocates an important change on the structures of everyday life and the forms of knowledge that underpin these as a consequence of chronic illness. Bury (1982) discussed three main aspects of disruption: the disruption of taken-for-granted assumptions and behaviours; the

disruption of explanatory systems normally used by individuals; and, the mobilisation of resources involved in the response to the altered situation. Indeed, the current study's participants seemed to be trapped in a life of chronic pain where:

- (i) their taken-for-granted assumptions about being healthy and capable to respond to life's challenges were called into question (theme 5);
- (ii) their pain did not fit into the commonly used explanations that are based on a diagnosed dysfunction (theme 3);
- (iii) they perceived to be compelled to develop an effective response to their disorder (theme 4).

Bunzli et al.'s (2013) metasynthesis of studies exploring the CLBP experience, discussed the notion of biographical suspension, which also seems to correlate with the current study's findings. The current findings highlighted that some of these participants were living a deferred life, where they were focused on making sense of NSCLBP and trying to deal with it. Even their future seemed to be purported according to the expected negative evolution of NSCLBP. Thus, participants' lives seemed to revolve around their NSCLBP and they considered that it would progressively worsen. They apparently expected to keep suffering due to circumstances that were out of their control (NSCLBP). This finding could be likened to Nielsen et al.'s (2009) notion of the Portuguese fatalistic mood and hopeless outlook of the future. Nielsen et al. (2009) explored the dialectic between fatalism and perseverance as an important paradox of the Portuguese culture: on the one hand, the Portuguese tend to perceive life events as a fatality; on the other, they reveal an underlying strength to overcome them. Thus, suffering seemed to play an important role and seemed to be used by the Portuguese as a means to delay active response (Nielsen et al., 2009). There seemed to be a cultural tendency to explain suffering as a consequence of external and uncontrollable causes that are perceived to be impossible to change (Ferreira-Valente et al., 2011), which may be applicable to the current participants' experiences of NSCLBP. Indeed, research has demonstrated some cultural differences in aspects such as the individuals' perceived control and use of active or passive coping mechanisms (Pillay et al., 2014). Although

research has established comparisons between specific categories (e.g. control and coping), questions regarding the comparison of the lived experiences remained unanswered.

Despite the episodes of strong pain reported in the current findings, it was not the intensity but the permanent presence and extended duration that most disturbed the participants. This finding may be further understood in the work of Snelgrove et al. (2013), who carried out a longitudinal study (semi-structured interviews carried out one and two years after the first data collection) with eight participants with CLBP in the UK. Snelgrove et al.'s (2013) IPA study emphasised continuity as an important part of the participants' experiences and called attention to the negative impact of unchanging CLBP experiences. Indeed, for the current participants, the chronic nature of pain seemed to be at the basis of its distressing and disabling impact. MacNeela et al.'s (2015) meta-ethnography of qualitative studies published on the subjective experience of CLBP also supports this finding by emphasising the NSCLBP's undermined effect on the individuals' ability to carry out essential activities, such as parenting, gardening or driving (MacNeela et al., 2015). Despite the relevance of Macneela et al.'s (2015) study in the discussion of the current findings, it is important to emphasise that none of the studies in their meta-ethnography referred to Portugal. The majority were carried out in the UK (24), and the remaining in Australia (5), the USA (3), Canada (1), Israel (1), Iran (1), New Zealand (1) and Sweden (1) (MacNeela et al., 2015). Since the data presented was related to different contexts (which were not presented in detail), the conjecture of convergence and divergence to the current study was limited.

Despite the reported overall impact of NSCLBP, the current participants' difficulty in performing their perceived mandatory tasks (such as professional tasks or housekeeping) was the most explored dimension throughout their interviews. The possibility of not being able to accomplish these tasks seemed to be disturbing, leading the participants to be driven by fear of what would happen to them, and in particular to their relatives, if they could not follow through with their obligations. This may be further understood in the work of Nielsen et al. (2009), which emphasised Portugal as a feminine society that

values human relationships over task achievement. The work of Coelho et al. (2014) also provides some context to this finding, as it highlighted the Portuguese underlying tension between more progressive values and a traditional and “familialist tradition” (Coelho et al., 2014, p.1) typical of Mediterranean communities. Despite being recently permeated by more individualistic values and equalitarian perspectives on gender roles, Portuguese families still seem to play a central role as providers of social support where the strong inter-generational connection is valued (Coelho, 2010; Ribeiro et al., 2015). This context may explain the current participants` focus on accomplishing their perceived duties and obligations, while hiding pain from others. Such an apparently absorbing task seemed to lead them to gradually restrict other dimensions of their life, in order to preserve their family life.

The idea of hiding pain from others and valuing the accomplishment of duties and obligations may be perplexing in a context characterised by supportive relationships. Ferreira-Valente et al. (2011), who carried out one of the few studies focused on Portuguese individuals with chronic musculoskeletal pain, found contrasting findings. These authors examined the associations between coping and adjustment to chronic pain in a sample of 117 patients with chronic MSK pain and compared the results with published results from two studies focused on 704 patients from the United States (Ferreira-Valente et al., 2011). According to this study`s findings, seeking social support, which tended to be inconsistently and weakly associated with pain interference in the North American sample, was moderately and positively associated with pain interference in the Portuguese sample (assessed by the brief version of Chronic Pain Coping Inventory - CPCI, and Portuguese Brief Pain Inventory, respectively) (Ferreira-Valente et al., 2011). Ferreira et al. (2011) explained these differences according to the Mediterranean cultural background, in which the stronger interpersonal relationships may facilitate seeking support. They contrasted this idea with the emphasis that is placed on autonomy in North America, which may lead individuals to perceive seeking support as an ineffective coping strategy (Ferreira-Valente et al., 2011). Despite Ferreira-Valente et al. (2011) study`s contribution to the interpretation of the current findings, it is important to take into account some limitations such as: although

all patients had musculoskeletal chronic pain, it stemmed from a range of aetiologies; also, test-retest reliability of the translated version of CPIC was not established. Nevertheless, while Ferreira-Valente et al.'s (2011) findings support a Portuguese response based on seeking support, the current findings highlight a contradictory response based on hiding pain and focusing on accomplishing duties and obligations. One cannot ignore that these studies were carried out under the influence of different research paradigms, used different methodological approaches and had their own limitations. However, the discussion of the current findings in relation to Ferreira et al.'s (Ferreira-Valente et al., 2011) study draws attention to the need to further understand this response, as the current findings diverged from previous literature.

Dealing with such a disruptive experience in a context of a dialectic relationship between fatalism and perseverance, places the above-mentioned restriction of everyday life as the only alternative available in the participants' view. A higher order visualisation of the interrelationship between the current study's emerged themes, may offer further understanding of this underlying sense of unavailability. More specifically, the participants' uncertainty about the explanations for NSCLBP (theme 2) as well as their sense of being the weakest element in the therapeutic relationships (theme 3), may be offered as aspects that contribute to their perceived lack of capacity of finding other alternatives to manage NSCLBP. Both themes are further discussed later in this chapter.

Sub-theme 1.2. Adopting strategies to deal with the impact of NSCLBP

Given the long duration of this experience and its disruptive nature, the current participants appeared to be compelled to reorganise their lives and find a way of dealing with NSCLBP. Discussing this finding through the lens of Nielsen et al.'s (2009) previously analysed notions about the Portuguese cultural background may support the idea that despite the perceived fatality of having NSCLBP, the current participants appeared to have the perseverance to overcome their NSCLBP. However, this was not free of obstacles as nearly all participants emphasised their difficulty in dealing with the unpredictable nature of NSCLBP. This finding concurred with those of Crowe et al. (2010) who drew attention to

the role of CLBP's unpredictability. In their qualitative study, which used thematic analysis of the interviews with New-Zealanders with CLBP, unpredictability was highlighted as one of the major impacts of CLBP. Participants reported frustration and concern about being unable to predict what actions would increase the pain, as it diminished or increased irrespective of what they did (Crowe et al., 2010a). Similar findings were found by Robinson et al. (2013), who interviewed Irish people with a variety of chronic pain conditions (for example back pain, fibromyalgia or rheumatoid arthritis) (Robinson et al., 2013). Additionally, Froud et al. (2014) carried out a systematic review of qualitative studies, in which the NSCLBP patients' inability to predict the onset of pain compromised their ability to plan ahead and increased their difficulty in the decision-making regarding social participation (Froud et al., 2014). It is important to take into consideration that the majority of papers included in this systematic review were from the UK (26), with the remaining coming from a limited number of countries such as Australia (6), the USA (5), New Zealand (3), Sweden and Canada (2), Iran, Israel, Netherlands and South Africa (1).

Despite apparently entrapped in their experiences, the current participants demonstrated an underlying desire to overcome pain. However, they seemed to hold different perspectives regarding this: while some accommodated the idea that they would not be able to do so, others were actively engaged in overcoming it. The participants who seemed to be accommodated to their lack of capacity to deal with NSCLBP tended to demonstrate an underlying frustration and sense of hopelessness in their accounts. The strategies they adopted to deal with the impact of their disorder were focused on reacting to pain or ignoring it until they reached a point where it became impossible to do so. On the other hand, the participants who actively tried to deal with the impact of NSCLBP seemed to perceive themselves as having some capacity to do so. The strategies they adopted to deal with their disorder seemed to be focused on preventing the increase of pain and looking for the best strategies to be able to keep doing some activities, such as the housework. A higher order visualisation of the interrelationship between the current study's emerged themes may offer further understanding about the current participants' endeavour to overcome

NSCLBP. Indeed, findings from the second theme suggested that those who perceived themselves as unable to overcome NSCLBP tended to invest in the quest of understanding it. On the other hand, for those who perceived themselves as able to deal with it, understanding NSCLBP did not appear to be a pre-requisite to do so. These findings seemed to be indicative of a relationship between the participants' perceptions of ability to overcome pain and their need to understand it, which is further explored in the following section.

7.1.2. Theme 2: Searching for the meaning of NSCLBP

In this theme, the participants' search for meaning that precedes their self-reflection, which was analysed in the subsequent themes, was articulated. This search for meaning included their interactions with health professionals (theme 3) and other people (theme 4), as well as with their sense of self (theme 5).

Sub-theme 2.1. Needing to understand NSCLBP

Despite the current participants' relentless efforts to understand and justify their disorder, the absence of a relationship with possible causes left them with a range of unanswered questions. The apparent ongoing and unfinished nature of this search for meaning had already been suggested by Osborn and Smith (1998), who carried out an IPA study exploring the experience of chronic benign lower back pain in the UK. In the Osborn and Smith's (1998) study, participants demonstrated a strong motivation to understand and explain their situation. Despite actively looking to make sense of their experience, the participants could not explain why their pain remained. The authors discussed this idea as not a simple question of ignorance, but as a profound state of bewilderment since the participants failed consistently to understand what was happening to them (Osborn & Smith, 1998). Osborn and Smith (1998) highlighted the active process of constructing understanding as a key element of the NSCLBP individuals' accounts, which has some resonance with the current study. Interestingly, despite the Osborn and Smith's (1998) study referring to a group of British people and eighteen years having passed since it was published, some facets of the patients' experiences do not seem to have changed when analysing the current findings. Indeed, the current findings are in line with a

meta-ethnography of patients' experience of chronic non-malignant MSK pain carried out by Toye et al. (2013), which emphasised an active struggle to find meaning for suffering. These authors used previous studies from Soderberg (1999), Dickson (2003) and Harding (2005) to highlight the chronic MSK pain patients' need for making sense about pain, seeking concrete explanations and reconstructing its meaning. Indeed, research in this area has highlighted the patients' development of an explanatory model as an important element to recovery (Johansson et al., 1999; Tavafian et al., 2008; Toye & Barker, 2012a; 2012b). Toye and Barker (2012a) used a grounded theory approach to explore the differences in narrative between patients with persistent non-specific low back pain who benefited from pain management and those who did not. These authors emphasised that patients need an acceptable explanatory model that fits their experience and personal narratives, as this seemed to be linked to recovery in their study.

A higher order visualisation of the interrelationship between the current study's emerged themes may provide further understanding of this struggle to understand NSCLBP, as it seemed to be linked to clinical encounters (theme 3). Indeed, the current participants emphasised the absence of health professionals' explanation for NSCLBP or when provided, it was perceived as confusing or incomprehensible. This led to successive unmet expectations that contributed to increasing the participants' struggle to understand their disorder. This idea is further discussed later in this chapter (theme 3).

Contrary to this sense of struggle, some of the current participants seemed to have accommodated the idea that they would not have a clear understanding of their NSCLBP. They did not consider the reason for their disorder's persistence to be worth questioning. Again, the previously discussed link with the third theme may offer an explanation for this finding, as the participants seemed to progressively lose faith in health care services and thus in the source of information that could allow them to understand their NSCLBP.

Sub-theme 2.2. Possible explanations for NSCLBP

Despite the reported lack of understanding of their disorder, all current participants had formulated an explanation of some sort. Their explanations were mostly rooted in the physical origin of pain, which seemed to be indicative of a physical mind-set in making sense of NSCLBP. This was consistent with previous studies that emphasised the dominance of biomedical model in the NSCLBP patients' attempts to conceptualise their pain, as they strive for organic explanation (Bowman, 1991; Osborn & Smith, 1998; Lillrank, 2003; Corbett et al., 2007; Toye & Barker, 2012b; Toye et al., 2013). Lillrank (2003) drew attention to the incoherence between both the subjective nature of pain and the biomedical model. Indeed, the biomedical model embraces some ideas that are antagonistic to the experience of those with NSCLBP: (i) the dualism of mind and body and the subsequent focus on treating diseases as entities that are located within the patients' body; (ii) the conceptualisation of illness in a framework of cause effect and the subsequent focus on finding the cause; and, (iii) the elimination of disease through the control of the body (Lupton, 2012). This may explain the current participants reported difficulty in formulating an explanation that could help them make sense of their disorder.

Accordingly, the participants' awareness of the inconsistencies in their explanations led them to propose alternative explanations based on the possible psychological nature of their NSCLBP. These alternative explanations tended to come later in the majority of the interviews, as the participants seemingly perceived the lack of physical evidence to possibly question the reality of their pain. This appeared to be indicative of the current participants' underlying conflict between biomedical and biopsychosocial models, which seemed to be prompted by the interactions with health professionals that are further explored in the next section (theme 3). Kugelman (1999) suggested that the dialogue between these two models is challenging for chronic pain patients because of the associated cultural polarity between what is considered real (body) and unreal (mind). Thus, admitting the psychosocial (unreal) nature of their pain seemed to be perceived by the current participants as synonymous to admitting that the pain was in their mind. They presented these alternative explanations as merely hypotheses that may have contributed to their pain, but

did not appear to see them as adequate explanations, since they were still looking for the one that could possibly legitimise their pain. This idea gained consistency throughout the analysis regarding the participants' social interactions (theme 4). Indeed, the lack of perceived acceptable explanations for NSLCBP seemed to prompt a quest for meaning where participants struggled to legitimise their disorder.

Conversely, other people's explanations for NSCLBP (such as relatives, friends or colleagues) seemed to have an impact on the current participants' mind-set for understanding it. Although there is little understanding about the illness representations of significant others, previous research has demonstrated their important influence on the experience of people with NSCLBP (Leonard et al., 2006). McCluskey et al.'s (2011) study provides an important context for the current findings. These authors conducted semi-structured interviews with five UK individuals experiencing non-specific low back pain along with their significant others. Findings from this exploratory study demonstrated that significant others shared and further reinforced patients' unhelpful beliefs such as fear of pain/re-injury. The previously reported similarity between the interviewed dyads' beliefs may provide further understanding as to why some of the current participants accepted and integrated other people's explanations. More specifically, they could identify with other people's ideas, which helped them in the meaning making of NSCLBP. Nevertheless, it is important to emphasise that all significant others included in the McCluskey et al.'s (2011) study had long-term health conditions, which seemed to justify both the reported shared understanding as well as high degree of empathy. The same did not occur in the current study, as the participants emphasised the lack of empathy from other people (theme 4). Moreover, some of the current participants' rejection of other people's explanations may also be related to this lack of empathy. Apparently, if the current participants perceived that a person was not able to be empathic, it meant that that person was not able to provide an adequate explanation for their NSCLBP.

Despite the explanations provided by the participants' immediate social networks, there was an underlying uncertainty regarding the participants' own

explanations. This led some to focus on getting confirmation from someone more knowledgeable. The integration of this idea into the third theme highlighted the participants' identification of health professionals as those who would give them this confirmation.

Sub-theme 2.3. Understanding NSCLBP and controlling it

The current participants' search for meaning seemed to uncover an underlying need to control NSCLBP. More specifically, for some participants, understanding the origin of their NSCLBP was perceived as the only alternative to controlling it. On the other hand, for others this understanding was not perceived as a pre-requisite to controlling their NSCLBP. This finding seemed to be indicative of the singular need to understand and control NSCLBP.

This notion of control has emerged in a number of qualitative studies such as the IPA study of Snelgrove and Lioffi (2009), which explored the experiences of a group of British people with CLBP or the study of Zander et al. (2013) who used a grounded theory approach to understand the experience of Iraqi women with chronic pain living in Sweden. The differences between the cultural backgrounds of these studies' participants as well as between the methodological approaches that were used, draw attention to a possible cross-cultural common need for control in the experience of NSCLBP. Nevertheless, the previously discussed Portuguese cultural background (Nielssen et al., 2009; Ferreira-Valente et al., 2011) seemed to offer a new angle to the understanding of this phenomenon, which needs to be considered in a dialectic relationship between fatalism and perseverance.

In the context of the aforementioned quest for understanding and retaining control, finding meaning and learning how to deal with unpredictability seemed to represent major challenges for the current participants. Finding meaning may not have necessarily required the formulation of a clear and detailed explanation, but the development of an acceptable one, or in other words, an explanation that made sense for the participants.

Indeed, it is possible that more than understanding NSCLBP *per se*, the current participants were looking for a way to retain a sense of control over their lives. However, it is important to emphasise that this idea is speculative since the current study did not provide evidence to support this convincingly. Though, it may suggest an interrelationship between understanding NSCLBP, finding meaning and retaining control that deserves to be explored in future research.

7.1.3. Theme 3: Clinical encounters that perpetuate the lack of understanding about NSCLBP

In this theme, the role of clinical encounters between the participants and health professionals (GP`s and PT`s) in perpetuating the lack of participants` understanding of NSCLBP was highlighted. Indeed, the health professionals seemed to play a significant role in the current participants` previously discussed search for meaning.

Sub-theme 3.1. Expectations of being given the ultimate explanation for NSCLBP

These participants seemed to consider the physician to be the only person who could provide an explanation for their NSCLBP. However, since these expectations were successively unmet, the current participants demonstrated a range of reactions such as anger, exasperation, disappointment or detachment, which seemed to increase their sense of struggle to understand their disorder. This is consistent with the findings from Campbell and Guy (2007) who ran group discussions once a week for four weeks with CLBP patients recruited from a hospital in the north-east of England. After a thematic analysis, these authors drew attention to the participants` unmet expectations and subsequent anger and frustration with the perceived ineptitude of the medical profession. Snelgrove and Lioffi (2009) also reported that two participants from a group of British people included in their IPA study demonstrated anger and frustration towards the perceived disorganisation of the health services.

Despite the reported reactions, the current participants` search for answers as to why their pain persisted led some to engage in a vicious cycle, in which they were still looking for the physician who would finally give them the expected explanation for NSCLBP. The further analysis of the current participants`

expectations suggested that they were driven by their previously presented physical mind-set for understanding NSCLBP (theme 2), in which the identification of a physical cause seemed to precede a cure. Indeed, the passiveness of the Portuguese regarding their health has been successively highlighted in the reports developed by the Portuguese Observatory on Health Systems and Policies (OPSS, 2009; 2010; 2011; 2012). Additionally, Gonçalves et al.'s (2010) study, which was carried out in the scope of the NHP 2011-2016, highlighted the Portuguese's passiveness and dependency on health professionals' knowledge as a fundamental issue to address in order to improve health care in Portugal. Although these authors did not explore the cultural basis for such passiveness, they seemed to relate this to the patients' lack of information and knowledge about their health as they made strong recommendations for investment on patients' literacy (Gonçalves et al., 2010). The emphasis was placed on providing information to patients in order to enable them to make decisions regarding their own health (Gonçalves et al., 2010).

In spite of the current participants' initial emphasis on the absence of health professionals' explanations, further exploration of this topic demonstrated that the latter did provide some explanations. However, the content and delivery did not seem to meet the current participants' expectations. This finding seemed to be a key aspect of the current study, as it drew attention to the idea that providing information *per se* may not be the best response in addressing NSCLBP patients' needs. This idea is further explored in the next section, together with the current participants' meaning-making of the health professionals' explanations for NSCLBP.

Indeed, the information provided led some of the current participants to question health professionals' competence in offering adequate explanations. In line with previous research (Walker et al., 1999; Harding et al., 2005; Campbell & Guy, 2007; Slade et al., 2009a; Toye & Barker, 2012b), some of them seemed to consider the health professionals (GP or PT) they met, not knowledgeable enough to solve their problem. Notwithstanding, a particular issue raised by the current study was that some participants started looking inwards, analysing their

lack of answers and assuming that they would not be able to understand the explanations they had been given. Contrary to the findings from similar studies (Walker et al., 1999; Harding et al., 2005; Campbell & Guy, 2007; Slade et al., 2009a; Toye & Barker, 2012b) carried out in different countries, the current participants not only questioned health professional's competency, but also their own capacity to understand the information they had been given, which may shed light on the previously reported passiveness. Indeed, this finding seemed to reinforce the current participants' perceived inability to have an active role in the management of their disorder.

Thus, on the one hand the current findings drew attention to the participants' needs to receive tailored information regarding their NSCLBP. On the other hand, they also highlighted the importance of health professionals' explanations and educative roles in the episode of care.

Sub-theme 3.2. Making sense of health professionals' explanations for NSCLBP

Regardless of the apparent lack of satisfaction with the health professionals' explanations, the current participants still devoted significant importance to them since they were perceived as a fundamental element in their search for meaning (theme 2). In this context, while some accepted health professionals' explanations despite these being perceived as vague or ambiguous, others seemed to emphasise their lack of coherence. These ideas are in line with Gonçalves et al.'s (2010) focus groups' findings, which emphasised the Portuguese individuals' lack of satisfaction with information provided by health professionals. The reasons reported were that the information provided was considered insufficient, inaccessible, confusing, technical and thus incomprehensible. Although Gonçalves et al. (2010) did not include individuals with NSCLBP in their interviews or focus groups, these findings provide some context for the interpretation of the current study, since they were focused on the Portuguese context. Interestingly, both the current findings as well as those from Gonçalves et al. (2010) contrast with a recent report published on the Portuguese satisfaction with health care by the Portuguese Directorate-General of Health (2015b). This report was carried out by the Portuguese department of

quality in health as well as by an independent polling company and presented the results of a survey of 2300 Portuguese individuals. According to this report, 93.9% of the respondents considered they were given clear and understandable explanations by their physicians and 89.2% considered they were given opportunities to ask questions and clarify doubts (Directorate-General of Health, 2015b). This draws attention to the contrast between findings that have emerged from qualitative approaches (such as the current study and the study by Gonçalves et al. (2010)) and those which have emerged from a quantitative approach (such as the report published by the Portuguese Directorate-General of Health). It may also indicate the complementary nature of these two approaches as well as the contribution of qualitative research in developing a deeper understanding of the phenomena under investigation.

The current study's findings suggest that the health professionals' explanations that met the previously discussed participants' physical mind-set for understanding NSCLBP tended to be accepted, although not necessarily understood. On the other hand, the health professionals' explanation that appeared to conflict with this mind-set seemed to reinforce the previously discussed continuing quest for meaning. This latter response is consistent with the findings from Harding et al. (2005), who carried out in-depth interviews with chronic pain patients in the UK. In this particular study, most of the participants tended not to wholly subscribe to the medical interpretation for their pain. According to Harding et al. (2005), the participants made sense of their pain according to previous events of their earlier life or health-related experiences, such as a previous surgery, which may have triggered NSCLBP. The medical explanations that did not match the patients' ideas did not seem to be accepted (Harding et al., 2005).

Thus, the perceived incoherence or the lack of health professionals' validation for the current participants' physical mind-set for understanding NSCLBP seemed to be at the basis of the latter struggle and perceived inability to control their disorder. Seemingly, these were also reinforced by the lack of a specific diagnosis, which appeared to lead some participants to consider the possibility of having an undiscovered disease. Although the current participants were

focused on finding meaning and not necessarily a diagnosis, some of them stated that having a diagnosis would be more important than having pain relief. Indeed, the need for a diagnosis has been reported by several studies carried out with NSCLBP patients (Tangum & Cherkin, 1998; Osborn & Smith, 1998; Harding et al., 2005; Campbell & Guy, 2007; Liddle et al., 2007; MacNeela et al., 2015). For example, in Campbell and Guy's (2007) study, participants from the north-east of England clearly stated that they wanted a diagnosis but were informed by their doctors that they were unlikely to receive one. Apparently, in the current study, the participants were not given such an assertive answer; rather they received vague answers that appeared to stimulate their search for the ultimate explanation for their NSCLBP. Indeed, in the Serbic and Pincus's (2013) study on British CLBP patients' understanding, feelings and behaviour in response to their diagnostic labels and the lack of clear diagnosis prompted more treatment seeking. Following a grounded theory approach, these authors emphasised that the prolonged absence of a clear diagnosis impacts how participants coped with back pain, how they perceived themselves and how they thought others perceived them. Thus, the issues related to the diagnosis could provide some context to the findings discussion concerning the current participants' relationships with their social contexts (theme 4) as well as with themselves (theme 5).

Sub-theme 3.3. Making sense of the therapeutic relationship with health professionals

As previously discussed, despite the current participants' investment in understanding their NSCLBP, they seemed to attribute the responsibility of providing a clear explanation to health professionals. This may be indicative of the participants' perception of their position in the therapeutic relationship – the participant as the person who could not understand or manage the disorder and the health professional as the person who was supposed to know about it and find a solution. The current study found some resonance with the previous work of Scheermesser et al. (2012) on the role of the cultural background in NSCLBP patients' perspectives regarding rehabilitation. Scheermesser et al. (2012)

argued that NSCLBP patients from south-east European cultures tended not to take responsibility for their health and attributed it to the health care system.

Although from a different region of the European continent, the current participants` tended to have a similar perspective about the therapeutic relationship, which seemed to be justified by a dependency on the health professionals and a subsequent perceived vulnerability. These participants seemed to accept an underlying asymmetry in the therapeutic relationship – for example, they reported to accept the health professionals` decisions without question despite not understanding them. The study carried out by Wallston et al. (1978) on the Development of Multidimensional Health Locus of Control Scales may offer new insights into the understanding of these findings. In the context of health, locus of control was defined as individuals` beliefs that their health can or cannot be influenced by their behaviour (Wallston et al., 1978). In his study Wallston et al. (1978) highlighted three dimensions of locus of control: “internal health locus of control”, “powerful other health locus of control” and “chance health locus of control”. The first dimension of locus of control was considered internal (health can be controlled by the individuals` behaviours), while the other two external (health cannot be controlled by the individuals` behaviours). The individuals who believed that powerful others were in control of one`s life may behave differently compared to those who believe the world is unpredictable and controlled by chance (Brosschot et al., 1994). Wallston et al. (1978) emphasised that a person with strong beliefs in external control by powerful others might be expected to continue a specific treatment, even experiencing side effects. On the other hand, a person with strong beliefs in external control by chance might be expected to abandon the treatment. Wallston et al.`s (1978) findings may offer new insights into the current findings, as they provide further understanding to the current participants` passive acceptance of an asymmetric therapeutic relationship, dependency on health professionals as well as abandonment of treatment in some cases (discussed in the following section).

Notwithstanding an apparent passive acceptance of health professionals` approaches, some of the current participants explicitly critiqued them for not

listening to their problems or considering their needs. Thus, these participants expressed a sense of disregard, disbelief and lack of respect for health professionals, which is in line with previous research carried out in other countries (Rhodes et al., 1999; Werner & Malterud, 2003; Howarth et al., 2014). Cooper et al.'s (2008) study drew attention to a possible relationship between communication and patients' perceived involvement in the physiotherapy process. These authors carried out semi-structured interviews with twenty-five individuals that had received physiotherapy for CLBP within the previous six months in Scotland. They reported that good communication, which included taking time over explanations, using appropriate terminology, listening, understanding and getting to know the patient as well as encouraging the patient's participation, was related to the patients' perception of being involved in the physiotherapy process (Cooper et al., 2008). Furthermore, these authors supported the view that some approaches to communication were more useful for some participants than others (Cooper et al., 2008).

Indeed, not being believed seemed to lead the current participants to perceive themselves as being disempowered to deal with their disorder and unable to collaborate in health care or establish a partnership with health professionals. This finding drew attention to the health professionals' impact on the patients' perceived capacity to participate in the decision-making. In particular, therapeutic relationships may be developed according to a range of models, which have significant influence on the patients' involvement in the decision-making (Goodyear-Smith & Buetow, 2001). Published literature has recommended a move from paternalism (model of therapeutic relationship where the health professional makes decisions on behalf of the patient, based on the principle of beneficence) to a patient-centred approach (where both the health professional's and the patient's knowledge inform the decision-making) (Charles et al., 1997; 1999; Mead & Bower, 2000; Trede, 2000a; Dow et al., 2012).

Rhodes et al.'s (1999) and May's (2001) qualitative studies with LBP patients from North America and the UK respectively, highlighted the participants' motivation to have an active involvement in their treatment. More specifically,

May (2001) carried out semi-structured interviews with individuals that had received physiotherapy for LBP some time the year before (the history of back pain varied from one single episode to a duration of thirty years). In this study, nearly all participants appreciated educational approaches based on active processes, rather than the transmission of knowledge to passive recipients. These participants valued information about the problem itself, but also about their role in back care, the treatment process and the prognosis. May (2001) emphasised that although effectiveness in terms of pain relief was considered a key outcome, developing a good understanding of their problem and learning self-management strategies was also very important for many participants.

The appraisal of May`s (2001) findings may reveal an important contrast to the current study`s, as although the current participants craved information they seemed to adopt a passive role in the healthcare system. Interestingly, a Portuguese report, carried out under the scope of the Pain Proposal initiative that studied the phenomenon of chronic pain in Portugal, highlighted that both patients` associations and health professionals working in this field emphasised the importance of involving patients in their own treatment (Castro-Lopes et al., 2010). Furthermore, interviews carried out with Portuguese individuals in Gonçalves et al.`s (2010) study highlighted that the participants wanted more information about health in general and their clinical condition in particular, which included information about the treatments prescribed. These participants also desired to be involved in the decision-making regarding diagnosis and treatments. Despite this, the authors emphasised that the desire to be involved did not necessarily mean that those participants were motivated or perceived to have the capacity to make decisions regarding their health (Gonçalves et al., 2010). Indeed, the Portuguese studies from Castro-Lopes et al. (2010) and Gonçalves et al. (2010) shed light on the current findings, as they highlighted that despite the Portuguese desire for more information and involvement in treatment, they do not seem to consider the possibility of having an active role in the decision-making. Thus, Portuguese health policies have consistently recommended that health professionals promote patients and families active participation in the treatment (OPSS, 2009; Gonçalves et al., 2010; OPSS, 2010; 2011; 2012). Nevertheless, the current participants` engagement in the

decision-making seemed to be inconceivable to them, as they restricted their expectations to the reception of information. This drew attention to the need to focus health policies not only on the health professionals, but also on the patients. Cooper et al. (2008) highlighted the importance of assessing patients' wishes regarding involvement in decision-making and tailoring the subsequent approach to that decision-making. They found that while some participants were happy for the physiotherapist to make most of the decisions, as long as they were complemented by good explanations, others wanted more involvement than they had experienced (Cooper et al., 2008).

Once again, the current findings contrast with those from the previously mentioned report published by the Portuguese Directorate-General of Health (2015b). According to this report, 87.2% of the respondents considered themselves to be involved in the decision-making regarding their health and treatments (Directorate-General of Health, 2015b). The concept of decision-making held by the respondents may be questioned, since data collection was performed through a survey and thus no explanations of the concepts were provided. Additionally, no information was presented regarding the health status of the respondents and, thus, it was not clear if individuals with NSCLBP were included.

The current participants' perceived inability to trust health professionals also emerged in the current study. Indeed the development of a trusting therapeutic relationship seemed to be prevented by the aforementioned vulnerability, passivity and dependency on health professionals. Previous literature has already emphasised that CLBP patients value therapeutic relationships based on trust and respect between equal partners (Liddle et al., 2007). In particular, Slade et al. (2009) carried out focus groups with individuals with NSCLBP in Australia. Following the principles of grounded theory, these authors demonstrated that all the participants wanted a confidence-based partnership with the health professionals they consulted. Specifically, the notion of confidence-based partnership included empathy, listening, respect and the reception of comprehensible explanation of the cause of their problems and the rationale for the treatment (Slade et al., 2009a). Although Slade (2009a)

focused her study on individuals with NSCLBP living in Australia, their perspective regarding confidence-base partnership seemed to be similar to those found in the current study.

Sub-theme 3.4. Losing faith in health professionals` approaches

The previous sub-themes of the current study suggest an underlying increasing discontent and disappointment with health professionals` approaches. The idea of losing faith reinforced the current participants` need to deal with the successively unmet expectations of health professionals` explanation and resolution of their NSCLBP and their lack of success. This concurred with previous literature that has drawn attention to the notion of lacking faith in diagnosis and treatment provided by health professionals (Liddle et al., 2007; Howarth et al., 2014).

The current participants emphasised that their complaints were not well analysed or managed. The perceived lack of investment from health professionals to do so was presented as the main justification, which was apparently more important than the lack of health professionals` knowledge previously explored by these participants. For example, they seemed to take the prescription of medical tests as a means of interpreting the value physicians attributed to their NSCLBP – the more detailed the test, the more attention and respect for their complaints. Rhodes et al. (1999) may offer further understanding for the current study as they relate the patients` struggle over the invisibility of their CLBP to the expected proof that medical tests could provide. These authors carried out thematic analysis of data from semi-structured interviews with CLBP patients from Atlanta, Dallas and Seattle, in the USA. Their analysis highlighted that these patients assumed that there was a correlation between their complaints and the results of the medical tests. In this context, the physician`s interest in understanding and responding to their needs implied a detailed look at them.

Furthermore, the current participants also considered the repetition of unsuccessful treatments as an indicator of the lack of physicians` investment in solving their problems – medication and physiotherapy were presented as

repetitive, exclusive and ineffective strategies. Accordingly, the successive unsuccessful treatments and the perceived lack of investment from health professionals seemed to lead the current participants to progressively abandon health care services. Some participants persisted and demonstrated a disinterested following of health professionals' recommendations, while others permanently left and seemed to be on their own since they did not refer to be looking for alternative treatments. This contrasts with some studies that have emphasised that patients frequently resort to these alternative treatments, such as yoga, massage, chiropractic or acupuncture (Borkan et al., 1995; Eaves et al., 2015). However, it is also possible that those Portuguese people who have completely rejected orthodox medicine might not even be included in the current study.

Despite demonstrating an underlying passiveness throughout their accounts, the current participants reported that information on how to deal with their disorder would be more useful than the standardised medication or the common standardised physiotherapy sessions. This finding supports the assertion regarding the need to focus treatment on the individual rather than a generic approach. Previous literature has highlighted the importance of tailoring treatment programmes according to the needs and difficulties experienced by the individuals on both a physical and emotional basis (McIntosh & Shaw, 2003; Liddle et al., 2007; Hibbard et al., 2009).

The current findings suggested that there was a strong argument for the need to align both the patients' and health professionals' perspectives regarding health care, which may include the explanatory models for NSCLBP as well as the model of therapeutic relationship that underpins clinical practice. The absence of such an alignment seemed to promote the maintenance of unsuccessful treatments or the eventual patients' abandonment of the health care services. The current findings contrast with those from the aforementioned report published by the Directorate-General of Health (2015b), according to which 87.2% of the respondents reported to be satisfied with health services and 83.1% stated that the services provided met their expectations. Despite the

apparent satisfaction suggested by these results, it is important to note that only 17% considered that the Portuguese health services worked well. Furthermore, 38.6% of the respondents reported that the Portuguese health services required considerable changes and 16% that they needed to be completely restructured (Directorate-General of Health, 2015b). Once again, the complementary nature of these findings should be addressed, as it seems to be indicative of the need to carry out more research regarding the Portuguese individuals' experiences in the health services.

7.1.4. Theme 4: Reshaping social interactions according to the meaning of NSCLBP

In the fourth theme, the current participants' meaning making of NSCLBP was expanded by integrating it into the context of their social interactions. More specifically, the participants' reshaping of their social interactions through the meaning making of NSCLBP was highlighted.

Sub-theme 4.1. Need to legitimate and validate NSCLBP

The current findings highlighted in the second and third themes suggested that the participants seemed to consider both their explanations and the health professionals' unsatisfactory. Furthermore, they appeared to consider that the lack of a specific diagnosis as well as the subsequent inconsistency with the biomedical model might question the reality of their disorder. This led them to engage in a continuous search for meaning within their social networks (family, colleagues, friends and community), in which the quest for NSCLBP legitimation and validation attained significant relevance.

The quest for legitimation and validation has been reported extensively in literature concerning the experience of people with chronic pain (Werner & Malterud, 2003; Holloway et al., 2007; Slade et al., 2009a; Snelgrove & Lioffi, 2009; Bunzli et al., 2013; Toye et al., 2013; Froud et al., 2014). In particular, Werner et al. (2004) conducted in-depth interviews with a group of ten Norwegian women with chronic muscular pain and analysed data using a feminist frame of reference as well as narrative theory and discourse analysis.

Their study shed some light on the current participants` efforts in being believed, understood and taken seriously by their closest family and friends.

Additionally, a higher order visualisation of the current study`s themes may offer an explanation for the aforementioned quest for NSCLBP legitimisation and validation, which could be related to the Portuguese focus on relationships (theme 1).

Despite the current participants` attempts to obtain NSCLBP legitimisation and validation, some of them eventually considered that it was not worth looking for other people`s recognition of their disorder. In their IPA study with a group of British people, Snelgrove and Lioffi (2009) emphasised that maintaining integrity was a difficult task due to the invisible and often indeterminate nature of CLBP.

These findings from Snelgrove and Lioffi (2009) seemed to shed some light on the current participants` perception that the absence of other people`s experience of NSCLBP made it impossible for them to understand it. Thus, the current participants seemed to be convinced that with the exception of the few people experiencing chronic pain they knew, other people could not have an empathic understanding of their experience and, thus could not recognise its legitimacy and validity. In particular, two of the current participants reported that finding someone with a similar experience was important since it appeared to help them to deal with NSCLBP in a more positive way. Previous research has emphasised the importance of recognition (Steihaug & Malterud, 2002; Steihaug et al., 2002). However, this research has been particularly focused on the approaches to treatment, exploring how this recognition may impact the perceived benefits of the treatment. Taking into account the possible impact of recognition in the approach to patients with NSCLBP, this topic is revisited within the analysis of the implications to clinical practice.

Beside the challenges inherent to the NSCLBP experience *per se*, the current participants had to deal with other people`s underlying scepticism and subsequent lack of support in dealing with their disorder. In particular, some considered their disorder to be disbelieved, mocked or pitied, which negatively affected their familial and professional lives. This could be likened to Holloway

et al.'s (2007) notion of stigmatisation. These authors carried out an IPA study with twelve British males and six British females who were recruited in the south of England and had chronic benign back pain. These participants emphasised the stigma from work colleagues, employers and significant others. Despite the apparent similarities between the current study and Holloway et al.'s (2007), some divergences can be identified in the way stigma was conceptualised and experienced. Specifically, in Holloway et al.'s (2007) study, the participants emphasised the moral stigma associated with sick leave as it was considered as a subterfuge to live off social benefits. Contrary, in the current study stigma was apparently associated with the lack of support and empathy from some colleagues (employers were not mentioned). It is important to clarify that with the exception of one participant of Holloway et al.'s (2007) study, all were unemployed and financially dependent on either their spouse or social benefits. Contrary in the current study, all participants were employed and perceived having a fundamental contribution to their families' economic situation.

Indeed, the possible impact of the global financial crisis that dramatically affected countries in the EU cannot be ignored in the discussion of the current findings. In Portugal specifically this crisis has significantly impacted the labour market, with increasing job insecurity and high unemployment rates (Coelho et al., 2014; Correia et al., 2015b). In this context, the Portuguese government signed a financial assistance programme, which was in place between 2011 and 2014 (Coelho et al., 2014; Correia et al., 2015b). This may provide some context to understanding the current participants low or even absence of sick leave, as keeping their jobs was perceived as fundamental to ensure their family's sustainability.

Nevertheless, the current participants' quest for legitimising and validating their NSCLBP through interaction with their social network seemed to have an unexpected result for them, since it eventually questioned the reality of their disorder - rather than being recognised, their NSCLBP was called into questioned.

Sub-theme 4.2. Isolation and alienation

Thus, an underlying sense of isolation and alienation emerged from the current participants' accounts, which seemed to be a consequence of their perception of the uselessness of externalising their thoughts or complaints about NSCLBP. After several attempts to arouse empathy from other people, they eventually avoided talking about their disorder.

On the one hand, the current participants seemed to avoid contact with others, whereas on the other, they demonstrated the need to be listened to regarding their NSCLBP. Literature focused on the Portuguese cultural background may provide further understanding of this finding. Despite the Portuguese strong group orientation (as opposed to an individualist society), there seems to be a pervasive attitude of loneliness and isolation (Nielsen et al., 2009). More specifically, although the Portuguese tend to communicate and share life struggles with others (an emotional escape described as *catharsis*), they also exhibit an attitude of submission and accommodation (Nielsen et al., 2009). Although the authors did not offer explanations for this paradox, it can shed light on the interpretation of the current findings. More specifically, this paradox may provide some context to the current participants' need to be listened to and simultaneous avoidance of the contact with others. Indeed, they seemed to be accommodated to their unsupportive contexts.

Isolation and withdrawal from social interactions have been extensively reported by literature, however the reasons behind these seemed to vary. For example, Ashby et al. (2010) carried out an ethnographic study with a group of eleven Australian men with CLBP, in which these participants' minimal involvement in social outings and leisure activities appeared to be related to their fear of movement. Ashby et al. (2010) emphasised the cross-cultural nature of the fear of movement and re-injury, since although the participants included were Australian they came from culturally diverse backgrounds (for example Australian, Croatian, El Salvadorian, Irish or Uruguayan).

Another explanation for the appeal of social isolation to CLBP patients may be related to its potential to ease their concerns about how they perceived they were seen by others and the subsequent pressure to behave in certain ways (Smith & Osborn, 2007). Accordingly, this withdrawal from others may be

interpreted as a way of avoiding the aforementioned stigmatization (Borkan et al., 1995), which may explain the current participants' isolation.

Sub-theme 4.3. Trying to put NSCLBP in second place

The NSCLBP's impact on the way patients related to other people has been emphasised in the literature (Strunin & Boden, 2004; de Souza & Frank, 2011; Young et al., 2011). The current participants reported an overall change in the way they related to their social networks due to the experience of NSCLBP. More specifically, the awareness of their lack of availability to listen and respond to others' needs seemed to motivate some participants to concentrate on trying to minimise their needs and put these after others', especially their relatives. Some of the current participants appeared to be engaged in a constant search for balancing their needs with other people's, while others tried to focus their attention on taking care of other people and ignoring their own needs. Tavaffian et al. (2008), who carried out focus groups with twenty-four Iranian women experiencing CLBP, emphasised that these participants were focused on relationships and mostly considered others first. These authors used the notion of "selflessness" to highlight this as a cultural idiosyncrasy, which seemed to have some resonance with the current findings.

The current participants' responses may be further understood if the aforementioned perceived lack of support from their social networks is considered - it seemed to be difficult to manifest their needs within a context where their experience was not recognised or validated. This perspective also shed light on the previously discussed unavoidable restriction of everyday life (theme 1), which also appeared to be motivated by the current participants' unsupportive contexts.

Furthermore, this apparent minimisation of their own needs may also impact the way these participants search for healthcare as well as on their expectations regarding treatment. This seems to deserve further exploration in future research.

Thus, the current participants` experience of having NSCLBP seemed to be characterised by an underlying perceived lack of social value, isolation and alienation. In conjunction with these aspects, a discredited social identity and an altered sense of self emerged as important elements in the participants` experience.

7.1.5. Theme 5: Defining the self through the meaning of NSCLBP

The participants` definition of their sense of self through the meaning of NSCLBP was highlighted in the fifth theme. More specifically, the way they dealt with the perception of having their own credibility questioned was analysed. Additionally, the way they dealt with an underlying altered sense of self was also examined.

Sub-theme 5.1. Being questioned and self-questioning

Possibly as a consequence of the previously discussed lack of NSCLBP`s legitimisation and validation, the current participants seemed to start looking inwards while engaging in a deeper analysis of their sense of self. Accordingly, some appeared to extend the aforementioned discussed need to legitimise NSCLBP (theme 4) into a quest for proving their credibility as individuals experiencing NSCLBP, while others speculated about the possibility of having imagined it. Thus, there seemed to be an underlying questioning, which in some cases was viewed as an indication of personal weakness and consequently perceived as a threat to their identity. This finding echoed previous research that has focused on the importance of considering the concepts of self and identity in relation to pain (Hellstrom, 2001; Smith & Osborn, 2007; Crowe et al., 2010). For example Smith and Osborn (2007), in their IPA study including patients experiencing CLBP, emphasised the negative impact of this disorder in the participants` self and identity. Despite the existence of several perspectives in the study of the concept of self, it has been presented as a stable but dynamic collection of core beliefs, affects or cognitions that are used by the individuals to define or represent themselves both privately and in their presentation to the outside world (Charmaz, 1995; Kelly & Field, 1996). The notion of altered sense of self has been reported in literature concerning the

experience of chronic pain (Osborn & Smith, 1998; 2006; Walker et al., 2006; Smith & Osborn, 2007; Snelgrove & Liossi, 2009; Crowe et al., 2010a; Morley, 2010). Patients with chronic pain need to make sense of both the pain and the perceived frightening change of identity that seems to occur with the chronic pain experience (Eccleston et al., 1997), which appears to be aligned with the current findings.

With respect to the interaction between pain and aspects of the self, Pincus and Morley (2001) proposed the self-pain enmeshment model, which looks at variations in the state of the person as the interaction between three schemas representing pain, illness and the self. In the context of this model, a schema contains elements that are interrelated and structured so that the activation of one of those elements will activate others close to it within the schema (Pincus & Morley, 2001). Although these schemas are considered relatively stable, they evolve in time through incorporation of new elements and inactivation of others (Pincus & Morley, 2001). The enmeshment happens when elements of schemas are repeatedly and simultaneously activated, which may result in the elements of one schema being incorporated into another (Pincus & Morley, 2001). The enmeshment between the three schemas, in which pain and illness become incorporated into the self, appears to happen in individuals with chronic pain. Although this model is very much related to the clinical approach to depressed patients (Pincus & Morley, 2001; Morley et al., 2005), which was not the focus of the current study, it can be useful in the interpretation and discussion of the current findings since it suggests an overlapping between the sense of self and pain. Indeed, it may allow conjecture regarding why some of the current participants converted the questioning of NSCLBP into the questioning of their own identities.

Additionally, despite the current participants' perceptions of being seen as weaker, they considered themselves stronger than those who did not suffer from NSCLBP. The self-discrepancy theory by Higgins (1987) may help to further understand this finding. Although this theory was initially developed with individuals that were not in pain, its applicability to CLBP patients was recently demonstrated (Waters et al., 2004; Morley, 2010). According to this theory, it

was postulated that if a person's own standpoint regarding their attributes does not match the ideal state that they personally hope or wish to attain, then this person would be vulnerable to disappointment and dissatisfaction (Higgins, 1987). This theory relates different types of discrepancies among self-state representations to negative emotions and distress (Higgins, 1987). These discrepancies may include discrepancies between the actual self and the ideal self, the ought self or the feared self (Higgins, 1987). Indeed, there seemed to be a discrepancy in the way the current participants considered themselves and the way in which they believed some significant others saw them. According to this theory, a person manifesting this discrepancy is predictable to be vulnerable to feeling threatened (Higgins, 1987), which is coherent with the previously discussed identity threat.

Although some participants seemed to be distressed by their altered sense of self, they took pride in their ability to endure the impact of pain in silence, as they perceived this as a sign of personal strength. This finding may be further understood if integrated in the context of the previously discussed social interactions (theme 4), as it offered a new perspective on the aforesaid participants' isolation and alienation - here it was connected with evidence of capacity to bear suffering.

The apparent interrelationship between the fourth and fifth themes suggests that the participants who perceived the aforementioned questioning as a threat to their identities were those who struggled with the lack of recognition, tended to withdraw from social interactions and avoided talking about their NSCLBP. This appears to be consistent to Helstrom's (2001) notion of the "entrapped self", which characterises a situation in which chronic pain patients were more physically isolated than earlier in life, because of both the reduced physical functioning and the inability to communicate their subjective experience of pain with pain-free others. They were stuck in what this author called a "viscous" present where events could not be controlled or predicted (Hellström, 2001), which seems to represent the current participants' perceived inability to make any changes in the disruptive events (such as NSCLBP) that are part of their lives.

On the other hand, for some of the current participants the previously discussed underlying questioning was vaguely purported and neither considered relevant nor a threat to their identity. These participants appeared to be those who tended to minimise their own needs and focused on taking care of others (theme 4). Thus, they seemed to give precedence to other goals such as ensuring the family's sustainability. Both the aforementioned Portuguese focus on family relationships, as well as the impact of the economic crisis in family's sustainability may have made a contribution to this response (Coelho et al., 2014; Correia et al., 2015b; Ribeiro et al., 2015).

Overall, both responses to the abovementioned underlying questioning – being engaged in a process of defending the self from what was perceived to be a threat to their identity or ignoring it – did not seem to facilitate the current participants' constructive adaptation to their situation.

Sub-theme 5.2. Relating the self to the disorder

While some of the current participants struggled to maintain the disorder and the self as separated identities, others appeared to assimilate their co-existence. Indeed, the former seemed to fear a possible intrusion of the disorder into the self. Contrary to the findings of Glenton (2003) they refused to be sick, since they tried to ignore pain in order to preserve their original self (the one who was not in pain and was able to carry out everyday life activities). This finding was consistent with the dualism between body and self that emerged in Hellstrom's (2001), Osborn and Smith's (2006) and Snelgrove and Lioffi's (2009) studies. After carrying out and analysing semi-structured interviews with six individuals with chronic pain, Osborn and Smith (2006) drew attention to the complex relationship between body, pain and sense of self. This may correspond to the previously mentioned Pincus's (2001) and Morley's (2005) references to the overlap of pain, illness and self. Osborn and Smith (2006) found that this relationship was defined more by alienation and exclusion than integration, accommodation or acceptance. Osborn and Smith (2006) highlighted this relationship as both protective and problematic – on the one hand it was defending and preserving a valued self, on the other it could be

impeding any constructive process of adjustment or rehabilitation. The current findings seemed to reveal an underlying contradiction regarding this subject, as on the one hand the participants wanted recognition for their NSCLBP in the interactions with health professionals (theme 3), and on the other they refused to consider themselves to be sick when reflecting on their sense of self.

Additionally, those who seemingly assimilated the co-existence of both the self and the disorder as inseparable identities appeared to accept the lack of concrete explanations for their NSCLBP (theme 2). This finding may offer some insights into Serbic and Pincus's (2013) question of whether acceptance of pain is possible in the absence of an acceptable diagnosis or explanation. In their study on CLBP patients' understanding, feelings and behaviour in response to their diagnostic labels, these authors emphasised the importance of clear acceptable explanations that may replace specific diagnoses. Indeed, for some of the current participants although an explanation was desired, it was not perceived as fundamental.

Some of the current participants also emphasised the emergence of a "new self", which they tended to compare to an "old self". This "old self" was perceived as the preferred and possibly recoverable if NSCLBP could be cured. Thus, these participants seemed to hold contrary expectations – on the one hand, they consider the possibility of recovering the "old self" if NSCLBP could be eliminated and, on the other hand, they expected NSCLBP to get worse over time (theme 1). This finding echoed Smith and Osborn (2007) who highlighted chronic benign low back pain patients' engagement in a process of defending their self-concept, seemingly as if the "new self with pain" was unwanted.

Once again, the aforementioned self-discrepancy theory (Higgins, 1987) may deepen the understanding of this finding. Indeed, the current participants desire to recover their "old self" seemed to be related to an underlying frustration or fear regarding their sense of new self. According to the aforementioned theory, this discrepancy or self-conflict may induce symptoms of depression such as feelings of failure, devaluation and shame (Higgins, 1987). Waters et al. (2010) found that self-discrepancies were related to psychological distress and depression in CLBP patients. Although these aspects were not explored in the

current study, it is important to take into consideration that the percentage of Portuguese individuals with chronic pain who were diagnosed with depression ranged from 13% to 17% (Castro-Lopes et al., 2010; Azevedo et al., 2012). This percentage assumes particular relevance when considered the prevalence of depression in general Portuguese population (from 5.04% 9.73%) (Directorate-General of Health, 2015c). Indeed, Ellegaard and Pedersen (2012) carried out a qualitative study based on a phenomenological-hermeneutic approach, which focused on CLBP patients` capacity to cope with their disorder when it was coupled with depression. These authors emphasised that both CLBP and depression negatively affect each other (Ellegaard & Pedersen, 2012).

Besides emotional consequences, self-discrepancies have also been associated with behavioural consequences (Huijnen et al., 2011; Kindermans et al., 2011). More specifically, the patients` motivation to reduce discrepancies, seem to lead to self-regulatory behaviours based on avoidance or persistence (Huijnen et al., 2011; Kindermans et al., 2011). Although literature on this topic is scarce, the few existing studies have hypothesised that ideal self-discrepancies might explain persistence behaviour, while feared self-discrepancies seem to be related to avoidance (Huijnen et al., 2011; Kindermans et al., 2011). Research has hypothesised that avoidance and persistence may predict disability and diminish quality of life, however contradictory results have been published (Huijnen et al., 2011; Kindermans et al., 2011).

Furthermore, for one of the current participants the emergence of a new self seemed to be integrated into a redefinition of self (which was still the “real self”). This participant was not looking for a cure, rather she was focused on moving forward, taking care of herself and having a comfortable life. This participant`s response seemed to echo Charmaz`s (1995) notion of adapting to impairment. In the context of this author`s research, adapting implies that the individual acknowledges impairment and alters their life and self as a way to accommodate and flow with the experience of illness. Indeed for the aforementioned participant in the current study, the NSCLBP experience

seemed to have prompted the possibility of developing new and deeper meanings of the relation between body and self. She seemed to have transcended her body and believed in her strength to live with NSCLBP. Indeed, she seemed to have developed the capacity to control the impact of NSCLBP on her life that all the remaining participants were looking for. Charmaz (1995) argued that adapting leads to taking responsibility for self. Thus, accommodating this responsibility for self may have been a key element for regaining control over her life.

Aldrich et al. (2000) drew attention to the concept of adjustment to chronic pain and highlighted that this may imply more than the acceptance of the impossibility of eliminating pain or adopting particular strategies, but changing fundamental aspects such as self-concept and identity. Further research in this area, would provide a better understanding of Portuguese individuals' self-concept and identity and how these relate to the experience of NSCLBP.

7.2. Overall discussion

Although a decision was made to maintain a separation of the themes in the previous section, their integration into an extended account is discussed in the following paragraphs.

This study suggested that the Portuguese individuals' experience of having NSCLBP seems to be integrated in a contextual dialectic relationship between both fatalism and perseverance, which has been frequently related to the Portuguese cultural background (Nielsen et al., 2009). The current participants dealt with both the perceived unavoidable restriction of everyday life and the need to overcome the impact of their disorder (theme 1). More specifically, they seemed to perceive themselves as entrapped in a life dominated by NSCLBP (Hellström, 2001), which was seen as a consequence of external and uncontrollable causes that were impossible to change (Ferreira-Valente et al., 2011). They restricted their lives to what they considered to be mandatory tasks, however the possibility of not being able to accomplish their perceived duties and obligations seemed to disturb them. Indeed, the strong Portuguese

orientation to preserve family life (2014; Coelho, 2010; Ribeiro et al., 2015) seemed to motivate this study's participants to persevere and overcome NSCLBP.

Accordingly, this study's participants appeared to be engaged in a deferred life (theme 1), where they focused their attention on searching for the meaning and control of NSCLBP (theme 2) and for someone who could relieve or remove it (theme 3), as well as on trying to prove the legitimacy and credibility of their disorder (theme 4) and also of themselves as individuals experiencing NSCLBP (theme 5).

Despite the participants' emphasis on their lack of a clear understanding of NSCLBP, all formulated an explanation of some sort (theme 2). The majority of these explanations were rooted in the hypothesis of a physical origin for pain, which seemed to reflect the dominance of the biomedical model in the NSCLBP patients' attempts to conceptualise their pain (Osborn & Smith, 1998; Corbett et al., 2007; Toye et al., 2013). This seemed to have resulted from the contacts with health professionals (theme 3) (Houben et al., 2005; Darlow et al., 2012). The participants' perceived incoherence in their physical mind-set for explaining NSCLBP left room for a range of possible alternative explanations and subsequent unanswered questions, which seemed to increase their struggle to understand it.

In this context, the clinical encounters seemed to perpetuate the lack of participants' understanding and sense making of the disorder, as well as the perceived inability to control it (theme 3).

The participants struggled to understand the health professionals' points of view. They accepted the physicians' decisions without question despite not understanding the rationale behind these decisions. Furthermore, they considered themselves as being disempowered to deal with their disorder and unable to collaborate in their treatment, or establish a partnership with health professionals. This finding was consistent with previous literature published in Portugal, which suggested that the Portuguese did not seem to consider the

possibility of having an active role in the decision-making (Castro-Lopes et al., 2010; Gonçalves et al., 2010). Accordingly, the absence of an alignment between the individuals with NSCLBP and the health professionals seemed to promote the maintenance of unsuccessful treatments, increased discontent as well as disappointment with health professionals' approaches and the ensuing abandonment of the health care services.

The lack of satisfactory answers from health professionals regarding their NSCLBP led this study's participants to engage in a continuous search for meaning within their social network (family, colleagues, friends and community), in which the quest for NSCLBP legitimation and validation attained significant relevance (theme 4). Thus, after several unsuccessful attempts to arouse empathy from other people, the participants tended to isolate themselves and restrict interactions to their closest family (Smith & Osborn, 2007; Nielsen et al., 2009).

It seemed to be difficult to manifest their needs within a context where their experience was not recognised or validated. This led them to minimise their own needs, which may have some impact in the way their search for healthcare.

The underlying scepticism from other people (theme 3 and theme 4) regarding NSCLBP led this study's participants to perceive their own credibility as being questioned (theme 5).

An apparent overlap between the sense of self and the disorder (Pincus & Morley, 2001) seemed to explain why some of the participants transformed the questioning of NSCLBP (theme 2) to the questioning of their own identities (theme 5). Thus, while some participants engaged in a process of defending the self from what was perceived to be a threat to their identity, others vaguely purported this and tended to minimise their needs. Overall, both responses did not seem to facilitate the participants' constructive adaptation to their situation (Pincus & Morley, 2001; Morley et al., 2005).

The findings reinforced that the capacity to control the impact of NSCLBP may be related to an enhanced responsibility for self (Charmaz, 1995; Aldrich et al.,

2000). The positive adjustment appeared to imply more than the adoption of particular strategies, or the acceptance of the impossibility of eliminating pain, but the change of fundamental aspects such as self-concept and identity.

7.3. Critique of the method

This study's findings are discussed in light of the methodological approach that was used. The impact of its strengths and limitations is addressed in the following sections.

7.3.1. Investigative approach

Since this study was underpinned by the interpretivist paradigm, it enabled the exploration of an area of health care in which there was no existing research in Portugal. Foundations from the interpretivist paradigm required the researcher to be focused on developing a deep understanding of the interactions between participants with NSCLBP and their personal contexts in making sense of their disorder (Creswell, 2003; Willis, 2007e; Petty et al., 2012). This meant that the researcher's interpretations about reality had an important role in the investigative approach. This justified a simultaneous reflexive account, excerpts of which have been presented throughout this thesis.

Furthermore, the lens of the constructionism view of knowledge as well as the relativism and realist ontology supported the researcher in defining her own position regarding the phenomenon under investigation. In coherence with constructionism, the researcher assumed that the participants' experiences took place in a specific context and were influenced by the values embedded in this context (Crotty, 1998a; Finlay, 2006; Creswell, 2007b; Willis, 2007f). This justified the presentation of a chapter devoted to the Portuguese context (chapter 3). Additionally, relativism and realism had important implications for the researcher's position adopted in this study (Crotty, 1998a; Willis, 2007d). More specifically, both supported the researcher in reporting how the reality - the experience of NSCLBP - was meaningfully constructed by the individuals engaged in it within a given community, in this case the Portuguese context.

The consideration of several methodological approaches (namely, GT, NA and TA) enabled the researcher to select the approach that best suited this study's purpose. The IPA focus on the individuals' experiences through exploring meanings that individuals attribute to it (Smith et al., 2009a), highlighted the adequacy of this methodological approach to answer the research question addressed in this study. Rather than producing an objective statement of this experience, the investigative approach adopted in this study allowed the exploration of Portuguese individuals' personal accounts of their experience of NSCLBP.

It is important to take into account that because this study was based on the experiences and perceptions of eight Portuguese individuals with NSCLBP, the findings cannot be considered representative of all other individuals with NSCLBP. Indeed, as broad generalizations are not coherent with this methodological approach, it is advisable to consider findings from IPA studies in terms of theoretical transferability rather than empirical generalizability (Smith et al., 2009f). Several procedures to address potential limitations to this transferability are discussed in the following sections.

7.3.2. Design and procedure

The one-to-one interview approach was identified as the research method that best suited this study's purpose, since it enabled the participants to offer in depth and detailed accounts of their experiences of NSCLBP disorder.

It is important to take into consideration that practice in conducting semi-structured interviews as well as a pilot study were undertaken, in order to ensure the quality and depth of data collection. Although the interviews were carried out in clinical settings, the researcher was not involved in the treatment of the participants.

Though in-depth interviews are recommended as the most suitable method of data collection in IPA studies, the focus on one single method of data collection may constitute a limitation. Indeed, other methods could be used to enable triangulation "within method" and subsequently improve the completeness of data. In particular, diaries have also been recommended for IPA studies,

although their use has been considerably low (Smith et al., 2009c). In this study, participants' diaries would possibly provide a more extended picture of each participant. More specifically, this information could be used to further explore how participants made sense of NSCLBP, which could improve the depth of analysis. However, its applicability and effectiveness in the Portuguese context raised some questions regarding the participants' receptivity, mainly regarding the level of literacy. Indeed, previous research that was considered in the background of this study highlighted the low level of literacy of people experiencing chronic pain (Rabiais et al., 2004; Azevedo et al., 2012; Gouveia et al., 2016), which may indicate a lack of reading and writing skills.

7.3.3. Sampling method

The number of participants included in this study may be seen as a potential limitation. Indeed, some authors have considered the smaller sample sizes as a weakness of IPA studies, compared to other qualitative studies (Creswell, 2007a). However, it is important to take into consideration that this perspective does not address the combination of core principles from phenomenology, hermeneutic and idiography that inform IPA studies. Since the aim of IPA studies is to gain insights into the individual, it provided a different perspective from other qualitative approaches (Smith et al., 2009f). In particular, the idiographic nature of IPA studies privileges the individual's in-depth understanding, which requires a smaller number of participants than other qualitative studies, such as grounded theory that tends to use larger samples in order to substantiate theory (Creswell, 2007a; Smith et al., 2009e). In the context of IPA studies, it is advocated that a reduced participant number allows a richer depth of analysis that might be inhibited with a larger sample (Smith et al., 2009d). The reduced number of participants seemed to be more aligned with the core principles of this methodological approach and may facilitate the transferability to other contexts, since more detailed information regarding each participant and his/her context is provided.

Despite the initial purpose of recruiting up to twenty individuals (appendix 1), a decision was made to interrupt data collection after analysing the first eight interviews in order to avoid collecting unnecessary data. Due to the volume and

depth of data collected, it was considered that enough detailed information had already been collected to enable the exploration of the individuals' experiences and perceptions of having NSCLBP disorder, as well as the development of meaningful points of convergence and divergence between interviews.

Additionally, the participants' homogeneity may also be seen as a potential limitation to the transferability of this study's findings. There seems to be an underlying tension in IPA studies regarding this topic: on the one hand, "*fairly homogenous samples*" are recommended in order to facilitate the analysis within the group through the identification of patterns of convergence and divergence (Smith et al., 2009d, p.49); on the other hand, too narrow and homogeneous groups may hinder judgements about transferability (Smith et al., 2009d). Thus, in the current study, two strategies were adopted in order to address this potential limitation: on the one hand, inclusion and exclusion criteria (e.g. to have experienced NSCLBP, to be aged between forty and sixty) were defined in order to ensure some uniformity within the group of participants recruited. On the other hand, data collection was carried out in different health sites (one academic clinic and two health centres) located in different regions of the country (the central interior of Portugal and the central Portuguese coast). It is important to highlight that the aim of the latter strategy was not related to potential representativeness, but to an attempt to provide a more diverse and richer picture of the phenomenon under investigation, which was expected to facilitate transferability.

7.3.4. Analysis

According to the principles of IPA, although the final interpretation of data was the researcher's responsibility, it could be important to consider the participants' feedback after interviews and subsequent dialogue (Smith et al., 2009a). Thus, this aimed to optimise a shared understanding of the phenomenon under investigation and a co-construction of meaning between both the researcher and the participants (Crotty, 1998b; Fleming et al., 2003; Willis, 2007e). Indeed, the researcher sent the transcript to each participant by e-mail or registered mail (according to the participants' preference).

Additionally, all participants were thanked once again and each one was requested to give feedback on any inaccuracies related to the preliminary emerging themes (the researcher's e-mail, work address and telephone were also resent in order to enable the participants' contact). No feedback was provided by any of the participants. Therefore, it was assumed that they were in agreement with the identified themes. There may however have been other reasons for a non-response, since the amount of time between the interview and the dispatch of the transcript and preliminary analysis was between 12 and 18 months. This was because it was anticipated that one third of the workload of this study would be devoted to data analysis, however the time allocated for the preliminary analysis was underestimated and therefore this delayed the circulation of the transcripts and preliminary themes to the participants.

The use of NVivo to organise and manage the data was helpful as it enabled the researcher to manage a large amount of data and quickly retrieve extracts of each participant's interview. However, it is important to take into consideration that the use of NVivo did not prompt the researcher's interpretative activity. Thus, other strategies were required, such as the researcher's reflexive journal, which was used in order to help the researcher identify her position, assumptions and biases from the early design of the study to the discussion of findings. The reflexive journal was particularly useful during the analytic process, as it enabled the researcher to: (i) document decisions regarding the analysis (e.g. why some ideas that emerged from the interviews were collapsed); (ii) develop strategies to increase the level of interpretations (e.g. writing participant's individual accounts, developing conceptual maps, raising questions regarding why the participants were exploring a particular idea); and, (iii) facilitate reflections on the researcher's influence on data analysis (e.g. how the researcher dealt with the complexity of the individuals' accounts and how this could impact on the final account produced).

It is important to emphasise that the process of data analysis was closely accompanied by the supervisory team. The researcher's analysis of each interview was individually discussed in supervisory meetings and comments

from supervisors were incorporated in this analysis. This included strategies such as: (i) following the first interview, in the initial stages of the analysis, both the researcher and one of her supervisors separately read and re-read the same interview and produced comprehensive and detailed notes as well as comments on the data (including descriptive, linguistics and conceptual comments), then both documents were discussed and both analyses were integrated in the same document, which was used for the following stages of data analysis - this was very beneficial for the researcher's analytic development and contributed greatly to confidence and abilities to carry out analysis independently of all the following interviews (ii) each interview's audit trail was discussed in supervisory sessions, where questions on the researcher's interpretations, decisions and impact on data analysis were discussed, occasionally the discussions led to the researcher developing new ideas, which were included in the analysis (further examples of the process are provided in section 7.8.). As the original data was collected in Portuguese, several translations (entire interviews and excerpts) were carried out in order to facilitate this process. These translations were carried out by the researcher and then checked by a certified bilingual translator. The accuracy of the final translations was subsequently reviewed by the researcher. This strategy ensured the preservation of meaning, despite the data being presented in a different language.

The translated excerpts allowed findings to be anchored in the participants' words - excerpts from each one were identified and included in all the emergent themes (chapter 6). The purpose was to enable the reader to assess and evaluate transferability to individuals with more or less similar contexts.

Indeed, the focus on a specific context, such as the Portuguese, may limit the transferability of this study's findings to other contexts. Thus, besides the attention dedicated to characterise the Portuguese context (chapter 3), detailed information on the participants' specific life contexts was provided (chapter 6). Additionally, situating the participants' accounts in relation to the existent literature (following section) also aimed to contribute to the aforementioned purpose.

Finally, it is also important to emphasise that additional strategies were used in order to ensure quality and rigour of data analysis. These strategies focused on respecting the principles of *transparency* and *systematicity* proposed by Meyrich (2006) as well as a range of criteria proposed by Yardley (2000), such as the principles of *sensitivity to context* or *commitment and rigour*, among others (chapter 5). For example, a detail pathway of the researcher's decision made during data analysis was developed (appendix 19) and the researcher's pre-existing assumptions were explored (reflexive accounts).

7.4. Contribution to knowledge

Given the dominance of quantitative methodologies in the area of NSCLBP, this study has addressed the recent recommendations regarding the need to carry out more qualitative research (Barker, 2015; Gooberman-Hill, 2015; Morse, 2015; Seers, 2015; Smith & Osborn, 2015). This need for qualitative research has been justified by the importance of developing new insights that may help researchers and clinicians to have a broader and deeper understanding of the NSCLBP phenomenon, particularly from the perspective of those who experience this disorder. Indeed, qualitative research seems to have the potential to provide access to areas that may not be accessible using quantitative research approaches (Howard & Davis, 2002; Lewin et al., 2015; Morse, 2015). In particular, an interpretative approach to qualitative inquiry promotes in depth contextual understanding regarding the individuals' experiences of having NSCLBP, which may have important implications for clinical practice (Curry et al., 2009; Concannon, 2015; Smith & Osborn, 2015; Zhang et al., 2015).

Although some studies have been carried out on the experiences of NSCLBP, this phenomenon has only been explored in a few countries, with the vast majority being carried out in the UK. In Portugal specifically, research in the area of NSCLBP is emerging, with the few existing studies being published mainly in the current decade. These studies have been particularly focused on the impact of the disorder nationwide (Castro-Lopes et al., 2010; Azevedo et al., 2012; 2013a; 2013b; 2016) and a few have been carried out in the area of

psychology, which explored the relations between some factors such as acceptance of pain, self-compassion or the influence of gender (Bernardes & Lima, 2010; Costa & Pinto-Gouveia, 2011; Ferreira-Valente et al., 2011). To the researcher's knowledge, no studies have been published regarding the experiences and perceptions of Portuguese individuals with NSCLBP. Thus, the development of a qualitative study in such an unexplored and unique context has allowed the first exploration of the NSCLBP experiences in Portugal.

Accordingly, this study's findings have drawn attention to several aspects that are considered to have contributed to the development of knowledge that may inform physiotherapy practice. Thus, the dissemination of this study's findings to a range of stakeholders, such as health professionals, researchers, patients, policymakers or commissioners attains major relevance. Information regarding the dissemination plans of this study's findings can be found in appendix 22.

The following paragraphs outline this study's main contributions to knowledge. Each refers to one emerged theme and resulted from the combination between data analysis and relevant literature.

- The Portuguese individuals' experience of having NSCLBP seems to be integrated in a contextual dialectic relationship between fatalism and perseverance, where these individuals deal with the perceived unavoidable restriction of everyday life and the need to overcome the impact of their disorder.
- Portuguese individuals with NSLCBP are looking for meaning and to retain a sense of control over their pain and lives, rather than merely understanding the disorder *per se*. There seems to be a need for an acceptable explanatory model that assimilates their experience and personal narratives.
- The clinical encounters appear to perpetuate the lack of understanding and sense making of NSCLBP. The absence of an alignment between the individuals experiencing NSCLBP and the health professionals seems to maintain the perceived unsuccessful treatments or the eventual

abandonment of the health care services. There seems to be an underlying asymmetry in the therapeutic relationship, which leads NSCLBP Portuguese individuals to consider themselves as being disempowered to deal with their disorder and unable to have an active role in the decision-making.

- The NSCLBP Portuguese individuals have to deal with other people's underlying scepticism and lack of support in dealing with their disorder. The social interactions become restricted to the closest family and work colleagues, as the jobs are perceived as fundamental to ensure the family's sustainability in a context of a financial crisis. Since NSCLBP experience is not recognised or validated, Portuguese individuals with this disorder minimise their own needs, which may impact the way they search for healthcare and their expectations regarding treatment.
- Some of the individuals experiencing NSCLBP transform the questioning of NSCLBP to the questioning of their own identities. The capacity to control the impact of NSCLBP seems to be related to an enhanced responsibility for self. This appears to reflect an underlying adjustment, which may not only imply the adoption of particular strategies, but also the change of fundamental aspects such as self-concept and identity.

7.5. Implications for patients, clinical practice and health services

This study has provided the first exploration of the NSCLBP experience in Portugal. The analysis of the participants' accounts reinforced the complex nature of this experience and suggested the importance of multidisciplinary and individually tailored approaches to the treatment of individuals with NSCLBP. Furthermore, the idiographic exploration of this experience may complement the existing knowledge provided by other research approaches.

Given the methodological approach selected, this study's findings do not intend to be applicable to all individuals with NSCLBP disorder. Rather, they have offered some insights into Portuguese individuals' experiences of having

NSCLBP disorder, which could help clinicians transfer some of this knowledge to the therapeutic approach towards individuals with similar experiences.

Thus, it is important to highlight this study's implications for patients, clinical practice and health services. It is also important to emphasise that this study's implications are stressed taking into account their relevance and feasibility in the Portuguese NHS (presented in chapter 3). Indeed, these implications are aligned with some of the central strategies for the development and the implementation of the NHP 2011-2016, such as the implementation of individualised care and inclusion of patients in the decision making, the implementation of self-management programmes, through the empowerment of patients to manage chronic diseases, among others (Directorate-General of Health, 2012). The following paragraphs explore these implications:

- **The focus of this study's findings on Portuguese individuals' experiences and perceptions of NSCLBP prompts for patients to have their voice heard.** Indeed, the findings are anchored in the NSCLBP Portuguese individuals' accounts, which provide the first insights into the experience of NSCLBP and the use of health services in Portugal. Previous research has emphasised that the integration of patients' experiences in the design of health care promotes health services that are more responsive to patients' needs (Entwistle et al., 2012; Barker, 2015). Indeed, there is strong evidence that patients' involvement in health care is associated to better treatments results, higher satisfaction and more responsive services (Frewer et al., 2001; Singer et al., 2011). **Considering the current Portuguese health policies' recommendations to empower patients, this study's findings shed some light on the potential of expanding this involvement into the design, evaluation and reconfiguration of health care services.**
- This study's findings suggest that the disruptive nature of NSCLBP prompts the NSCLBP Portuguese individuals' urge and desire for meaning to be found. The perceived incoherence of their physical mind-set for explaining NSCLBP leaves room for a range of possible explanations and subsequent

unanswered questions, which seems to increase the NSCLBP Portuguese individuals' struggle to understand their disorder. **This finding draws attention to the importance of facilitating patients' understanding and sense making of NSCLBP. In order to accomplish this, health professionals need to understand the personal meanings and the impact of NSCLBP on a patient's life. This may require a shift in the traditional assessment of these patients, with an increasing focus on their individual accounts.** Several authors have indicated the importance of exploring patients' illness perceptions (van Wilgen et al., 2014; Zanini et al., 2014) in order to individualise the clinical approach to patients' needs and characteristics (May et al., 2008; Smith et al., 2008) and to optimise patients' outcomes (Foster & Delitto, 2011). Furthermore, it is important to take into consideration that the exploration and understanding of patients' illness experiences, meaning perspectives, contexts, beliefs and culture are considered key elements towards patient-centred care (Charon, 2001; 2004; Edwards et al., 2004a; Kumagai et al., 2008; Howarth et al., 2014; Kidd et al., 2011).

- The findings also indicate that despite the NSCLBP Portuguese individuals' emphasis on their lack of a clear understanding of their disorder, they tend to formulate an explanation of some sort. The majority of these explanations seem to be rooted in the hypothesis of a physical origin for pain, which according to the literature is not possible to identify in 90% of the cases (van Tulder et al., 2002). The NSCLBP Portuguese individuals' conceptualisation of their disorder according to this mind-set appears to be counter-productive, since it increases the struggle of understanding and making sense of NSCLBP. Additionally, according to previous research, the patients' perceptions of pain may promote the maintenance of pain as well as high levels of functional disability (Crombez et al., 1999; Main & Waddell, 2004; Woby et al., 2004; 2007; Crombez et al., 2012; Verkerk et al., 2012). **Accordingly, health professionals need to address NSCLBP patients' explanations for their disorder in order to help them transform these explanations into more adaptive ones.** Some authors have suggested that

although individuals' mind-sets for understanding pain are difficult to challenge, they are not necessarily static (Toye & Barker, 2012a; Ojala et al., 2015). Thus, the aforementioned perceived incoherence, unanswered questions, and struggle to understand NSCLBP may open patients to other explanations and prompt opportunities for positive change.

- The findings of this study also indicate that the content and delivery of health professionals' explanations for NSCLBP do not seem to meet the patients' expectations. Indeed, NSCLBP Portuguese individuals appear to be successively confronted with what they perceive as incomprehensible explanations from health professionals. **This draws attention to the idea that providing information *per se* may not be the best response in addressing NSCLBP patients' needs.** Indeed, in the context of patients' education, didactic approaches, i.e. simply giving information to patients have not been recommended (Moore & Jull, 2012). Rather, identifying patients' learning needs and providing information according to the patients' learning styles has been advocated (Moore & Jull, 2012). Previous research has systematically highlighted patients' education as one of the most recommended approaches to treatment of NSCLBP patients (Airaksinen et al., 2006; Savigny et al., 2009; Koes et al., 2010; Engers et al., 2011). However, there is no consensus about the best educational approaches, as there are studies supporting a range of approaches such as the back schools (Heymans et al., 2011) or, more recently, education based on the neurophysiology of pain (Moseley et al., 2004; Ryan et al., 2010; Nijs et al., 2011; Louw et al., 2012; Moseley & Butler, 2015). **What this study adds is that NSCLBP Portuguese individuals seem to need an acceptable explanatory model that assimilates their experience and personal narratives. Thus, finding meaning and understanding their disorder may not necessarily require the formulation of a clear and detailed explanation, but the development of an acceptable one. In other words, an explanation that makes sense to the patients.**
- There seems to be a discrepancy between the health professionals'

explanations and the NSCLBP Portuguese individuals' interpretation of their disorder. In this context, clinical encounters seem to perpetuate NSCLBP individuals' difficulty in understanding their disorder. Additionally, the variety of explanations provided by different health professionals appears to increase the aforementioned difficulty. Thus, NSCLBP Portuguese individuals seem to struggle to understand the health professionals' points of view. This led them to question the health professionals' competence and blame the latter for the persistence of their disorder. Indeed, some authors have carried out research that has drawn attention to the health professionals' difficulty in dealing with the lack of a concrete diagnosis in NSCLBP (Slade et al., 2011; Jeffrey & Foster, 2012). Previous research has already emphasised that disorders such as NSCLBP challenge the foundations of medical knowledge (Chew-Graham & May, 1999; Steihaug, 2005). More specifically, in western societies pain is biomedically understood, which means that medical knowledge is viewed as objective and thus separated from the subjective experience (Steihaug, 2005). Accordingly, the discrepancy between subjective symptoms and objective findings lies at the very core of NSCLBP and seems to constitute a problem for both the patient and the health professional (Steihaug, 2005). **This study's finding suggests that the health professionals' need to review both their vision and conceptualisation of NSCLBP as well as their approaches towards the promotion of patients' understanding of their disorder.**

- The findings also suggest an underlying increasing discontent and disappointment with health professionals' approaches. Seemingly, this discontent and disappointment is related to the NSCLBP Portuguese individuals' perceived lack of investment in analysing and managing their complaints from health professionals. There seems to be an absence of an alignment between the individuals experiencing NSCLBP and the health professionals, which appears to promote the maintenance of unsuccessful treatments as well as the eventual abandonment of the health care services. Published literature has drawn attention to an apparent discrepancy between the perspectives of both patients and health professionals regarding the

treatment as well as the outcomes assessed (Harding et al., 2005; Scheermesser et al., 2012; Gartlehner & Flamm, 2013; Concannon, 2015). More specifically, the treatments do not seem to address NSCLBP patients' needs and the outcomes assessed appear to be focused on aspects that are relevant to the health professionals and not necessarily to the patients (Kyte et al., 2015). **This study's finding draws attention to the health professionals' need to re-think their overall approach to NSCLBP and consider models of practice that take into account the patients' perception of what is helpful when planning treatment and evaluating the outcomes** (Underwood et al., 2006; Froud et al., 2014). **Indeed, the NSCLBP Portuguese individuals' accounts are indicative of the need of individually tailored treatment, suggesting the applicability of international recommendations** (Hibbard et al., 2009; Fishman et al., 2013) **in the Portuguese context.**

- The Portuguese NSCLBP individuals appeared to demonstrate vulnerability, passivity and dependency on health professionals, despite claiming not being able to trust the latter. Seemingly, they accept an underlying asymmetry in the therapeutic relationship, which may include for example, the acceptance of the physicians' decisions without question in spite of not understanding them. They seem to consider themselves as passive recipients of information. On the other hand, they critique physicians for not listening to their problems or considering their needs. Thus, despite NSCLBP individuals' desire for more information, they do not seem to consider the possibility of having an active role in the decision-making. More specifically, they appear to consider themselves as being disempowered to deal with their disorder and unable to collaborate in their treatment, or establish a partnership with health professionals. **This finding draws attention to the health professionals' role in the NSCLBP Portuguese patients' perceived inability to participate in the decision-making.** It is important to take into consideration that several authors have emphasised the importance of collaborative decision-making as a core component of patient-centred care (Edwards et al., 2004b; Atkins & Ersser, 2008; Trede & Higgs, 2008). **Thus,**

health professionals need to focus on empowering NSCLBP patients to become active agents capable of taking action that may change their situation. This recommendation attains particular relevance in the context of a disruptive experience, where patients perceived themselves as unable to make any changes in the events that happen throughout their lives.

- This study's findings reinforce previous research (Bury, 1982; Frank, 2004; Bunzli et al., 2013), by emphasising NSCLBP as a disruptive experience that advocates important changes in the structure of patients' everyday life. What this study seems to add is a contextual dialectic relationship between fatalism and perseverance that places NSCLBP as a condition that is simultaneously perceived as out of control and as an obstacle that needs to be overcome. More specifically, despite the cultural tendency to explain suffering, and thus NSCLBP, as a consequence of external and uncontrollable causes that are considered to be impossible to change, NSCLBP Portuguese individuals are looking for both meaning and retaining a sense of control over their lives, rather than merely understanding the disorder *per se*. **In particular, this finding indicates that the international recommendations for interventions based on self-management (Moore et al., 2000; Lorig, 2003; May, 2007; Caiata Zufferey & Schulz, 2009; Cooper et al., 2009; Matthias et al., 2012) may be meaningful in the Portuguese context. It also draws attention to the need to focus the approach to NSCLBP Portuguese patients on strategies that increase their capacity to control the impact of pain on their lives.**
- The findings also suggest an apparent negative impact of social networks (family, friends, colleagues and community) on the experience of NSCLBP Portuguese individuals. More specifically, NSCLBP Portuguese individuals tend to look at their social interactions for support in dealing with the disorder. However, these social interactions eventually become an issue as they call the reality of NSCLBP into question, and prompt feelings of being disbelieved, mocked or pitied. Moreover, the comparisons from and to other

people indicate a discrepancy in the way the NSCLBP Portuguese individuals perceive themselves and the way in which they think they live in the mind of others. More specifically, despite their perception of being seen as weaker, they seem to believe they are stronger than average, since they have to deal with more adversity in life. This apparent discrepancy allied with the aforementioned scepticism may be on the basis of both a perceived identity threat as well as a tendency for isolation. Indeed, interactions eventually become focused on family, whose sustainability seems to be perceived by these patients as their main responsibility. Although the concepts of stigma and identity threat have already been reported in previous international literature (Holloway et al., 2007), these may be interesting findings in the context of a society that values human relationships over task achievement, such as the Portuguese. **These findings draw attention to the importance of expanding the health professionals' approach to the patients' social network, as the latter seems to contribute to the former's development of maladaptive responses to NSCLBP. In order to achieve this, it seems to be important to consider educational approaches that include members of the nuclear family of the NSCLBP patient as well as the overall community.**

- The findings of this study emphasise the NSCLBP Portuguese individuals' difficulty in manifesting their needs within a context where their disorder is not recognised or validated. Seemingly, both the aforementioned stigmatisation and identity threat motivate NSCLBP Portuguese individuals to concentrate on minimising or ignoring their health needs. More specifically, some engage in a constant search for balancing their needs with other people's, while others try to focus on taking care of other people and ignoring their own needs. Simultaneously, the former seem to engage in a process of defending the self from what is perceived to be a threat to their identity, while the latter ignore this. These responses may have some impact on the way people experiencing NSCLBP search for healthcare, leading patients to almost exclusively consult the GP. **This finding draws attention to the importance of orientating NSCLBP Portuguese patients into the health**

system, in order to facilitate the access to health professionals that may complement and improve the clinical approach to these patients.

- The findings also reinforce previous research (Osborn & Smith, 1998; 2006; Walker et al., 2006; Smith, 2007; Snelgrove & Lioffi, 2009; Crowe et al., 2010a; Morley, 2010), by indicating the relevance of addressing how NSCLBP Portuguese individuals relate their selves with their disorder. Seemingly, while some NSCLBP individuals defend a clear separation between both the self and the NSCLBP and try to ignore their disorder, others accommodate the emergence of a new self. This finding is particularly relevant in the context of this study, since the aforementioned responses appear to play an important role in the process of regaining control over pain. More specifically, there are patients who in due time seem to be impeding any constructive process of adjustment or rehabilitation, while others appear to accept responsibility for the new self, which may be a key element in regaining control over pain, and thus, in life. This latter response seems to reflect an underlying adjustment, which implies more than the adoption of particular strategies, or the acceptance of the impossibility of eliminating pain, but the change of fundamental aspects such as self-concept and identity. **This finding draws attention to the need of addressing how NSCLBP Portuguese patients relate themselves with their disorder, since this relationship seems to determine their capacity to develop adaptive responses based for example, on their capacity to control NSCLBP.**

7.6. Implications for health professionals` education

This study`s insights into the Portuguese individuals` experiences of having NSCLBP disorder may also be taken into account in health professionals` education. The following paragraphs explore implications in this area.

- Although this study was not focused on health professionals, the NSCLBP Portuguese individuals` accounts suggest that the models of practice have

been more clinician-centred than patient-centred. Previous research carried out in the Portuguese context has already indicated that the approach of both physiotherapy students and expert physiotherapists to clinical reasoning and practice is more consistent with a traditional biomedical model of practice (Cruz et al., 2012a; 2012b), which fails to explain or treat chronic musculoskeletal pain (Nijs et al., 2013). **Thus, this study's findings are reinforced by previous research and strengthen the need to re-design undergraduate and post-graduate training in order to promote a shift towards new models of clinical reasoning and practice based on understanding the patient's perspective, sharing power and responsibility and developing therapeutic alliances within a biopsychosocial and patient-centred care frameworks** (Cooper et al., 2008; Lévesque et al., 2013; Sanders et al., 2013).

- The findings suggest that NSCLBP Portuguese individuals are familiar with didactic approaches, which are centred on what the health professionals perceive as important for patients (Cross et al., 2006). Indeed, these educational approaches tend to be used in contexts dominated by the biomedical model of practice, such as the Portuguese (Moore & Jull, 2012; Cruz et al., 2012a). **This draws attention to the need to include educational theory in undergraduate and post-graduate curricula, in order to support health professionals providing educational approaches that suit NSCLBP patients' needs.**
- The findings are also indicative of the dominance of the biomedical model in the NSCLBP Portuguese individuals' attempts to make sense of their pain, which may possibly reflect the health professionals' conceptualizations of NSCLBP. Indeed, literature has demonstrated that the health professionals' attitudes and beliefs are associated with their patients' beliefs (Houben et al., 2005; Darlow et al., 2012). Previous research has emphasised the challenges inherent to the incorporation of psychosocial perspectives within physiotherapists' management of LBP (Foster & Delitto, 2011; Alexanders et al., 2015; Synnott et al., 2015; Sanders et al., 2014). Additionally, literature

has already reported major deficits in the knowledge of all health care professionals regarding the mechanisms and management of pain (IASP, 2010). **Thus, this study's findings are aligned with international recommendations that emphasise the need to educate health professionals about modern pain neuroscience education, in order to enable them to assess relevant factors that might modulate the pain experience and provide effective pain management** (Jones & Hush, 2011; Moseley & Butler, 2015).

- This study's findings also suggest problems in the therapeutic relationship, since the NSCLBP Portuguese individuals report a sense of disregard, disbelief and lack of respect from health professionals and believe that they do not listen to their problems or consider their needs. **This study's findings are indicative of the need to increase sensitivity to patients' needs, which implies developing skills in listening, empathising and showing respect.** The importance of promoting the development of these skills has already been reported by previous literature (Barker et al., 2009). **It may enable the health professionals to implement individualised pain management, following the current international recommendations for individual tailored treatment** (Hibbard et al., 2009; Fishman et al., 2013).
- The findings indicate that the NSCLBP Portuguese individuals are looking for both meaning and retaining a sense of control over their disorder, which suggest the adoption of a clinical approach that promotes self-management. However, it is important to take into consideration that this requires a shift towards the empowerment of health service users, which may be particularly challenging in biomedical and clinician-centred contexts, such as the Portuguese one (Cruz et al., 2012a; 2012b). Indeed, previous research has already identified obstacles to self-management such as the healthcare professionals' resistance and lack of knowledge (Corbett et al., 2009; Lawn et al., 2009; Littlewood et al., 2015). Furthermore, a recent study has already emphasised tensions and differences in the conceptualisation of self-management among a diversity of stakeholders and health service users,

which may impede the effective implementation of this approach (Stenner et al., 2015). **Thus, the current study's findings suggest the need to design and implement health professionals' education and training, in order to develop knowledge and skills to carry out effective self-management in the approach to individuals experiencing NSCLBP.**

- Finally, this study's findings indicate that NSCLBP Portuguese individuals are treated by health professionals from different fields, such as a GP or a PT, which is consistent with previous research carried out in Portugal (Azevedo et al., 2013b). In addition, previous studies have recommended multidisciplinary approaches to NSCLBP (Scascighini et al., 2008; Dufour et al., 2010; Kamper et al., 2014). However, it is important to take into consideration that barriers for the development of interprofessional collaboration between GPs and PTs have also been identified in previous research (Paz-Lourido & Kuisma, 2013). **Thus, interprofessional educational programmes should be considered at undergraduate and postgraduate levels, in order to provide a common basis for different professions regarding the understanding of pain mechanisms and major biopsychosocial concepts.** Indeed, this recommendation is in alignment with the IASP interprofessional pain curriculum, which considers the development of collaborative competences as mandatory (IASP, 2012).

7.7. Suggestions for future research

This study's findings suggest the need for further research in order to develop a better understanding of the phenomenon under investigation. The following paragraphs present some suggestions for future research.

- This study suggests that giving voice to the NSCLBP patients may offer a wealth of potential for reshaping health services, with particular emphasis on promoting a shift towards patient-centred care. Further qualitative research on patients' experiences of NSCLBP and using health services could provide valuable insights into the experience of care.

- The richness of the data collected in this study`s interviews, suggests the relevance of carrying out IPA single case studies that could help researchers to explore particular concepts. For example, some concepts emerged from the current study that deserve further exploration: the concept of control and the nature of its relationship with the concepts of understanding NSCLBP and finding meaning; the concept of seeking support and the nature of its relationship with the cultural background.

- The findings emphasise the impact of key people in the experience of Portuguese individuals with NSCLBP – family and health professionals (GPs and PTs). A multi-perspectival study using IPA may allow the exploration of the concept of NSCLBP from multiple perspectives, which could provide a more detailed and multifaceted account of this phenomenon.

- Besides the IPA approach, it may be useful to consider other qualitative methodological approaches, since they enable the development of distinctive and complementary knowledge. For example, rather than maintaining the focus on the lived experience of a small number of individuals with NSCLBP and on the convergence and divergence between them as in IPA, a grounded theory study could possibly push the focus towards a more conceptual explanatory level. Subsequent grounded theory studies may allow the expansion of a preliminary idiographic theorizing into the generation of a broader theory. Additionally, narrative research studies could provide a new perspective of the NSCLBP Portuguese individuals` meaning-making about their disorder through their own life stories.

- This study also draws attention to the relevance of patient education in the context of NSCLBP approach. More than receiving information *per se*, NSCLBP Portuguese individuals seem to need an acceptable explanatory model that assimilates their experience and personal narratives. Thus, further research on NSCLBP Portuguese individuals` expectations as well as what they perceive as effective education may provide important recommendations for clinical practice and subsequent research on this topic.

- The Portuguese health professionals' approaches to patient education also seem to be an issue that deserves further investigation. More specifically, it may be important to understand Portuguese health professionals' perceptions of what NSCLBP patients need to learn, as well as their educational practices. The current findings suggest that didactic and therapist-centred approaches are possibly being used in clinical practice, however little is known about what educational roles GPs and PTs are prepared to take in NSCLBP patients' education, how well they know NSCLBP patients' expectations and capacity to learn and change and, how prepared they are to adopt experience-based and patient-centred models of education.
- This study's findings emphasise the NSCLBP Portuguese patients' perceived inability to participate in the decision-making, which contrasts with the current Portuguese health policies' recommendations to empower patients. Considering these recommendations advocate supporting patients to become active agents capable of taking action towards their health status, it is important to develop further research on their perceptions regarding decision-making as well as what could help them to adopt a more active role.
- Additionally, since the models of therapeutic relationship determine the roles adopted by both health professionals and patients, it may be important to investigate the nature of the relationship established between Portuguese health professionals and NSCLBP patients. Indeed, the current findings are indicative of the need to increase the Portuguese health professionals' sensitivity towards NSCLBP patients' needs. However, little is known about how the power relationship between them is asserted, who makes the decisions regarding treatment, or what is needed to promote more collaborative models of practice.
- The findings also emphasise the need to focus the clinical approach to NSCLBP Portuguese patients on strategies that increase their capacity to control the impact of pain. Further research on NSCLBP Portuguese patients'

perceptions about self-management or possible barriers for self-management could provide important insights for clinical practice. Moreover, it may be important to understand, for example, the characteristics and experiences of those who perceive themselves more prepared to self-manage or those who are more likely to self-manage. On the other hand, it could be important to explore Portuguese health professionals' perceptions about self-management as well as about any possible learning and training needs. Additionally, further research to pilot self-management interventions for Portuguese individuals with NSCLBP is required and further studies should also focus on outcome measures for self-management, before any other specific recommendations can be made.

7.8. Reflexive account

Contrary to my initial expectations, the process of data analysis has persisted throughout the discussion. As previously mentioned in my reflexive account regarding data analysis, although I had started this process cautiously (completing one step after another), I soon realised that I needed to challenge myself in order to engage in the hermeneutic circle and add depth to my interpretation of data. In the context of the work presented in this chapter, the “dialogue” with the authors of previous literature enriched the process of data analysis, since it helped me to move back and forth with a range of different ways of thinking about the data. Indeed, previous literature prompted this movement, since it enabled me to look at the data from different perspectives.

A range of thoughts and questions accompanied me throughout the process of data analysis and discussion. For example, I questioned myself several times about whether I was answering the research question and whether the methodological approach selected was really helping me to do this.

Since the research question addressed in this study was “What are the experiences and perceptions of Portuguese individuals with NSCLBP?”, IPA revealed to be an appropriate choice. Indeed, IPA seeks to get what an experience is like for an individual, despite recognising that pure experience is

never accessible (Smith et al., 2009f). Smith et al. (2009f) tried to provide a deeper understanding of what getting an experience is in the context of IPA research by emphasising that this can be understood as research that is “experience close” (Smith et al., 2009f, p.33). Thus, since the person is assumed as a sense-making creature, the meaning that is attributed by this person to a determined experience represents the experience itself. Accordingly, as an IPA researcher I was focused on seeking what the experience of NSCLBP was like for the Portuguese individuals who had this disorder, or in other words, what meanings these individuals attributed to their disorder.

In this context, as an IPA researcher I was supposed to develop a deep understanding of how this study’s participants made sense of their experiences of NSCLBP. Thus, the interpretative nature of IPA and its connection with hermeneutics attained major relevance in this study. The idea of the hermeneutic circle accompanied me throughout the entire process of data analysis and discussion. The constant movement between the parts and the whole helped me in the process of analysis and simultaneously increased its depth. As previously mentioned in the fourth chapter, the parts and the whole operated at different levels throughout the process: for example, in the initial stages the parts could be sentences of one interview, and the whole could be the entire transcript; in more advanced stages, the parts could also be one interview and the whole the eight interviews; or, in the final stages, the parts could be arguments defended by an author in a previous paper and the whole my research project.

Additionally, this interpretative activity also required the need to be aware of my preconceptions regarding the phenomenon under investigation. Contrary to my previous expectations of needing to be conscious of my own preconceptions before starting the data analysis, I realised that this was going to be a very dynamic process. Indeed, I became progressively aware of my preconceptions as the interpretative activity was underway. Gradually, the need to follow the principles of IPA challenged me to engage in a dynamic and non-linear process of interpretation, which I believe has improved the quality of this study.

Finally, the idiographic element of IPA also played an important role in answering this study's research question. The commitment to focusing on the particular individuals helped me to add depth to the analysis. The idiographic orientation supported me in understanding how NSCLBP was perceived from the perspective of the particular participants included in this study, who were integrated in the Portuguese context.

Furthermore, I also questioned myself several times about whether this study was going to provide a different understanding of NSCLBP and if it could add to the existing knowledge.

Although previous research in the experience of NSCLBP had already been carried out, it took place in a few countries, with the majority of studies being carried out in the UK (MacNeela et al., 2015; Toye et al., 2013). Both the cultural impact on this experience and the high prevalence of NSCLBP in Portugal supported the need to carry out the current study in the Portuguese context. As this was the first investigative approach to Portuguese individuals' experiences of NSCLBP, I was keen to explore how this phenomenon was perceived in Portugal. I had some expectations, possibly influenced by my preconceptions, however I also expected to go beyond these expectations.

Indeed, this study's findings highlighted the participants' need to understand their disorder, which was coherent with my expectations.

These expectations were related to my previous experiences as a physiotherapist. Indeed, most of the literature that supported my clinical practice emphasised the importance of patient education. It is possible that the strong biomedical roots of my profession, led me to assume that educating patients meant explaining why he/she had had pain. Thus, I had expected that this would be an important emergent topic from this study's findings. Indeed, my initial comments on data analysis were mainly focused on these ideas. However, as the analysis progressed I expanded my approach to data and started to explore other ideas that I had not expected. Indeed, this study's findings draw attention to a range of topics that I did not expect, such as:

(i) the relationship between fatalism and perseverance – as a Portuguese

female living in Portugal, I was deeply engaged in the Portuguese culture. Thus, this relationship between fatalism and perseverance was possibly part of my “taken-for-granted” preconceptions. In fact, I had never realised that they were there, possibly influencing all Portuguese individuals’ lives. This idea emerged in the final stages of data analysis. Despite being presented in this thesis in the first theme, it was actually the last theme to be identified and explored. There was an underlying tension between fatalism and perseverance since the beginning of the analytic process. However, as it was not directly expressed by the participants, I could only identify it in the deepest stages of interpretation. The analysis of literature concerning the Portuguese context supported me in emphasising this idea;

(ii) the search for meaning that attained more relevance than understanding the disorder *per se* – this questioned all my initial preconceptions regarding the participants’ need for a detailed explanation of the pain. In the first stages of interpretation I had highlighted the participants’ need for explanations, however as I “dug deeper” I became aware that it was not simply about an explanation, for some individuals it was about finding meaning. For a physiotherapist the phrase “finding a meaning” could be difficult to transfer to the context of clinical practice. As a researcher and as a physiotherapist, I questioned myself several times about how health professionals would help patients to find this meaning. Interestingly, literature in this area led me to consider that this was very much related to the therapeutic relationships and models of health care. It also helped to establish connections across different emergent themes;

(iii) the contribution of the therapeutic relationships on perpetuating the participants’ struggle to make sense of their disorder – I knew, from international literature, that health professionals’ biomedical beliefs impacted on patients’ beliefs. I was also aware that most patients I observed in my clinical practice had complaints regarding previous encounters with health professionals. Nevertheless, I did not expect that the therapeutic relationship could have such a relevant contribution to perpetuating the participants’ struggle in making sense of their disorder. The analysis of data regarding this theme albeit challenging, made me feel uncomfortable. It was challenging because I was making sense of new information, and thus stretching my views

of the phenomenon under investigation. But it made me feel uncomfortable, as it was about health professionals in general, and thus about myself too. Since this theme became one of the most explored by this study's participants, it could eventually stimulate health professionals' reflection on their approach to patients, as it did to me.

(iv) the lack of support from the participants' networks – This idea went against my initial preconceptions. I was aware that Portuguese society considered family as one of the central aspects of life, as was also confirmed by the literature. Thus, I took it for granted that in cases of illness, patients would be supported by their families. However, what I had not considered was that in the context of NSCLBP there was no “visible illness”. This theme also emerged in the deepest stages of interpretation. In this case, this may have happened because I had not considered it and was therefore looking for the opposite i.e. how participants' were supported by their families.

(v) the impact of NSCLBP on the definition of a new sense of self – I was far from considering that NSCLBP could have an impact on a person's sense of self. In the initial stages of the analytic process, I looked at the participants' words regarding this idea and was perplexed. The emergent topics related to this remained grouped in an untitled excel column for a long time. The development of conceptual maps in my reflexive journal and further reflections on the literature regarding the experiences of NSCLBP had a prominent role in increasing the depth of my interpretation.

As expected, some of this study's findings were in line with previous literature and some may have provided new insights into the experience of NSCLBP. Nevertheless, a range of implications for patients, health professionals' clinical practice and education emerged from this study's findings.

7.9. Chapter summary

In this chapter, the investigative approach has been discussed, with particular emphasis on its strengths and limitations. Additionally, the main findings have been discussed in relation to previous research. Furthermore, the contribution to

knowledge has been discussed, as well as its implications for patients, clinical practice, health services and health professionals` education. Moreover, suggestions for future research have been presented. In the next chapter this study`s main conclusions are outlined.

Chapter 8: Conclusion

This IPA study has been the first qualitative study focusing on the experiences of individuals with NSCLBP in Portugal.

This study's findings have provided novel insights into Portuguese individuals' experiences and perceptions of NSCLBP as well as diagnostic and treatment approaches, such as:

- The disruptive nature of the experience of NSCLBP, which is integrated in a contextual dialectic relationship between both fatalism and perseverance;
- The Portuguese individuals need for meaning and retaining a sense of control over their NSCLBP and lives, rather than merely understanding the disorder *per se*;
- The lack of alignment between Portuguese individuals with NSCLBP and health professionals, which contributes to the perpetuation the patients' lack of understanding and capacity to manage their disorder;
- The asymmetry in the therapeutic relationship between patients and health professionals, which leads NSCLBP Portuguese individuals to consider themselves as being disempowered to deal with their disorder and unable to have an active role in the decision-making;
- The Portuguese individuals' capacity to self-manage NSCLBP, which requires more than the adoption of particular strategies (e.g. based on movement), but the change of fundamental aspects related to identity, such as an enhanced responsibility for self.

It is important to take into account that this study's findings cannot be considered representative of all individuals with NSCLBP. These findings were considered in terms of theoretical transferability rather than empirical generalizability. Thus, several procedures were undertaken in order to address potential limitations to the aforementioned transferability - for example, attention was given to characterising the Portuguese context and the participants' specific life contexts.

The development of research in such a previously unexplored and unique context has brought attention to relevant knowledge that needs to be used nationally to inform clinical physiotherapy practice in Portugal. The following paragraphs address this study's key clinical implications, which when implemented are expected to produce relevant improvements to patients and health services:

- Health professionals need to explore NSCLBP individuals' explanations of their disorder in order to help them explore these as part of clinical interventions to promote the individuals' understanding of their experience, so they can feel more enabled to deal with their situation. This may not necessarily require the formulation of a specific and detailed justification for NSCLBP (focused exclusively on the health professional's knowledge), but the development of health professional/patient's explanation of NSCLBP that makes sense to the patients;
- Health professionals should involve NSCLBP Portuguese individuals in the development of an acceptable explanation of their disorder that assimilates the individuals' experiences and personal meanings. This requires a shift in the health professionals' traditional clinician-centred assessment of these patients, with an increasing focus on the individual patient's account and becoming more patient-centred.
- Health professionals should re-think their overall approach to Portuguese individuals with NSCLBP and consider interventions that include the individuals' perception of what is helpful when they plan treatment and evaluate the outcomes. This may create opportunities to develop individually tailored approaches and move the focus of treatment from what appears relevant to the health professional to what is currently important to the patient.
- Health professionals' approaches to Portuguese individuals experiencing NSCLBP should focus on working with the patient in the decision-making and management of their health condition. This demands that health professionals re-think their role in the therapeutic relationship as well as their model of practice. It also creates opportunity to move from the predominance of biomedical approach to patient-centred approaches.

Additionally, this study's findings may also prompt the re-design of Portuguese undergraduate and post-graduate curricula in order to promote a shift towards new models of clinical reasoning and practice based on understanding the patient's perspective, sharing power and responsibility, and developing therapeutic alliances within a biopsychosocial and patient-centred care framework.

Further research is recommended: i) on the exploration of NSCLBP individuals' expectations regarding treatment and on what they perceive as effective education; ii) NSCLBP individuals' perceptions regarding decision-making and what could help them to adopt a more active role in their treatment and management; iii) health professionals' educational practices as well as the educational roles they are prepared to take in NSCLBP patients' education.

The study's findings have therefore emphasised the relevance, importance and increasing potential of expanding NSCLBP individuals' involvement in the process of developing an explanation for their health condition. Additionally, the findings have also stressed the need to re-think health professionals' approaches to these patients and consider new models of practice that enable patients to participate in the design, evaluation and eventual reconfiguration of health care services.

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Appendices

Appendix 1: Project protocol submitted to FREGC

Research Proposal Faculty of Health and Social Science Research Ethics & Governance Committee

Clinical Research Centre for Health Professions

July 2011

An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Abstract

This study aims to explore how Portuguese individuals with non-specific chronic low back pain (CLBP) disorder understand and make sense of their condition.

The methodological approach will be Interpretative Phenomenological Analysis and semi-structured one-to-one interviews will be carried out in order to collect Portuguese individuals' accounts about their experiences of having non-specific CLBP disorder.

Individuals with non-specific CLBP disorder referred for physiotherapy in Portuguese health centres will be recruited purposefully, according to a range of inclusion and exclusion criteria.

The final expected outcome will be an account of the researcher's interpretation of participants' experience of having a non-specific CLBP disorder. The knowledge produced by this study will contribute to a better understanding of Portuguese individuals' experiences of having non-specific CLBP disorder and will inform recommendations to help improve non-specific CLBP management in Portugal.

I. Introduction

The International Association for the Study of Pain defines chronic pain (CP) as *“a pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be 3 months)”* (IASP, 1986; quoted by Harstall and Ospina, 2003, p.1). Non-specific chronic low back pain (CLBP) constitutes one of the variants of CP and it is not attributable to a recognisable specific pathology (Airaksinen et al., 2004). This term does not intend to be a diagnosis but rather a description of back pain for which a cause cannot be identified and a precise diagnosis cannot be established (Slade et al., 2009).

The epidemiological literature has highlighted the growing impact of non-specific CLBP disorder in western societies (Anderssen, 1999; Goubert et al., 2004; Breivik et al., 2006; Castro Lopes et al., 2010). In Portugal, although research is quite scarce, a report produced by Castro-Lopes et al., (2010)

demonstrates the high prevalence of non-specific CLBP disorder. According to this report, conducted in all regions of the country, the prevalence of CP is estimated at 36%. From this percentage, more than 40% of the individuals suffer from low back pain. Similarly to other European countries, in Portugal CP is more common in females and is more prevalent in the lower back region (Breivik et al., 2006; McBeth & Jones, 2007; Castro-Lopes et al., 2010). Another Portuguese study, Rabiais et al., (2002), also offered preliminary information about demographic characteristics associated with low back pain in Portugal. According to this study, the prevalence of low back pain is higher in females (59,4%), between the ages of 55 and 64 (63,9%), with a lower educational level (67,2%) and housewives (65,9%).

Some authors based in other parts of the world have suggested that the growing impact of non-specific CLBP disorder could be related to health professionals' approach to this condition (Waddell, 2004; McBeth & Jones, 2007). The long duration of CP and the complex biopsychosocial nature of this phenomenon, determines a high dependence of individuals with non-specific CLBP disorder on health services (Waddell, 2004). While seeking treatment for their problem, individuals with non-specific CLBP disorder establish contact with a range of health care providers. According to some authors these contacts are contributing to the development or maintenance of disability. This seems to be justified by a predominantly biomedical approach (Rainville et al., 2000; Daykin & Richardson, 2004; Houben et al., 2005).

Although in Portugal there is no research concerned with treatment approaches to individuals with non-specific CLBP disorder, the research carried out abroad shows that, traditionally, individuals with non-specific CLBP have been treated under the major influence of the biomedical model, which explains pain and its impact through physical injury related exclusively to sensory input (Main and Parker, 2000; Daykin and Richardson, 2004; Waddell, 2004). The research carried out over the last three decades has highlighted the influence of psychosocial factors in non-specific CLBP and related disability (Waddell, 2004; McBeth & Jones, 2007). Thus, research has brought attention to the multidimensional nature of CP, which is best suited to a biopsychosocial model of care (Daykin and Richardson, 2004; Waddell, 2004; McBeth & Jones, 2007).

In the 1970s, pain research increased dramatically through the use of a mainly positivist approach, associated with quantitative methodologies. This research approach has offered a significant contribution to the knowledge about pain management. Simultaneously, the recognition of biopsychosocial model of care had a major influence on pain research and the studies concerned with the influence of psychosocial factors, such as fear-avoidance beliefs, catastrophising, coping, self-efficacy or depression have increased dramatically (Woby et al., 2004; 2007). According to some authors however, although these studies have offered valuable information about psychosocial variables related with pain and disability, they tend to illustrate a disembodied picture of CP (Osborn & Smith, 2006).

As a reaction to the need to understand the experience of pain sufferers, qualitative research has become increasingly recognised within pain research. Interpretative approaches to research, associated with the use of qualitative methodologies, have become particularly relevant to the growing of the body of knowledge concerned with the understanding of the experience of having CP (Mitchell & MacDonald, 2009). Recent qualitative research has offered valuable insights into the multidimensional experience of non-specific CLBP disorder (Mitchell & MacDonald, 2009). However, researchers are still emphasising the need to carry out more research on this topic. These recommendations are particularly relevant when it is taken into consideration that the experience of having non-specific CLBP disorder is deeply influenced by cultural contexts and the vast majority of research has been carried out only in a small number of countries such as the United Kingdom and Australia (Waddell, 2004; Tavafian et al., 2008).

The volume of research produced in Portugal within the area of CP is considerably low. The few existing studies are mainly concerned with incidence and prevalence as well as the relations between some factors such as acceptance of pain, self-compassion or the influence of gender (Costa & Pinto-Gouveia, 2010; Bernardes & Lima, 2010).

Portugal is a small country located in southwestern Europe on the Iberian Peninsula. The Portuguese population reached approximately 10,6 million in 2009 (National Statistics Institute, 2010). For the last four decades, Portugal has suffered dramatic social changes. The average age of the Portuguese has increased faster than other European countries and the birth rate has decreased significantly. Family structures, education and work contexts have changed dramatically (Barreto, 2002). All of these factors have had a major influence on Portuguese culture. Although the Portuguese health system has not suffered any significant changes in financing since the 1990s, several measures have been considered to improve the performance of the health system. Most of these measures have been carried out very recently, which makes it difficult to measure their effect at this time (Barros & Simões, 2007).

Considering that there is no research in Portugal about the individuals' experiences of having non-specific CLBP and based on the assumption that understanding this will offer the possibility of designing approaches closer to their needs, this study aims to explore how Portuguese individuals with non-specific CLBP disorder understand and make sense of their condition.

II. Research Approach

Aims

The research question to be addressed in this study is: How do Portuguese individuals with non-specific CLBP disorder understand and make sense of their condition?

This study aims to explore the overall concept of non-specific CLBP in a Portuguese setting. Specifically, the research aims will be: to explore the experiences of participants with non-specific CLBP disorder; to explore the impact of having non-specific CLBP disorder on participants with non-specific chronic low back pain disorder; to explore how participants with non-specific CLBP disorder understand and make sense of their condition.

Epistemological and Ontological Position

The constructionism view of knowledge supports the development of this study. The researcher will engage with individual's reality by exploring his/her accounts of CLBP. The knowledge produced will be the product of this engagement. It will be unique, in the sense that it will result from a co-construction of meaning between both the researcher and the participant (Crotty, 1998; Willis, 2007). This study will also be conducted through the "lens" of the interpretative paradigm, which means that the researcher will be focused on developing a deep understanding about the interactions between participants with non-specific CLBP disorder and their contexts in making sense of their condition (Crotty, 1998; Willis, 2007).

The rationale for choosing both the constructionism view of knowledge and the interpretative paradigm is closely related to the nature of the phenomenon under investigation as well as the scope of the research question that informs this study. Pain constitutes the result of a dynamic process of perception and interpretation of a wide range of incoming stimuli, some of which are associated with actual or potential harm and some which are benign but are interpreted and described in terms of damage (Main & Watson, 1999). This view of the pain phenomenon highlights the importance of interpretation of a pain experience, which constitutes the main focus of the research question of this study.

Methodological Approach

The methodological approach will be Interpretative Phenomenological Analysis (IPA). It focuses on the exploration of human experience, in the way that this experience could be understood through exploring meanings that individuals attribute to it (Smith & Osborn, 2008; Smith et al., 2009). It aims to perform this exploration in a way that makes possible to express individual's personal accounts of their experience of having non-specific CLBP, rather than produce an objective statement of this experience (Smith & Osborn, 2008). These assumptions link IPA to phenomenology (Smith et al., 2009).

IPA is also concerned with interpretation, which reflects the strong influence of hermeneutics. IPA involves a "double hermeneutic", in the way that the researcher is making sense of the participant, who is making sense of a specific

experience (Smith & Osborn, 2008; Smith et al., 2009). The final expected outcome is an account of how the researcher makes sense of participants making sense of their experience of having non-specific CLBP disorder.

It is also important to consider that IPA has an idiographic element, in the sense that it focuses on a specific issue of an individual's experience. In this study, the approach is concerned with the detailed analysis of particular cases of individuals' experience of having non-specific CLBP disorder, followed by the analysis of common elements shared by individuals as well as variations in their experiences (Smith et al., 2009).

Participants

Considering the research question and the methodological approach of this study, the participants will be selected purposefully. Purposeful sampling is considered more adequate when the purpose is to study in-depth information-rich cases rather than formulate empirical generalizations typical from quantitative research (Patton, 2002). In this study, participants will be selected on the basis of their specific knowledge and unique experience, which opens access to particular perspectives about the phenomenon under investigation (Smith et al., 2009). In this sense, Portuguese individuals with non-specific CLBP disorder will be included in this study in order to develop insights and an in-depth understanding of how they understand and make sense of their condition.

In IPA research the participants homogeneity should be taken into consideration in order to facilitate the process of analysing variability within the group through identification of pattern convergence and divergence (Smith et al., 2009). A range of inclusion criteria will be used in order to ensure homogeneity.

Participants will:

- have experienced a non-specific CLBP disorder (which means to have low back pain that it is not related to a specific diagnosis, persisting for a period longer than 3 months), identified by the general practitioner;
- have had non-specific CLBP disorder for at least 1 year, that was not relieved by previous health care;
- be aged between 25 and 65 years;

- have intellectual capacity and psychological maturity to understand the nature of the research and his/her involvement and ability to make self-directed and self-determined choices;
- be able to communicate effectively in Portuguese (Smith & Osborn, 2007; Snelgrove and Liossi, 2009).

Simultaneously, the following exclusion criteria will be used:

- the presence of any chronic diseases;
- participants with any nationality other than Portuguese, due to the cultural basis of this study.

There are some factors, such as the area of study, the nature of topic, the richness of the data collected, etc, that make it possible to estimate an average number of participants recruited (Morse, 2000). In IPA, emphasis is placed on a detailed report of the individual's experience, which means that quality is favoured rather than quantity. It is expected that enough detailed information will be collected to explore individuals' experience of having non-specific CLBP disorder and to develop meaningful points of convergence and divergence between interviews. Simultaneously, the collection of too much data that makes it impossible to look at the particular will be avoided (Smith et al., 2009). Given the factors considered above, up to twenty participants will be recruited, which is expected to provide enough detailed information without losing the sense of the particular.

Recruitment Strategies

Individuals with non-specific CLBP disorder who are referred to physiotherapy services in several Portuguese health centres will be recruited. The following Portuguese health centres will be approached with regard to involvement in this study: Unidade de Saúde de Sao Sebastião (Health Unit of São Sebastião) and Unidade de Saúde Familiar de Santiago (Health Centres Group of Setúbal and Palmela), which are both governed by the same clinical council, and Centros de Saúde de Aljustrel e Ourique (Health Centres of Aljustrel and Ourique) which are integrated in the Unidade Local de Saude do Baixo Alentejo (The Local Health Unit of Lower Alentejo) and are governed by the same clinical council. The reason for choosing these specific health centres has been determined by

the high incidence and prevalence of chronic pain in these regions of the country (Pereira & Neves, 2010).

The recruitment process will include three phases. The first will concern the preliminary selection of health service centres, according to the factors mentioned above. In this first stage the researcher has checked information about epidemiological data in Portugal and has taken into account the pragmatics of travelling to the suitable areas.

The second phase will relate to the contact of key people in suitable areas. A letter of introduction to the clinical council of each Group of Health Centres will be sent by registered mail (appendix 1) and telephone contact with the administrator of each clinical council will be established in order to book an appointment with the members of each clinical council. The aim of these appointments is to present the purpose and the main procedures of the study and to discuss the Institution`s availability to participate in the study. At the end of these meetings, the researcher will ask the clinical council for physiotherapists` contact details (which could include the location of the room where they work in each health centre or their mobile phone contacts, if they work mainly in domiciliary contexts). After this, the researcher will contact each physiotherapist and meetings with them will be arranged. In these meetings the same information about the study will be given as well as more detailed information about participants inclusion and exclusion criteria and related procedures to be carried out by both the physiotherapists and the researcher (appendix 3).

The third phase will include the selection of specific participants according to the inclusion and exclusion criteria. The physiotherapists will be asked to identify potential participants for this study and then give them an envelope which contains a letter of invitation (appendix 5) to participate in this study, an information sheet (appendix 7) with more detailed information about the study and a stamped addressed envelope for those who are interested in participating.

The researcher will contact participants who return the stamped addressed envelopes by phone to answer any questions and determine if they are interested in participating. The individuals who decide to participate will be invited for an interview in the health centre where they are being treated on a date that is convenient to them.

When participants come to health centres, the researcher will meet them in the private room where the interviews will take place and will consider a previous period to answer any questions. A copy of the information sheet will be passed out to the participants who do not bring their copy with them. They will be given time to read it again and to raise any questions about the study they may have. Finally, the participants will be asked to give their informed consent and a signed copy of this will be given to them (appendix 9).

Participant information and consent procedures

Informed consent is an important procedure to ensure that the researcher accurately informs participants of the nature of research (O`Leary, 2004; 2005). In order to inform individuals` possible participation in this study, written information will be given to allow them to have a full understanding of their involvement in the study, including time commitment, type of activity, topics that will be covered in the interview as well as any emotional risks potentially involved (O`Leary, 2004; 2005). It is important to ensure that participants are aware of the research being conducted in order to support them making voluntary decisions (O`Leary, 2004; 2005).

Participants will be given an oral explanation as well as a written information sheet. This information sheet will be only one part of the process of seeking informed consent and will include information about the purpose of the study, the reason why participants were chosen as well as what is expected from them, and a clear explanation about the voluntary nature of participation, and precautions to ensure confidentiality, etc (National Patient Safety Agency, 2007). Confirmation of approval by an ethics committee will be given and the reasons why the ethics committee is not based in Portugal will also be explained in the information sheet. This explanation should clarify that there are no identified Ethic Committees in Portugal that are relevant for this study.

The researcher`s contact details (mobile phone, work number and e-mail contacts) will be given as well as the contact of an independent party to whom additional information can be asked or a complaint can be made if felt appropriate (National Patient Safety Agency, 2007). For this purpose, the telephone contact and e-mail address of a senior research administrator at the University of Brighton will be given. The research administrator speaks fluent Portuguese, which will be important when participants do not speak English. The research administrator will facilitate contact with an independent senior academic in The School of Health Professions at the University of Brighton. Finally, informed consent will be used to confirm that participant is consenting to everything described in the information sheet. It will be dated and signed by both the participant and the researcher, and a copy will be given to the participant (National Patient Safety Agency, 2007).

This study does not involve any kind of procedures that could produce physical damage. However, because participants will be invited to talk about their experience of having non-specific CLBP disorder, it is fundamental to evaluate to what extent this could include issues that may be sensitive and therefore constitute “harm”. The schedule will include mainly open questions, which gives participants the freedom to answer, as they prefer.

If the interview becomes upsetting for any participants, he or she will be provided with the contact of “SOS Voz Amiga” (SOS Friendly Voice) to access to appropriate support after the interview. The “SOS Voz Amiga” is a Portuguese centre that gives free psychological support, by telephone.

Data Collection and Storage

In this study the method of data collection will invite participants to offer rich, detailed accounts of their experiences of having non-specific CLBP disorder (Smith et al., 2009). The research method that best suits this purpose and is, simultaneously, congruent with the philosophical assumptions of the working paradigm is the interview technique (Crotty, 1998; Smith et al., 2009). This method of data collection will involve the researcher seeking open answers about individuals` experiences of having non-specific CLBP disorder (O`Leary,

2005). Participants will be asked about their experience by answering open-questions such as *“Please tell me about your experience of living with chronic low back pain?”*. The one-to-one interviews, using an informal style, will be used as a means for exploring and gathering insights into this as well as establish rapport, gain trust and open up lines of communication (Flick, 2006).

Semi-structured interviews will be used, which means that they will not have a fully fixed neither a free structure (O’Leary, 2004). Participants will be encouraged to speak freely, talk about their experience and reflect on their ideas (Smith et al., 2009). An interview schedule (appendix 11) will support the researcher in focusing on the topics for discussion (Smith et al., 2009). The interview schedule will be piloted in order to ensure the smooth running of the subsequent interviews. Two pilot interviews will be carried out with participants from the health centres selected, who will be recruited according to the inclusion and exclusion criteria previously defined. The data will be included in data analysis, unless the main structure of the interview schedule changes as consequence of the pilot study. Interviews will be audio recorded, which will allow its preservation for analysis at a later date. It is anticipated that the interviews will last no longer than an hour and a half.

A researcher diary will be used in order to collect researcher thoughts about data collection and analysis. It will also offer the possibility of documenting a critical reflexive and reflective account on the researcher’s role and influence on data collection and analysis. This information could be presented later in the study, as a mean to promote the transparency of the process by giving detailed information about researcher’s decisions (Willis, 2007; Smith et al., 2009).

In order to guarantee restrict access to the data (which includes audiotapes and transcriptions documents), the researcher will store it in a safe and secure place, which only the researcher can access.

Audiotapes will be preserved until the end of the PhD study and the written data will be preserved for a maximum of five years after the end of the study. The researcher will respect and guarantee the need for permission for subsequent use of the data (for publishing in scientific journals or conferences’ presentations) (Flick, 2006).

Analysis

The interviews will be transcribed verbatim to provide a text with which to engage in dialogue. It is important to note that text is not only the written transcript, but also the taped words, written comments about the interview situation and observations made by researcher in field notes. All of these aspects could influence understanding and therefore can be considered “text” (Fleming et al., 2003).

The researcher will carry out all the transcriptions. In this process, although the final interpretation is a responsibility of the researcher, it is important to previously consider feedback and subsequent dialogue with participants in order to reach a shared understanding of the phenomenon and a co-construction of meaning, between both the researcher and the participant (Crotty, 1998; Flemming et al., 2003; Willis et al., 2007). In this sense participants will be asked to review the transcriptions as well as the first themes identified through the researcher’s analysis. The researcher will send the transcription to each participant by registered mail and will established a phone contact to ask for their revision of the document and to present and check the themes, which have initially emerged.

In order to contextualise participants, their personal accounts will be presented as short vignettes. The use of vignettes will be useful in placing the participants in the discussion. In coherence with the methodological approach selected, this strategy will allow readers to situate participants as individuals in “parts” of the text and then relate them to the “whole”. The vignettes will outline the main information about their personal accounts and will include details about age, gender, living context, family, profession, current employment status and perceived total length of time with non-specific CLBP disorder (Smith et al., 2009).

Data analysis will be based on the six steps suggested by Smith et al (2009): the first is concerned with multiple readings of the transcript; the second includes the initial noting; the third aims to start the process of developing the emergent themes; the fourth involves searching for connections across emergent themes; in the fifth step the researcher moves to the next case and repeats the process from the beginning; and, finally, in the sixth step attention is

focused on looking for patterns across cases (Smith et al., 2009). The analysis of data collected will be concerned with the participants' experience of having non-specific CLBP disorder and the meaning they make of their condition. By using the analytic process of IPA, the final result will be an account of how researcher makes sense of participants making sense of their condition (Smith et al., 2009).

In order to maintain confidentiality, the following issues will be considered in both data analysis and dissemination: pseudonyms will be used to hide participants' identity and the use of data only for academic purposes will be guaranteed (Flick, 2006).

Potential outcomes/ Impact of the research

The knowledge produced by this study will contribute to a better understanding of Portuguese individuals' experiences of having non-specific CLBP disorder and will inform recommendations to help improve non-specific CLBP management in Portugal. In this sense, this study responds to the recommendations of the Portuguese Health Plan (called the National Health Plan for 2011/2016), which has highlighted not only the significant impact of non-specific CLBP disorder in Portuguese society but also the need to develop effective responses to this problem.

The study's findings do not intend to be applicable to all individuals with non-specific CLBP disorder. Rather, they will offer insights into the Portuguese individuals' experience of having non-specific CLBP disorder, which could help clinicians to transfer some of this knowledge to the approach to individuals with similar experiences.

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Appendix 1 | Letter of introduction to the clinical council of health centres

Dr. XXXX

Director of XXXXX

XXXXXXXXXXXX

XXXXXXXXXXXX

XXXXXXXXXXXX

Carmen Caeiro

PhD Student

University of Brighton

Clinical Research Centre for Health

Professions

Aldro Building

49 Darley Road

Eastbourne BN20 7UR

Telephone 01273 643647

Fax 01273 643944

<http://www.brighton.ac.uk/sohp/research/>

Dear Dr. XXX

Subject: Collaboration in a PhD study entitled “An exploration of how Portuguese individuals with non-specific chronic low back pain understand and make sense of their condition”.

My name is Carmen Caeiro and I am writing you to seek your collaboration in a research study concerning Portuguese individuals experiences of having non-specific chronic low back pain (CLBP) disorder. This study is part of a PhD programme of work registered in the University of Brighton in the United Kingdom, which has been approved by the Faculty of Health and Social Research Ethics and Governance Committee.

I am asking for your authorization to interview individuals with non-specific CLBP disorder referred to physiotherapy. Participants will be invited to participate in a one to one interview, concerning their individual experience of having non-specific CLBP disorder. The purpose of these interviews is to explore how they understand and make sense of their condition. The knowledge produced by this study will contribute to a better understanding of Portuguese individuals' experiences of having non-specific CLBP disorder and will inform recommendations to help improve non-specific CLBP management in Portugal.

I (the researcher) will carry out all interviews. I will ask participants a set of open questions about their experience of having non-specific CLBP disorder. It is anticipated that the interviews will last no longer than an hour and a half. The interviews will be audio recorded, however, the participants` identity will remain confidential. Special precautions have been established to protect the confidentiality of participants` responses. A fictional name will be used in any reference to them and in their interview transcript. The data obtained will be referred to by code and will therefore be anonymous. I will ask participants to review the transcription of the interview. All information about participants will be held in strict confidence. Audiotapes will be preserved until the end of the PhD study at which time they will be destroyed and the written data will be preserved for a maximum of five years after the end of the study.

Participants will be given an information sheet and a consent form in order to ensure that the researcher has accurately informed them of the nature of research and also to facilitate their choice to participate or not.

If you are interested in collaborating in this research, I am available to meet with the Clinical Council and discuss any details about the study. You can contact me on my mobile phone X or my work number X or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

Kindest regards,

Carmen Caeiro

Appendix 2 | Portuguese version of the letter of introduction to the Clinical Council of Health Centres

De: Carmen Caeiro
Estudante de Doutoramento
Universidade de Brighton. Reino Unido.
Centro de Investigação Clínica em
Profissões de Saúde
Aldro Building
49 Darley Road
Eastbourne BN20 7UR

Para: Ex.ma Senhora Directora
Agrupamento de Centros de
Saúde xxxx
Dr.^a XXXX

Tlf.: 01273 643647
Fax: Fax: 01273 643944
Sítio na <http://www.brighton.ac.uk/sohp/research/>
Internet

Tlf.: xxxxxxxx
Fax: xxxxxxxx

Assunto: Colaboração num trabalho de doutoramento intitulado “An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition”.

O meu nome é Carmen Caeiro e venho por este meio solicitar a colaboração de vossas excelências num estudo sobre a experiência dos indivíduos portugueses com dor crónica lombar (DCL) de natureza não-específica. Este estudo faz parte do meu programa de doutoramento a decorrer na Universidade de Brighton, no Reino Unido, e foi aprovado pela comissão de ética da referida universidade (Faculty of Health and Social Research Ethics and Governance Committee).

Neste sentido, venho solicitar a autorização de vossas excelências para entrevistar indivíduos com DCL de natureza não-específica, que sejam referenciados para a realização de fisioterapia. Os participantes serão convidados a participar numa entrevista individual, focada na sua experiência de DCL. O propósito desta entrevista é o de explorar a forma como este indivíduos compreendem e atribuem significado à sua condição clínica. O conhecimento resultante deste estudo irá contribuir para uma melhor

compreensão da experiência dos utentes com esta condição e, em última instância, irá contribuir para informar a abordagem a estes utentes, contribuindo para uma melhoria dos cuidados de saúde prestados em Portugal.

Todas as entrevistas serão conduzidas por mim, enquanto investigadora principal. Nestas entrevistas, serão colocadas questões abertas aos participantes sobre a sua experiência de DCL de natureza não-específica. Espera-se que cada entrevista tenha uma duração não superior a uma hora e meia. As entrevistas serão gravadas em formato áudio, contudo, a identidade dos participantes permanecerá confidencial. Neste âmbito, são asseguradas um conjunto de precauções com o intuito de garantir a confidencialidade das respostas dadas pelos participantes: será utilizado um nome fictício para cada participante na transcrição da respectiva entrevista; qualquer informação será divulgada de forma codificada assegurando o anonimato dos participantes. Será também solicitado aos participantes que revejam as transcrições das respectivas entrevistas. Todos os dados recolhidos serão mantidos em confidencialidade. As gravações áudio serão destruídas após a finalização do doutoramento e todas as transcrições serão preservadas por um período máximo de cinco anos.

Será fornecido a cada participante uma ficha informativa, com informação detalhada sobre o estudo, bem como um formulário para consentimento informado. Estes procedimentos visam garantir que o investigador informa adequadamente os participantes sobre a natureza do estudo e que todos os participantes tomam uma decisão informada relativamente à sua participação.

Ao dispor para qualquer esclarecimento ao conselho clínico relativo à possível colaboração com este trabalho de investigação.

Com os melhores cumprimentos,

Carmen Caeiro

Tlm.: X

Telf.: X

E-mail: carmen.caeiro@ess.ips.pt ; C.S.FradeCaeiro@brighton.ac.uk

Appendix 3 | Information for physiotherapists

University of Brighton, Clinical Research Centre for Health Professions

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Dear Physiotherapist

This document aims to summarize our previous meeting and includes two parts: part 1 gives you information about the purpose of the study, methods, expected outcomes, etc; and part 2 gives you information about participants and recruitment strategies as well as the collaboration you may have in this process.

Part 1 | The Study

This study aims to explore how Portuguese individuals with non-specific chronic low back (CLBP) disorder understand and make sense of their condition.

The study consists of data collection carried out using semi-structured one to one interviews. The interviews will be focused on individuals' accounts of their experiences of having non-specific CLBP disorder.

Individuals with non-specific CLBP disorder who have been referred to physiotherapy will be recruited according to a range of inclusion and exclusion criteria.

The expected outcome of the study will be a detailed account of the researcher interpretation of the participants' experiences of having non-specific CLBP disorder and may inform recommendations to help improve non-specific CLBP management in Portugal.

Part 2 | Participants and Recruitment Strategies

In this study, participants will be selected on the basis of their specific knowledge and unique experience. In this sense, individuals with non-specific CLBP disorder will be included in this study in order to develop insights and an in-depth understanding of how they understand and make sense of their condition.

A range of inclusion and exclusion criteria will be used in order to select participants.

Inclusion Criteria

Participants will:

- have experienced a non-specific CLBP disorder (which means to have low back pain that it is not related with a specific diagnosis, persisting for a period longer than 3 months), identified by the general practitioner;
- have had non-specific CLBP disorder for at least 1 year, that was not relieved by previous health care;
- be aged between 25 and 65 years;
- have intellectual capacity and psychological maturity to understand the nature of the research and his/her involvement, ability to make self-directed and self-determined choices;
- be able to communicate effectively in Portuguese;

Exclusion Criteria

- the presence of any chronic diseases;
- participants with any nationality other than Portuguese, due to the cultural basis of this study.

Your collaboration is sought for the recruitment process, in relation to the following:

- Identifying potential participants for this study (among patients referred to physiotherapy) according to the inclusion and exclusion criteria mentioned above;
- After identifying a potential participant, giving him/her one of the envelopes that were provided;

- When giving the envelope to potential participants the following information should be highlighted:
 - This is an invitation for those wishing to participate in a study concerning individuals experience of having non-specific chronic low back pain;
 - This study is completely independent from their prescribed treatment;
 - The envelope was given to you by the researcher and contains an invitation letter for participating in this study and an information sheet with more detailed information about the study, as well as a stamped addressed envelope. If individuals are interested in participating in this study they should fill in the form and send it back to the researcher in the stamped addressed envelope provided.

After this process, the researcher will contact participants who have returned envelopes by phone to answer any questions and determine if they are still interested in participating. The individuals who decide to participate will be invited for an interview in the health centre on a date and time that is convenient to them.

The researcher will meet them in the private room where the interviews will take place and will consider a previous period to answer any questions. A copy of the information sheet will be provided to participants who do not bring their copy with them. They will be given time to read it again and to raise any questions about the study they may have. Finally, the participants will be asked to give their informed consent and a signed copy of this will be given to them.

If you have any questions about this study or about your collaboration please do not hesitate to contact me on my mobile phone or work number, X or X or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk. If I am not available when you call, please leave a message and I will return your call.

Thank you very much for reading this document,
Carmen Caeiro

Appendix 4 | Portuguese version of the information for physiotherapists

University of Brighton (Reino Unido) | Clinical Research Centre for Health Professions

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Caro(a) Fisioterapeuta

Este documento foi escrito para si e pretende sumariar os conteúdos discutidos na reunião prévia com a investigadora, incluindo duas partes: a parte 1 apresenta informação sobre os objectivos do estudo, a metodologia e métodos utilizados, assim como os resultados esperados; a parte 2 contempla informação sobre os participantes e as estratégias para o seu recrutamento e ainda a colaboração que poderá ter neste processo.

Parte 1 | O estudo

Este estudo pretende explorar a forma como os indivíduos portugueses com dor crónica lombar (DCL) de natureza não-específica compreendem e atribuem significado à sua condição.

O estudo baseia-se na recolha de informação através da realização de entrevistas individuais e semi-estruturadas. As entrevistas centram-se na experiência dos participantes com a referida condição.

Serão recrutados para este estudo indivíduos com DCL de natureza não-específica, referidos para a fisioterapia em centros de saúde, de acordo com um conjunto de critérios de inclusão e exclusão previamente definidos.

O resultado esperado é a compreensão detalhada da experiência dos indivíduos com DCL de natureza não-específica. Este conhecimento irá contribuir para informar a abordagem dos profissionais de saúde a estes indivíduos, contribuindo para uma melhoria dos cuidados de saúde prestados em Portugal.

Parte 2 | Participantes e Estratégias de Recrutamento

Neste estudo, os participantes serão seleccionados com base no seu conhecimento específico e experiência única. Neste sentido, serão seleccionados indivíduos com DCL de natureza não-específica com o intuito de desenvolver um entendimento aprofundado sobre a forma como compreendem e atribuem significado à sua condição clínica.

Para a selecção dos participantes será utilizado um conjunto de critérios de inclusão e exclusão.

Critérios de Inclusão

- Ter experienciado DCL de natureza não-específica (o que significa ter dor lombar sem qualquer relação com um diagnóstico específico, que persista por um período superior a 3 meses), identificada por um médico;
- Ter experienciado DCL de natureza não-específica por um período mínimo de 1 ano, sem qualquer alívio decorrente de cuidados de saúde prestados;
- Ter entre 25 e 65 anos;
- Ter capacidade intelectual e psicológica para compreender a natureza do estudo, o seu possível envolvimento e capacidade de tomar decisões de forma autónoma;
- Ter capacidade para comunicar em português de forma efectiva;

Critérios de Exclusão

- Ter qualquer doença crónica associada;
- Ter outra nacionalidade que não a portuguesa.

A sua colaboração neste estudo, será solicitada nos seguintes aspectos:

- Identificar os potenciais participantes para este estudo, entre os utentes referidos para a fisioterapia, de acordo com os critérios de inclusão e exclusão previamente referidos;
- Depois de identificar os potenciais participantes, deve entregar-lhe um dos envelopes que lhe foram cedidos pela investigadora;
- No momento da entrega do envelope a cada participante deverá transmitir a seguinte informação:
 - Trata-se de um convite para participar num estudo sobre a experiência dos indivíduos com DCL;

- Este estudo é completamente independente do tratamento prestado no centro de saúde;
- O presente envelope foi-lhe entregue pela investigadora responsável por este estudo e inclui um convite para participar neste estudo, uma ficha informativa com informação detalhada sobre o estudo e um envelope selado. Os indivíduos interessados em participar deverão preencher o formulário e enviá-lo para a investigadora;

Depois desta etapa, os participantes serão contactados pela investigadora que poderá responder a qualquer questão sobre o estudo e aferir o interesse em participar. Os indivíduos interessados em participar serão convidados para uma entrevista que terá lugar no centro de saúde onde são acompanhados, numa data que lhes seja conveniente.

No centro de saúde, os indivíduos serão recebidos pela investigadora na sala onde irão decorrer as entrevistas, sendo considerado um período prévio para responder a eventuais questões. Uma cópia da ficha informativa será entregue aos participantes que não tenham trazido a ficha que lhes foi entregue no envelope. Será disponibilizado um período de tempo de forma a permitir que a ficha seja novamente lida e para responder a eventuais questões que sejam colocadas. Finalmente, será solicitada a assinatura do formulário de consentimento informado, ficando uma cópia com a investigadoras e outra com o(a) participante.

Se tiver qualquer questão sobre este estudo ou sobre a sua colaboração, por favor não hesite em contactar-me via telemóvel ou telefone ou através do e-mail, carmen.caeiro@ess.ips.pt ou C.S.FradeCaeiro@brighton.ac.uk.

Se no momento em que o fizer não conseguir contactar-me por favor deixe uma mensagem, para que possa contacta-lo(a) assim que me for possível.

Muito obrigada por ler este documento,
Carmen Caeiro

Appendix 5 | Invitation letter for participants

University of Brighton, Clinical Research Centre for Health Professions

Invitation Letter

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Dear Sir or Madam

My name is Carmen Caeiro and I am writing to you to invite you to participate in a research study concerning Portuguese individuals experience of having non-specific chronic low back pain disorder. This study is part of a PhD programme of work registered in the University of Brighton in the United Kingdom.

I am asking for your agreement to participate in a one to one interview, concerning your individual experience of having chronic low back pain disorder. The purpose of this interview is to explore how you understand and make sense of your condition.

It is anticipated that the interview will last no longer than an hour and a half. I will ask you a set of questions about your experience of having non-specific chronic low back pain disorder. This interview will be carried out at a time convenient for you, in a private room in the health centre where you are being treated. The interview will be audio recorded, however, your identity will remain confidential. Special precautions have been established to protect the confidentiality of your responses. A fictional name will be used in any reference to you and your interview transcript. The data obtained will be referred to by code and will therefore be anonymous. I will send you a written copy of your interview to ask you to review it for accuracy and I will call you to check you are happy with the accuracy of the transcriptions as well as the main themes that I will identify from your interview.

You are free to withdraw from the study at any time and without giving any reason. All information about you will be held in strict confidence. Audiotapes will be preserved until the end of the PhD study at which time they will be destroyed and the written data will be preserved for a maximum of five years after the end of the study.

Please find enclosed an information sheet, which gives you more detailed information about the study.

After reading the information sheet and if you wish to participate in this study, I would like to invite you to fill the form at the bottom of this page and send it back to me using the stamped addressed envelope attached. This will help me in contacting you with an interview date should you agree to participate.

If you have any questions about this study please do not hesitate to contact me on my mobile phone or work number, X or X, or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk. If I am not available when you call, please leave a message and I will call you back.

Thank you very much for reading this letter.

Carmen Caeiro

✂-----

I _____ (name)

accept to be contacted by the researcher on

_____ (mobile phone or telephone

number) to discuss the possibility of participating in this study.

This contact does not implicate any obligation in participating.

Appendix 6 | Portuguese version of the invitation letter for participants

Universidade de Brighton, Reino Unido

Centro de Investigação para as Profissões na Área da Saúde

Convite

Para participação num estudo sobre a experiência
dos indivíduos portugueses com dor crónica lombar

Exmo(a) Sr.(a)

O meu nome é Carmen Caeiro e escrevo-lhe para o(a) convidar a participar num estudo sobre a experiência dos indivíduos portugueses com dor crónica lombar. Este estudo faz parte do meu doutoramento, a decorrer na Universidade de Brighton, no Reino Unido.

Venho por este meio convidá-lo(a) a participar numa entrevista individual sobre a sua experiência de dor crónica lombar. O propósito desta entrevista é explorar a forma como compreende e atribui significado à sua condição.

É esperado que esta entrevista não tenha uma duração superior a uma hora e meia. Eu, enquanto investigadora principal, irei colocar-lhe algumas questões sobre a sua experiência de dor crónica lombar. Esta entrevista será conduzida num horário que lhe seja conveniente, numa sala reservada onde ninguém terá acesso no decorrer da entrevista, no centro de saúde onde está a ser acompanhado(a). A entrevista será gravada em formato áudio, contudo, a sua identidade permanecerá confidencial. Neste sentido, são asseguradas um conjunto de precauções com o intuito de garantir a confidencialidade das respostas dadas por si: será utilizado um nome fictício na transcrição da sua entrevista; qualquer informação será divulgada de forma codificada assegurando o seu anonimato. Irei também solicitar-lhe que reveja o texto referente à transcrição da sua entrevista e irei fazer um telefonema para o confirmar. Nesse telefonema irei também apresentar um sumário com os principais temas que identifiquei na sua entrevista e aferir a sua adequabilidade.

É livre de desistir do estudo, em qualquer momento, sem que tenha que apresentar qualquer razão para o fazer. Toda a informação que lhe diga respeito será mantida em confidencialidade. As gravações serão destruídas após a finalização do estudo e a informação escrita será preservada por um período máximo de cinco anos.

Em anexo, pode encontrar uma ficha informativa que lhe oferece informação mais detalhada sobre o estudo. Depois de ler esta ficha, e no caso de ponderar participar no estudo poderá preencher o formulário no final desta página e enviá-lo através do envelope selado também em anexo. Desta forma, poderei contactá-lo(a) mais tarde para conversarmos sobre a possibilidade de participar neste estudo.

Se tiver qualquer questão sobre este estudo, por favor não hesite em contactar-me via telemóvel ou telefone, X ou X, ou através do e-mail, carmen.caeiro@ess.ips.pt ou C.S.FradeCaeiro@brighton.ac.uk.

Se no momento em que o fizer não conseguir contactar-me por favor deixe uma mensagem, para que possa contactá-lo(a) assim que me for possível.

Muito obrigada por ler esta carta.

Os melhores cumprimentos,

Carmen Caeiro

✂-----

Eu _____ (nome)

aceito ser contactado(a) pela investigadora

_____ (telemóvel ou telefone fixo) para

conversar sobre a possibilidade de participar neste estudo.

Este contacto não implica qualquer obrigação da minha parte em participar no estudo.

Appendix 7 | Participant information sheet

University of Brighton, Clinical Research Centre for Health Professions

Participant Information Sheet

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

This document includes two parts: part 1 tells you the purpose of this study and what will happen to you if you take part; and, part 2 gives you more detailed information about the conduct of the study.

Ask me if there is anything that is not clear or if you would like any more information. Take time to decide whether or not you wish to take part.

Part 1 | Purpose of the study and what will happen to the participants

What is the purpose of the study?

The purpose of this study is to explore how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition.

Why have I been invited?

You have been invited because your doctor referred you to physiotherapy for your back problem and also because of your particular experience of having chronic low back pain. Your participation will inform the understanding of individuals' experiences of having chronic low back pain, which may help improve health care provided in Portugal to individuals with similar experiences.

Do I have to take part?

It is up to you to decide. I will describe the study to you and go through this information sheet with you in detail. You will have time to read it and to raise any questions. If you wish to take part I will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving any reason. If you choose to withdraw, this will not affect the standard of care you receive in any way.

What will happen to me if I take part?

You will come to the health centre where you are being treated, to participate in a one to one interview. In this interview I will ask you questions related to your experience of living with chronic low back pain (for example: *"Please tell me about your experience of living with chronic low back pain"*). The interview will take place outside of your normal treatment sessions and will be set up at a convenient time for you and for the researcher. It is anticipated that the interview will last no longer than an hour and a half. You will be interviewed only once, in a private room which no one else can access during the interview time. The interview will be audiotaped.

What will I have to do?

You will be asked questions about your experience of living with chronic low back pain. You have freedom to answer questions as you wish.

What are the possible disadvantages and risks of taking part?

The only disadvantage is that you will need to allocate approximately 1h30 of your time for the interview. Possible risks are concerned with the fact that because you will be invited to talk about your experience of having chronic low back pain this could include sensitive issues for you. If the interview becomes upsetting, I (as an interviewer) will stop the interview immediately as well as audio-recordings and give you the chance to recover and decide if you want to continue or not. If you continue to feel upset the interview will be stopped out and I will provide you the telephone contact number to access appropriate

support after the interview. The detailed information on this is given in Part 2 of this information sheet.

What are the possible benefits of taking part?

You will have the opportunity to be actively listened to by someone who is trying to understand your experience of living with chronic low back pain. The information I get from this study may help inform the management of patients suffering from chronic low back pain with similar experiences.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this information sheet.

Will my taking part in the study be kept confidential?

Yes, the study follow ethical and legal practices and all information about you will be handled in confidence. The details are included in Part 2 of this information sheet.

If the information in Part 1 has interested you and you are considering participating, please read the additional information in Part 2 before making any decision.

Part 2 | Conduct of the study

What will happen if I don't want to carry on with the study?

Your participation is totally voluntary and you are free to withdraw from the study at any time without giving reason. If you withdraw from the study, the audiotape and transcriptions will be destroyed. Therefore, no information about yourself will be used in the study. This will not affect the standard of care you receive.

What if there is a problem?

If you have any concerns about any aspect of this study, ask to speak with me (the researcher) and I will do my best to answer all your questions. You can contact me by mobile phone, work number or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

If you want any additional information from the University or wish to complain formally you can contact a senior research administrator Mrs Marilia Vasquet-Whittome, by telephone or by e-mail (M.Vasquet-Whittome@brighton.ac.uk). The research administrator speaks fluent Portuguese and will facilitate your contact with an independent senior academic in The School of Health Professions at the University of Brighton.

What if the interview becomes upsetting?

You can contact “SOS Voz Amiga” (SOS Friendly Voice) on 213544545, 912802669 or 963524660. This is a Portuguese centre that gives psychological support. After your first call for identification, the centre will return your call.

Will my taking part in this study be kept confidential?

All information about your identity will be held in strict confidence. The data obtained will be referred to by code and will therefore be anonymous. A fictional name will be used to hide your identity.

What will happen to any information I give?

The information you give will be audio recorded and then analyzed. I (the researcher) will store the audio recordings safely, to avoid any possible access by a second party. The recordings will be preserved until the end of the PhD study and the written data will be preserved for a maximum of five years, after the end of the study.

What will happen to the results of the research study?

The results will be used exclusively for academic purposes and may be published in scientific journals. In both situations, verbatim quotations for the transcriptions will be used without mentioning your identity in any circumstance. In both situations a fictional name will always be used.

Who has reviewed the study?

This study has been reviewed and given favorable opinion by the Faculty of Health and Social Research Ethics and Governance Committee of the University of Brighton. There have been not identified Ethics Committees in Portugal that have been relevant for this study.

Contact details

Researcher: Carmen Caeiro

Mobile Phone: X

Work Number: X

E-mail: carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

University | Senior Research Administrator: Mrs Marilia Vasquet-Whittome

Telephone: X

E-mail: M.Vasquet-Whittome@brighton.ac.uk

SOS Voz Amiga (SOS Friendly Voice)

Mobile Phone: 91 280 26 69 or 963524660

Telephone: 21 354 45 45

Website: <http://www.sosvozamiga.org/>

Thank you very much reading this document,
Carmen Caeiro

Universidade de Brighton, Reino Unido

Centro de Investigação para as Profissões na Área da Saúde

Ficha Informativa para Participantes

Estudo sobre a forma como os indivíduos portugueses com dor crónica lombar compreendem e atribuem significado à sua condição clínica

Gostaria de convidá-lo(a) a participar neste estudo. Antes de tomar qualquer decisão, é importante que compreenda as razões pelas quais esta investigação está a ser conduzida e o nível de envolvimento que lhe é pedido. Por favor, utilize o tempo que necessitar para ler a informação que se segue. Poderá falar com outras pessoas sobre este estudo, se o desejar.

Este documento inclui duas partes: a parte 1 apresenta-lhe informação sobre o propósito deste estudo e o nível de envolvimento que lhe será pedido; a parte 2 oferece-lhe informação mais detalhada sobre a forma como o estudo será conduzido.

Se algum aspecto não for claro ou se desejar mais informação por favor não hesite em colocar-me as suas questões. Utilize o tempo que necessitar para decidir se deseja ou não participar neste estudo.

Parte 1 | O propósito do estudo e o nível de envolvimento que lhe é pedido

Qual é o propósito deste estudo?

O propósito deste estudo é explorar a forma como os indivíduos portugueses com dor crónica lombar compreendem e atribuem significado à sua condição clínica.

Por que fui convidado(a)?

Depois de referido para a fisioterapia, pelo seu(sua) médico(a) de família, foi convidado(a) para participar neste estudo pela sua experiência de dor crónica

lombar. A sua participação irá contribuir para uma melhor compreensão sobre a experiência dos indivíduos com dor crónica lombar e poderá contribuir para melhorar os cuidados de saúde prestados.

Tenho mesmo que participar?

A decisão é sua. Eu irei descrever-lhe o estudo ao longo desta ficha informativa. Terá o tempo que necessitar para a ler e colocar questões. Se decidir participar irei convidá-lo(a) a assinar um consentimento informado, que confirma a sua livre vontade em participar. É livre de desistir do estudo a qualquer momento, sem que tenha que o justificar. Esta decisão não terá qualquer impacto no seu tratamento.

O que acontece, se aceitar participar?

Será convidado para uma entrevista individual, no centro de saúde onde está a ser acompanhado(a). Nesta entrevista, irei colocar-lhe algumas questões sobre a sua experiência de dor crónica lombar (por exemplo: *“Fale-me sobre a sua experiência de dor crónica lombar”*). Esta entrevista sera planeada à parte do seu tratamento e sera marcada num período do dia que lhe seja conveniente. Estima-se que a entrevista tenha uma duração não superior a uma hora e meia. Será entrevistado(a) uma única vez, numa sala do centro de saúde reservada para este efeito, e onde outras pessoas não poderão aceder durante este período.

O que terei que fazer?

Terá que responder a questões sobre a sua experiência de dor crónica lombar. Terá liberdade de responder conforme preferir.

Quais são as possíveis desvantagens ou riscos se aceitar participar?

A única desvantagem é que terá de despende de cerca de 1h30 do seu tempo. Os possíveis riscos estão relacionados com o facto poder algum momento da entrevista sentir a necessidade de falar sobre aspectos mais sensíveis da sua experiência. Se, por alguma razão, a entrevista se tornar desagradável, a entrevista sera imediatamente interrompida e o gravador desligado. Ser-lhe-á

dado o tempo que necessitar para se recompor e decidir se deseja continuar a entrevista. Se necessitar, também poderão ser fornecidos contactos telefónicos através dos quais poderá aceder a apoio apropriado depois da entrevista. Na parte 2 deste documento, poderá encontrar mais informação sobre este aspecto.

Quais são as possíveis vantagens em participar?

Terá a oportunidade de ser ouvido por alguém que está realmente interessado em compreender a experiência dos indivíduos Portugueses com dor crónica lombar. A informação obtida a partir deste estudo poderá contribuir para melhorar os cuidados de saúde prestados em Portugal a indivíduos com este problema.

E se houver algum problema?

Qualquer queixa que tenha sobre este estudo, sobre a forma como foi abordado(a) ou qualquer dano associado serão considerados. Na parte 2 deste documento, poderá encontrar mais informação sobre este aspecto.

A minha participação neste estudo será confidencial?

Sim. Eu irei seguir um conjunto de princípios éticos e legais de forma a assegurar que a sua participação será mantida em confidencialidade. Na parte 2 deste documento poderá encontrar mais informação sobre este aspecto.

Se a informação disponibilizada na parte 1 lhe despertou interesse em participar, por favor leia a informação adicional apresentada na parte 2 antes de tomar qualquer decisão.

Parte 2 | A forma como estudo será conduzido

O que acontece se eu não aceitar participar no estudo?

A sua participação é totalmente voluntária e é livre de desistir do estudo a qualquer momento, sem que tenha que o justificar. Se desistir do estudo, eu destruirei a gravação e as transcrições. Nessa situação, qualquer informação que lhe diga respeito não será utilizada no estudo. Esta decisão não terá

qualquer impacto no tratamento que lhe está a ser prestado no centro de saúde.

E se houver algum problema?

Se tiver alguma queixa sobre qualquer aspecto deste estudo, deverá falar comigo (a investigadora). Nessa situação, farei o meu melhor para responder às suas questões. Poderá contactar-me no meu telemóvel, ou no telefone, ou ainda através do e-mail, carmen.caeiro@ess.ips.pt ou C.S.FradeCaeiro@brighton.ac.uk.

Se pretende informação adicional da Universidade que suporta esta investigação, ou se desejar fazer uma reclamação poderá contactar uma administrativa da Universidade, a Sra. Marília Vasquet-Whittome, através do telefone ou através do e-mail (M.Vasquet-Whittome@brighton.ac.uk). A pessoa indicada fala português fluentemente, pelo que poderá facilitar o seu contacto com um investigador da Universidade de Brighton.

E se a entrevista se tornar desagradável ou triste para mim?

Poderá contactar o centro “SOS Voz Amiga”, através do telefone 213544545, ou do telemóvel 912802669 ou 963524660. Trata-se de um centro português que oferece apoio psicológico gratuito, via telefone. A primeira chamada é paga e serve apenas para identificação. Imediatamente a seguir o centro devolve-lhe a chamada.

A minha participação neste estudo será confidencial?

Toda a informação relacionada com a sua identidade será mantida em estrita confidencialidade. Toda a informação será mencionada de forma codificada e será anónima. Será utilizado um nome fictício para esconder a sua verdadeira identidade.

O que irá acontecer às informações que eu der sobre mim?

A informação que transmitir durante a entrevista será gravada em formato áudio com o intuito de ser analisada posteriormente. Eu (a investigadora) encarregar-me-ei de guardar todas as gravações num lugar seguro de forma a

impedir o seu acesso por outras pessoas. As gravações serão mantidas até ao final do estudo, a informação escrita será preservada por um período máximo de cinco anos após o término do estudo.

O que irá acontecer com os resultados deste estudo?

Os resultados serão utilizados exclusivamente para fins académicos e poderão ser publicados em revistas científicas na área da saúde. Em qualquer uma das situações, serão utilizadas transcrições do discurso dos participantes, sem que seja mencionada a sua verdadeira identidade em qualquer circunstância. Em qualquer uma das situações será utilizado um nome fictício.

Quem avaliou a adequabilidade deste estudo?

Este estudo foi avaliado positivamente pela comissão de ética da universidade de Brighton, no Reino Unido. Recorreu-se a uma comissão estrangeira pelo facto de não ter sido identificada nenhuma comissão portuguesa para este efeito

Contactos

Investigadora: Carmen Caeiro

Telemóvel: X

Telefone: X

E-mail: carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

Universidade de Brighton | Administrativa: Marilia Vasquet-Whittome

Telefone: X

E-mail: M.Vasquet-Whittome@brighton.ac.uk

SOS Voz Amiga

Telemóvel: 91 280 26 69 or 963524660

Telefone: 21 354 45 45

Sítio na internet: <http://www.sosvozamiga.org/>

Muito obrigada por ler este documento,

Carmen Caeiro

Appendix 9 | Participant consent form

UNIVERSITY OF BRIGHTON

Participant Consent Form

An Exploration of how Portuguese Individuals with non-specific chronic low back pain disorder understand and make sense of their condition

- ◆ I agree to take part in this research which is looking at the Portuguese individuals experience of having non-specific chronic low back pain disorder.
- ◆ The researcher has explained to my satisfaction the purpose of the study and the possible risks involved.
- ◆ I have had the procedure explained to me and I have also read the information sheet. I understand the procedures fully.
- ◆ I am aware that I will be required to answer questions about my experience of having non-specific chronic low back pain disorder and my answers will be taped.
- ◆ I understand that any confidential information will normally be seen only by the researchers and will not be revealed to anyone else.
- ◆ I understand that I am free to withdraw from the investigation at any time.

Name (please print).....

Signed

Date

Appendix 10 | Portuguese version of participant consent form

UNIVERSIDADE DE BRIGHTON, Reino Unido

Consentimento Informado

Estudo sobre a forma como os indivíduos portugueses com dor crónica lombar compreendem e atribuem significado à sua condição clínica.

- ◆ Eu aceito participar neste estudo que procura explorar as experiências dos indivíduos portugueses com dor crónica lombar.
- ◆ A investigadora explicou-me de forma satisfatória o propósito deste estudo e os possíveis riscos envolvidos.
- ◆ Foram-me explicados todos os procedimentos e li cuidadosamente a ficha informativa que me foi entregue juntamente com o convite para participar neste estudo. Compreendo todos os procedimentos.
- ◆ Sei que me serão colocadas questões sobre a minha experiência de dor crónica lombar e que as minhas respostas serão gravadas em formato áudio e posteriormente transcritas.
- ◆ Compreendi que qualquer informação confidencial que me diga respeito será apenas manuseada pela investigadora e não será revelada a ninguém.
- ◆ Compreendi que sou livre de desistir do estudo, a qualquer momento.

Nome (maiúsculas)

Assinatura.....

Data

Appendix 11 | Interview Schedule

University of Brighton, Clinical Research Centre for Health Professions

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Interview Schedule

Introductory key messages

Thank you very much for accepting my invitation. Your participation will be very important in the development of this study.

As I have already told you, I am very interested in your experience of having chronic low back pain. There are no right or wrong questions. It is all about your ideas, thoughts and feelings about your experience.

Because I am very interested in your experience, I will try to say very little in order to allow you to speak freely. But sometimes I may ask you some questions. Please, take your time in thinking and talking.

Do you have any questions before we start the interview?

Key Questions

- Please tell me about your experience of living with chronic low back pain?
Do you have any experience in particular, which was more important for you?
Can you describe a typical day when you have pain?
How has this pain influenced your life?

Probing Questions

You have talked about... why do you think it is important?

You have mentioned... what are/were your thoughts about this?

Can you describe... in more detail?

Can you give me an example of that?

Is there anything important we haven't talk about?

Appendix 12 | Risk Assessment

Risk Assessment

Please tick the appropriate boxes.

Will the research study involve:

1. Causing participants physical damage, harm or more than minimal pain? Yes No
2. Manual handling of participants, vigorous physical exercise, or physical activity from which there is a likelihood of accidents occurring? Yes No
3. Intrusive physiological or psychological interventions or procedures? These might include: the administration of drugs or other substances; taking samples (eg blood, saliva or urine) from participants; use of probes or other equipment to measure or monitor bodily performance; techniques such as hypnotherapy. Yes No
4. Exposure of participants to hazardous or toxic materials, such as radioactive materials? Yes No
5. Inducing psychological stress, anxiety or humiliation? Yes No
6. Questioning of participants regarding sensitive topics, such as beliefs, painful reflections or traumas, experience of violence or abuse, illness, sexual behaviour, illegal or political behaviour, or their gender or ethnic status? Yes No
7. Vulnerable groups of people, for example children, people with learning disabilities or mental health problems? Yes No
8. Groups where permission of a gatekeeper is normally required for access to its members, for example ethnic groups? Yes No
9. Access to records of personal or confidential information? Yes No
10. Any other risk not identified above Yes No

Sufficient safeguards and monitoring procedures must be put in place in relation to any anticipated risks. If you answer “yes” to any of the above questions, you should describe the safeguards and monitoring procedures in place on a separate sheet of paper and attach it to this application form.

Please describe:

Issues surrounding the experience of having non-specific chronic low back pain may cause distress to participants because it is an opportunity for them to talk and reflect about their personal experiences. In order to avoid any psychological or emotional, the interview schedule will be carefully designed. The schedule includes mainly open questions, which gives participants the freedom to answer, as they prefer. If the interview becomes upsetting for any participants, he or she will be provided with the contact of “SOS Voz Amiga” (SOS Friendly Voice) to access to appropriate support after the interview. The “SOS Voz Amiga” is a Portuguese centre that gives free psychological support, by telephone.

“SOS VOZ AMIGA” (SOS Friendly Voice) telephone contacts:
(00351) 21 354 45 45 | 91 280 26 69 | 96 352 46 60

“SOS VOZ AMIGA” (SOS Friendly Voice) website:
<http://www.sosvozamiga.org/>

Appendix 13 | Governance Checklist

Governance Checklist

You are requested to answer the following questions to ensure that you will conduct the study within the Research Governance Framework of the University of Brighton and to fulfil your responsibility as the principal investigator or the supervisor.

1. I believe that the proposal is scientifically sound and ethical, and I am submitting the work to FREGC for independent expert scientific and ethical review. I agree that the study does not start without the approval of the FREGC and, if applicable, the NHS REC/LA. Yes No
2. I agree that the study will be conducted according to the proposal approved by FREGC, and that the study will comply with all the legal and ethical requirements. I shall ensure that the study will be carried out to the standards described in the Research Governance Framework of the University of Brighton, and if applicable, the Department of Health and any funding body. Yes No
3. I shall report any major changes in research methods or serious adverse events to the FREGC (and if applicable, NHS REC and any funding bodies) during the conduct of the study. Yes No
4. I have prepared and submitted the appropriate participant information sheet and consent form to FREGC. I shall ensure that the research team will give priority at all times to the dignity, rights, safety and well-being of participants. Yes No
5. I shall lead and manage the research work and submit annual progress and completion reports to the FREGC. Yes No
6. I shall ensure that the experience and expertise of all researchers are sufficient to discharge their role in the study. In the case of student project, I shall ensure that students have adequate supervision, support and training. Yes No
7. I confirm that procedures and arrangements are in place for the management of financial and all other resources required for the study, including the management of any intellectual property arising. Yes No
8. I shall ensure that, where relevant and appropriate, service users and consumers are involved in the research process. Yes No
N/A
9. I confirm that there are appropriate procedures for the collection, handling and storage of data. (The university guidelines on data protection are provided in Appendix 1 of this application pack.) Yes No
11. I shall ensure that findings of the research will be open to critical review through the accepted scientific and professional channels Yes No

and, where appropriate, they will be disseminated promptly and appropriately.

12. As the principal investigator or the supervisor, I accept a key role in detecting and preventing scientific misconduct. Yes No
13. For applications requiring NHS sponsorship, I confirm that agreement with the relevant Trust has been reached about the provision of compensation in the event of non-negligent harm. I have read the information about the university's indemnity cover (Appendix 3) which is normally sufficient for low-risk research projects. If this is not sufficient, I shall seek advice from the University's Insurance Officers and appropriate arrangement will be made. Yes No
N/A

Appendix 14 | Faculty of Health and Social Science Research Ethics & Governance Front Sheet

Faculty of Health and Social Science Research Ethics & Governance Front Sheet

Note: You should allow at least 3 weeks for FREGC to review your proposal and be aware that you may be required to revise your proposal and resubmit for further review.

This form must be completed by the Principal Investigator/Supervisor as indicated below. No signature is required but the form must be submitted from the mailbox of the Principal Investigator/Supervisor. Submission from one's mailbox constitutes the signature, and the application is considered with the understanding that all researchers agree to all the information provided and believe that it is accurate to the best of their knowledge. The FREGC does not accept application directly from students and it is expected that all students' work will be reviewed by the supervisor before submission.

FREGC No:

(For official use only)

Section A

General Information

Title of project: An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition.

Is the project a PhD/ProfD/MPhil study BSc/MSc study Staff research
(Check as appropriate)

Name of Principal Investigator / Supervisor: Carmen Caeiro

(This will be the contact person for all correspondence with FREGC. Please indicate if you are the principal investigator or the supervisor of a student project by crossing out the inappropriate description.)

School/Division: School of Health Professions. Clinical Research Centre for Health Professions

Contact details: Email: carmen.caeiro@ess.ips.pt
C.S.FradeCaeiro@brighton.ac.uk

Telephone: x

Name of Student(s) (for student project only): Carmen Caeiro

Names of All Other Researchers: Professor Ann Moore and Dr. Lee Price (Supervisory Team)

Does the project require IRAS/LA application?

Yes No

Does the project require the sponsorship of the University of Brighton?

Yes

No

How will this project be funded? List all sources of funds (e.g. research grants, commercial sponsorship, school funds etc).

This project is sponsored by the Advance Training Programme, called PROTEC (programme to support the advance training of teachers of Polytechnic).

Has the project been subject to scientific or peer review (e.g. scientific review conducted by research councils or other funding agencies etc)?

Yes

No

If Yes, give details

The first outline of this project was submitted for scientific approval to The Foundation of Science and Technology – Ministry of Science, Technology and Higher Education in Portugal (Fundação para a Ciência e Tecnologia – Ministério da Ciência, Tecnologia e Ensino Superior).

It had a classification of 4.55 in 5. The project was assessed on the following criteria: merit of candidate (4,5 in 5), merit of proposal (5 in 5) and merit of University (4 in 5).

In consequence of this submission, it has been given the sponsorship mentioned above.

Do any researchers have any financial interests in this research or its outcomes, or any relevant affiliations?

Yes

No

If Yes, give details

If you answer “Yes” to the above question, have you included an appropriate comment on the Participant Information and Consent Form? Yes No

Proposed timescale of study

Start Date: 1st August 2011

Completion date: 1st February 2013

Appendix 2: Ethical approval from FREGC

FREGC FREGC-11-029

Faculty of Health and Social Science Research
Ethics and Governance Committee

An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Journal:	<i>Faculty of Health and Social Science Research Ethics and Governance Committee</i>
Manuscript ID:	FREGC-11-029
Manuscript Type:	Ethics Application
Date Submitted by the Author:	03-Jun-2011
Complete List of Authors:	Caeiro, Carmen; University of Brighton, Clinical Research Centre for Health Professions Moore, Ann; University of Brighton, Health Professions Price, Lee; University of Brighton
Keywords:	chronic low back pain, individuals experiences, interpretative phenomenological analysis , qualitative research

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Manuscripts

<http://mc.manuscriptcentral.com/fr egc>

From: J.Scholes@brighton.ac.uk
Subject: **Faculty of Health and Social Science Research Ethics and Governance Committee - Decision on Manuscript ID FREGC-11-029.R1**
Date: 14 de julho de 2011 16:04:32 GMT+01:00
To: carmen.caeiro@ess.ips.pt

14-Jul-2011

Dear Miss Caeiro:

It is a pleasure to approve your application entitled "An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition". The comments of the reviewer(s) who reviewed your manuscript are included at the foot of this letter.

Please report any change of design or adverse incidents to the Committee immediately.

Sincerely,
Prof. Julie Scholes
Editor-in-Chief, Faculty of Health and Social Science Research Ethics and Governance Committee
J.Scholes@brighton.ac.uk

reviewer one - no additional comments

Reviewer(s)' Comments to Author:

Reviewer: 2

Comments to the Applicant

Participant information and consent procedures (in English): your response if they get upset is now fine. Your 2nd last sentence (within the summary of changes to the proposal, page 2) contains two typographical errors 'stopped out' and 'you the telephone contact'. Please ensure this does not occur in final version to participants.

Pilot interviews: I'd be tempted to 'pilot' the interview with friends and then just go for it and learn on the way. I agree with you to use the data from your 'pilot' interview.

I'd suggest that you tell the participant that anonymised quotes may be used in publications so that you seek their consent initially and don't have to go back to them afterwards.

I'm not sure your participants will know what 'actively listened to' means. Suggest replace with 'You will have the opportunity to talk about your experience of living with chronic low back pain'.

Appendix 3: Approval from the Local Health Unit of Baixo Alentejo (pilot study)

EDOC - Distribuição EDOC/2011/63402 Page 1 of 2

Alexandra Abreu - ULSBA
Pendentes: 290

Tarefas | Registo | Distribuição | Processo | Global

Distribuição EDOC/2011/63402 (Pendente - REUNIÃO CA) Executar:

Dados gerais | Outros Dados | Documentos | Relatórios

Assunto: Investigação em DCL
 Observações: Pedido de autorização para realização de estudo de investigação em utentes com Dor crónica lombar
 Prazo de execução: Sem prazo

Processos:

Código	Assunto	Data Início	Estado	Classificação
Reuniões CA/2011/34	06.09.2011	06-09-2011		Reuniões CA

Etapas: Página 1/1 (Total de 9 Etapas) Listar: 50

Ordem	Ind.	Interveniente	Leitura	Envio	Estado	Suspende	Prazo	Percurso
1		Filipa Santos - ULSBA	29-08-2011 11:44	29-08-2011 11:51				
2		Horácio Feltreiro - ULSBA	29-08-2011 17:19	31-08-2011 15:48				
3		Filipa Santos - ULSBA	01-09-2011 17:06	02-09-2011 15:26				
4		Administração - Secretariado (Alexandra Abreu - ULSBA)	02-09-2011 16:01	02-09-2011 16:02				
5		José Mestre - ULSBA	02-09-2011 17:26	02-09-2011 17:27				
6		Administração - Secretariado (Vitória Rodrigues - ULSBA)	02-09-2011 17:30	02-09-2011 17:31				
7		Alexandra Abreu - ULSBA	02-09-2011 17:34	09-09-2011 14:41				
8		Aniceta Cavaco - ULSBA	27-09-2011 15:54	27-09-2011 16:12				
<9>		Alexandra Abreu - ULSBA	27-09-2011 16:15	---				

Mover: 1

Terminar | Devolver | Suspender

Etapa: 9 - Concluir distribuição
 Prazo de execução: Sem prazo

Etapa anterior:

Parecer/Informação de Aniceta Cavaco - ULSBA na etapa 8:
 Aprovado do ponto de vista ético, uma vez que prevê a participação voluntária com assinatura de consentimento informado e garantia de anonimato dos doentes entrevistados, com utilização dos dados apenas para a finalidade descrita e sua destruição posterior.

Parecer/Informação:

AUTORIZADO

Acta N.º 37

04.10.2011

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O Conselho da Administração da Unidade Local de Saúde do B. A., EPE

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Vogal Executivo

José António Soares
Director Clínico

José António Pereira
Enfermeiro Director

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Appendix 4: Pilot study of recruitment and interview schedule

The **aims** of the pilot study were as follows:

1. To pilot the procedures involved in the participants` recruitment, namely the pragmatics with the physiotherapists collaborating in the study and potential participants, as well as the adequacy of the inclusion and exclusion criteria;
2. To pilot the interview schedule in order to ensure the smooth running of subsequent interviews.

The **procedures** that were carried out in order to achieve the aforementioned aims were as follows:

- Gathering information about epidemiological data regarding chronic pain in Portugal and considering the pragmatics of travelling to the selected health centre (130 Km away from where the researcher was based);
- Contacting key people in the institution and sending a letter of introduction to the head of the Unit (appendices 5 and 6);
- Contacting the physiotherapist who was indicated to collaborate in the study, after receiving permission from the head of Unit (appendix 3);
- Meeting the physiotherapist to provide information about the study, with particular emphasis on details about the inclusion and exclusion criteria as well as the procedures to be carried out by both the physiotherapist and the researcher (appendices 9 and 10). Asking the physiotherapist to identify potential participants for the study and then giving each of them the envelope containing the letter of invitation (appendices 11 and 12), the information sheet (appendices 13 and 14) and the stamped addressed envelope for those who would be interested in participating;
- Booking the interviews, after receiving three envelopes from individuals who were interested in participating;
- Taking the informed consent that confirms the participants consent to everything described in the information sheet, immediately before the interviews (appendices 15 and 16);

- Carrying out three pilot interviews with participants who were recruited according to the inclusion and exclusion criteria initially defined. All interviews took place in a private room in the health centre;
- Audio-recording, transcribing verbatim and translating the three interviews in order to facilitate the analysis and reflections about the interview schedule;
- Carrying out a preliminary analysis of the interviews, which enabled the assessment of the interview schedule;
- Discussing the translated versions of the interviews and the analysis with the supervisory team.

The **outcomes** of the pilot study were as follows:

- Several adjustments were made to the inclusion and exclusion criteria (detailed information in table 1., in the following page);
- No changes were made regarding the overall procedures;
- No changes were made in the interview schedule.

The main **conclusions** of the pilot study were as follows:

- These pilot interviews were important not only to: test the interview schedule, since it enabled the researcher to evaluate the appropriateness of the questions, but also to assess the accuracy of the recruitment process.
- As a consequence of the pilot study, the interview schedule remained the same, however part of the recruitment process concerning the inclusion and exclusion criteria was adjusted, as previously described.

Inclusion criteria used in pilot study	Problems identified	Changes in the inclusion criteria as a consequence of the pilot study
To have experienced a non-specific CLBP disorder (which means to have low back pain that it is not related to a specific diagnosis, persisting for a period longer than 3 months), identified by the general practitioner.	<p>One of the participants recruited had chronic neck pain and no relevant complaints in the lower back.</p> <p>In order to avoid future problems, the use of a more specific definition was considered important.</p> <p>The definition selected also provided some examples, which was considered useful.</p>	To have experienced “ <i>non-specific chronic low back pain, i.e. low back pain that is not attributable to a recognizable, known specific pathology (e.g. infection, tumour, osteoporosis, fracture, structural deformity, inflammatory disorder (e.g. ankylosing spondylitis), radicular syndrome or cauda equina syndrome</i> ” (Airaksinen et al. 2006, National Collaborating Centre for Primary Care 2009, Savigny et al. 2009)
To have had non-specific CLBP disorder for at least 1 year, that was not relieved by previous health care.	No problems were identified. The phrase “1 year” was replaced by “12-month period”, as it was considered more familiar to physiotherapists.	To have had non-specific CLBP disorder for at least 12-month period, and which was not relieved by previous health care;
To be aged between 25 and 65 years.	<p>This range of ages was considered too large, as it could include participants in very different stages of life.</p> <p>The new range of ages was defined according to the epidemiological research carried out in Portugal and other European countries (for instance, Rabiais et al. 2004, Breivik et al. 2006, Azevedo et al. 2012)</p>	To be aged between 40 and 60 years (Rabiais et al. 2004, Breivik et al. 2006).
To have intellectual capacity and psychological maturity to understand the nature of the research and his/her involvement and ability to make self-directed and self-determined choices.	No problems were identified.	No changes.
To be able to communicate effectively in Portuguese.	No problems were identified.	No changes.
Exclusion criteria used in pilot study	Problems identified	Changes in the exclusion criteria as a consequence of the pilot study
The presence of any chronic diseases;	One of the participants recruited had bipolar disorder. Although this was a problem, it did not occur because of the recruitment process as this participant decided to omit this when asked by the physiotherapist. This information was revealed to the researcher at the end of the interview.	No changes.
Participants with any nationality other than Portuguese, due to the cultural basis of this study.	No problems were identified	No changes.
	This criterion was added after the pilot study because one of the participants recruited by the physiotherapist had recently had back surgery.	Spine surgery in the last two years.

Table 1. Inclusion and exclusion criteria

257 **Susan:** Yeah. Why?! Sometimes I say: "But why? Why me? "

258 **Researcher:** Have you asked yourself about this?

259 **Susan:** That's right! What have I done wrong? Why me? Like many people who also ask "Why
 260 me?" But we should never ask this (Why me?) because there are so many people... Only those
 261 who don't watch TV and don't go to a hospital... they don't realise this. Sometimes I... Before
 262 I've asked myself more "Why me?". Today, I have pain here, tomorrow I have pain there. So,
 263 I've asked "But what's this?" This is like "cesões" [traditional expression meaning spasm].
 264 Every single day I have pain and the "cesões" is day in, day out. I have [pain] every single day,
 265 one day is here... The next day I have pain in another part of my body. But what's this? What is
 266 my problem? I don't know, I can't explain what's this. Sometimes I'm even ashamed of saying
 267 that I've pain because people... I think people don't believe me, they think I'm just
 268 complaining... "Today she complains about pain in her back, tomorrow in her leg" But it's true! I
 269 haven't an explanation for this pain. I have not, I do not know! I do not know what I can do with
 270 my life. It is... It is pain... I have pain every single day, and I lie down with pain and I get up with
 271 pain and life like this is very complicated, very complicated really... And because of my age, I'm
 272 just forty six years... I think it is even more complicated... because I was an active person... I

Figure 1. Excerpt from the transcription of one pilot interview

(Translated from Portuguese to English)

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Appendix 5: Letter of introduction to the health services

Dr. XXXX

Director of XXXXX

XXXXXXXXXXXX

XXXXXXXXXXXX

XXXXXXXXXXXX

Carmen Caeiro

PhD Student

University of Brighton

Clinical Research Centre for Health

Professions

Aldro Building

49 Darley Road

Eastbourne BN20 7UR

Telephone 01273 643647

Fax 01273 643944

<http://www.brighton.ac.uk/sohp/research/>

X June 2011

Dear Dr. XXX

Subject: Collaboration in a PhD study entitled “An exploration of how Portuguese individuals with non-specific chronic low back pain understand and make sense of their condition”.

My name is Carmen Caeiro and I am writing you to seek your collaboration in a research study concerning Portuguese individuals experiences of having non-specific chronic low back pain (CLBP) disorder. This study is part of a PhD programme of work registered in the University of Brighton in the United Kingdom, which has been approved by the Faculty of Health and Social Research Ethics and Governance Committee.

I am asking for your authorization to interview individuals with non-specific CLBP disorder referred to physiotherapy. Participants will be invited to participate in a one to one interview, concerning their individual experience of having non-specific CLBP disorder. The purpose of these interviews is to explore how they understand and make sense of their condition. The knowledge

produced by this study will contribute to a better understanding of Portuguese individuals' experiences of having non-specific CLBP disorder and will inform recommendations to help improve non-specific CLBP management in Portugal.

I (the researcher) will carry out all interviews. I will ask participants a set of open questions about their experience of having non-specific CLBP disorder. It is anticipated that the interviews will last no longer than an hour and a half. The interviews will be audio recorded, however, the participants' identity will remain confidential. Special precautions have been established to protect the confidentiality of participants' responses. A fictional name will be used in any reference to them and in their interview transcript. The data obtained will be referred to by code and will therefore be anonymous. I will ask participants to review the transcription of the interview. All information about participants will be held in strict confidence. Audiotapes will be preserved until the end of the PhD study at which time they will be destroyed and the written data will be preserved for a maximum of five years after the end of the study.

Participants will be given an information sheet and a consent form in order to ensure that the researcher has accurately informed them of the nature of research and also to facilitate their choice to participate or not.

If you are interested in collaborating in this research, I am available to meet with the Clinical Council and discuss any details about the study. You can contact me on my mobile phone X or my work number X or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

Kindest regards,

Carmen Caeiro

Appendix 6: Portuguese version of the letter of introduction to the health services

De: Carmen Caeiro
Estudante de Doutoramento
Universidade de Brighton. Reino Unido.
Centro de Investigação Clínica em
Profissões de Saúde
Aldro Building
49 Darley Road
Eastbourne BN20 7UR

Para: Ex.ma Senhora Directora
Agrupamento de Centros de
Saúde xxxx
Dr.ª XXXX

Tlf.: 01273 643647
Fax: Fax: 01273 643944
Sítio na Internet <http://www.brighton.ac.uk/sohp/research/>

Tlf.: xxxxxxxx
Fax: xxxxxx

X Junho de 2011

Assunto: Colaboração num trabalho de doutoramento intitulado “An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition”.

O meu nome é Carmen Caeiro e venho por este meio solicitar a colaboração de vossas excelências num estudo sobre a experiência dos indivíduos portugueses com dor crónica lombar (DCL) de natureza não-específica. Este estudo faz parte do meu programa de doutoramento a decorrer na Universidade de Brighton, no Reino Unido, e foi aprovado pela comissão de ética da referida universidade (Faculty of Health and Social Research Ethics and Governance Committee).

Neste sentido, venho solicitar a autorização de vossas excelências para entrevistar indivíduos com DCL de natureza não-específica, que sejam referenciados para a realização de fisioterapia. Os participantes serão convidados a participar numa entrevista individual, focada na sua experiência de DCL. O propósito desta entrevista é o de explorar a forma como este indivíduos compreendem e atribuem significado à sua condição clínica. O conhecimento resultante deste estudo irá contribuir para uma melhor compreensão da experiência dos utentes com esta condição e, em última

instância, irá contribuir para informar a abordagem a estes utentes, contribuindo para uma melhoria dos cuidados de saúde prestados em Portugal.

Todas as entrevistas serão conduzidas por mim, enquanto investigadora principal. Nestas entrevistas, serão colocadas questões abertas aos participantes sobre a sua experiência de DCL de natureza não-específica. Espera-se que cada entrevista tenha uma duração não superior a uma hora e meia. As entrevistas serão gravadas em formato áudio, contudo, a identidade dos participantes permanecerá confidencial. Neste âmbito, são asseguradas um conjunto de precauções com o intuito de garantir a confidencialidade das respostas dadas pelos participantes: será utilizado um nome fictício para cada participante na transcrição da respectiva entrevista; qualquer informação será divulgada de forma codificada assegurando o anonimato dos participantes. Será também solicitado aos participantes que revejam as transcrições das respectivas entrevistas. Todos os dados recolhidos serão mantidos em confidencialidade. As gravações áudio serão destruídas após a finalização do doutoramento e todas as transcrições serão preservadas por um período máximo de cinco anos.

Será fornecido a cada participante uma ficha informativa, com informação detalhada sobre o estudo, bem como um formulário para consentimento informado. Estes procedimentos visam garantir que o investigador informa adequadamente os participantes sobre a natureza do estudo e que todos os participantes tomam uma decisão informada relativamente à sua participação.

Ao dispor para qualquer esclarecimento ao conselho clínico relativo à possível colaboração com este trabalho de investigação.

Com os melhores cumprimentos,

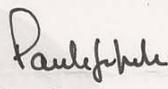
Carmen Caeiro

Tlm.: X

Telf.: X

E-mail: carmen.caeiro@ess.ips.pt ; C.S.FradeCaeiro@brighton.ac.uk

Appendix 7: Approval from the Health School of the Polytechnic of Castelo Branco

 Instituto Politécnico de Castelo Branco Escola Superior de Saúde Dr. Lopes Dias			
Largo Dr. José Lopes Dias Apartado 39 6000-909 Castelo Branco Tel. 272 340 560 Fax. 272 340 568 E-mail. esald@esald.ipcb.pt			
Exma Senhora Dr. ^a Carmen Caeiro Universidade de Brighton Reino Unido			
V/Ref.	V/Comunicação	N/Ref.	Data.
Assunto.		1182/16	2011-11-09
Colaboração num trabalho de doutoramento			
Vimos comunicar a V.Ex. ^a que está autorizada a realização do estudo sobre a experiência dos indivíduos portugueses com dor lombar crónica (DLC) de natureza não-específica.			
Com os melhores cumprimentos.			
A DIRECTORA			
			
Ana Paula Gonçalves Antunes Sapeta (Prof. Coordenador)			
/EV			
 			
Mod.IPCB.EX.04.02			
<small>Processos de gestão, de avaliação e melhoria e dos serviços de recursos humanos, académicos e de acção social, e órgãos e serviços de apoio à gestão.</small>			

Appendix 8: Approval from the Health Centres Group of Setúbal and Palmela

From: "Cristina Pereira" <secretariado_2@csssebastiao.min-saude.pt>
Subject: **FW: Pedido de colaboração I Investigação**
Date: 25 de maio de 2012 11:20:43 GMT+01:00
To: <carmen.caeiro@ess.ips.pt>
Cc: <fisioterapeuta_1@csssebastiao.min-saude.pt>, <fisioterapeuta_1@cspalmela.min-saude.pt>

Encarregou-me a Sra. Directora Executiva Dra Cristina Cabeçadas de informar que o pedido de colaboração no estudo "An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition", tem o parecer favorável.

Ao dispor
O Secretariado do ACES de Setúbal e Palmela

Cristina M Pereira
Assistente Técnica

Appendix 9: Information for physiotherapists

University of Brighton, Clinical Research Centre for Health Professions

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Dear Physiotherapist

This document aims to summarize our previous meeting and includes two parts: part 1 gives you information about the purpose of the study, methods, expected outcomes, etc; and part 2 gives you information about participants and recruitment strategies as well as the collaboration you may have in this process.

Part 1 | The Study

This study aims to explore how Portuguese individuals with non-specific chronic low back (CLBP) disorder understand and make sense of their condition.

The study consists of data collection carried out using semi-structured one to one interviews. The interviews will be focused on individuals' accounts of their experiences of having non-specific CLBP disorder.

Individuals with non-specific CLBP disorder who have been referred to physiotherapy will be recruited according to a range of inclusion and exclusion criteria.

The expected outcome of the study will be a detailed account of the researcher interpretation of the participants' experiences of having non-specific CLBP disorder and may inform recommendations to help improve non-specific CLBP management in Portugal.

Part 2 | Participants and Recruitment Strategies

In this study, participants will be selected on the basis of their specific knowledge and unique experience. In this sense, individuals with non-specific CLBP disorder will be included in this study in order to develop insights and an in-depth understanding of how they understand and make sense of their condition.

A range of inclusion and exclusion criteria will be used in order to select participants.

Inclusion Criteria

Participants will:

- have experienced “*non-specific chronic low back pain, i.e. low back pain that is not attributable to a recognizable, known specific pathology (e.g. infection, tumour, osteoporosis, fracture, structural deformity, inflammatory disorder like ankylosing spondylitis, radicular syndrome or cauda equina syndrome)*” ;
- have had non-specific CLBP disorder for at least 1 year, that was not relieved by previous health care;
- be aged between 40 and 60 years;
- have intellectual capacity and psychological maturity to understand the nature of the research and his/her involvement, ability to make self-directed and self-determined choices;
- be able to communicate effectively in Portuguese;

Exclusion Criteria

- spine surgery in the last two years;
- the presence of any chronic diseases;
- participants with any nationality other than Portuguese, due to the cultural basis of this study.

Your collaboration is sought for the recruitment process, in relation to the following:

- Identifying potential participants for this study (among patients referred to physiotherapy) according to the inclusion and exclusion criteria mentioned above;
- After identifying a potential participant, giving him/her one of the envelopes that were provided;
- When giving the envelope to potential participants the following information should be highlighted:
 - This is an invitation for those wishing to participate in a study concerning individuals experience of having non-specific chronic low back pain;

- This study is completely independent from their prescribed treatment;
- The envelope was given to you by the researcher and contains an invitation letter for participating in this study and an information sheet with more detailed information about the study, as well as a stamped addressed envelope. If individuals are interested in participating in this study they should fill in the form and send it back to the researcher in the stamped addressed envelope provided.

After this process, the researcher will contact participants who have returned envelopes by phone to answer any questions and determine if they are still interested in participating. The individuals who decide to participate will be invited for an interview in the health centre on a date and time that is convenient to them.

The researcher will meet them in the private room where the interviews will take place and will consider a previous period to answer any questions. A copy of the information sheet will be provided to participants who do not bring their copy with them. They will be given time to read it again and to raise any questions about the study they may have. Finally, the participants will be asked to give their informed consent and a signed copy of this will be given to them.

If you have any questions about this study or about your collaboration please do not hesitate to contact me on my mobile phone or work number, X or X or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk. If I am not available when you call, please leave a message and I will return your call.

Thank you very much for reading this document,
Carmen Caeiro

Appendix 10: Portuguese version of the information for physiotherapists

University of Brighton (Reino Unido) | Clinical Research Centre for Health Professions

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Caro(a) Fisioterapeuta

Este documento foi escrito para si e pretende sumariar os conteúdos discutidos na reunião prévia com a investigadora, incluindo duas partes: a parte 1 apresenta informação sobre os objetivos do estudo, a metodologia e métodos utilizados, assim como os resultados esperados; a parte 2 contempla informação sobre os participantes e as estratégias para o seu recrutamento e ainda a colaboração que poderá ter neste processo.

Parte 1 | O estudo

Este estudo pretende explorar a forma como os indivíduos portugueses com dor crónica lombar (DCL) de natureza não-específica compreendem e atribuem significado à sua condição.

O estudo baseia-se na recolha de informação através da realização de entrevistas individuais e semi-estruturadas. As entrevistas centram-se na experiência dos participantes com a referida condição.

Serão recrutados para este estudo indivíduos com DCL de natureza não-específica, referidos para a fisioterapia em centros de saúde, de acordo com um conjunto de critérios de inclusão e exclusão previamente definidos.

O resultado esperado é a compreensão detalhada da experiência dos indivíduos com DCL de natureza não-específica. Este conhecimento irá contribuir para informar a abordagem dos profissionais de saúde a estes indivíduos, contribuindo para uma melhoria dos cuidados de saúde prestados em Portugal.

Parte 2 | Participantes e Estratégias de Recrutamento

Neste estudo, os participantes serão seleccionados com base no seu conhecimento específico e experiência única. Neste sentido, serão seleccionados indivíduos com DCL de natureza não-específica com o intuito de desenvolver um entendimento aprofundado sobre a forma como compreendem e atribuem significado à sua condição clínica.

Para a selecção dos participantes será utilizado um conjunto de critérios de inclusão e exclusão.

Critérios de Inclusão

- Ter experienciado DCL de natureza não-específica, isto é dor lombar que não é atribuída a uma causa específica (exemplo: infecção, tumor, osteoporose, fractura, deformidade, estados inflamatórios como espondilite anquilosante, ou síndrome da cauda equina);
- Ter experienciado DCL de natureza não-específica por um período mínimo de 1 ano, sem qualquer alívio decorrente de cuidados de saúde prestados;
- Ter entre 40 e 60 anos;
- Ter capacidade intelectual e psicológica para compreender a natureza do estudo, o seu possível envolvimento e capacidade de tomar decisões de forma autónoma;
- Ter capacidade para comunicar em português de forma efectiva;

Critérios de Exclusão

- Cirurgia à coluna nos últimos dois anos;
- Ter qualquer doença crónica associada;
- Ter outra nacionalidade que não a portuguesa.

A sua colaboração neste estudo, será solicitada nos seguintes aspectos:

- Identificar os potenciais participantes para este estudo, entre os utentes referidos para a fisioterapia, de acordo com os critérios de inclusão e exclusão previamente referidos;
- Depois de identificar os potenciais participantes, deve entregar-lhe um dos envelopes que lhe foram cedidos pela investigadora;
- No momento da entrega do envelope a cada participante deverá transmitir a seguinte informação:

- Trata-se de um convite para participar num estudo sobre a experiência dos indivíduos com DCL;
- Este estudo é completamente independente do tratamento prestado no centro de saúde;
- O presente envelope foi-lhe entregue pela investigadora responsável por este estudo e inclui um convite para participar neste estudo, uma ficha informativa com informação detalhada sobre o estudo e um envelope selado. Os indivíduos interessados em participar deverão preencher o formulário e enviá-lo para a investigadora;

Depois desta etapa, os participantes serão contactados pela investigadora que poderá responder a qualquer questão sobre o estudo e aferir o interesse em participar. Os indivíduos interessados em participar serão convidados para uma entrevista que terá lugar no centro de saúde onde são acompanhados, numa data que lhes seja conveniente.

No centro de saúde, os indivíduos serão recebidos pela investigadora na sala onde irão decorrer as entrevistas, sendo considerado um período prévio para responder a eventuais questões. Uma cópia da ficha informativa será entregue aos participantes que não tenham trazido a ficha que lhes foi entregue no envelope. Será disponibilizado um período de tempo de forma a permitir que a ficha seja novamente lida e para responder a eventuais questões que sejam colocadas. Finalmente, será solicitada a assinatura do formulário de consentimento informado, ficando uma cópia com a investigadoras e outra com o(a) participante.

Se tiver qualquer questão sobre este estudo ou sobre a sua colaboração, por favor não hesite em contactar-me via telemóvel ou telefone, X or X, ou através do e-mail, carmen.caeiro@ess.ips.pt ou C.S.FradeCaeiro@brighton.ac.uk. Se no momento em que o fizer não conseguir contactar-me por favor deixe uma mensagem, para que possa contacta-lo(a) assim que me for possível.

Muito obrigada por ler este documento,

Carmen Caeiro

Appendix 11: Invitation letter for participants

University of Brighton, Clinical Research Centre for Health Professions

Invitation Letter

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Dear Sir or Madam

My name is Carmen Caeiro and I am writing to you to invite you to participate in a research study concerning Portuguese individuals experience of having non-specific chronic low back pain disorder. This study is part of a PhD programme of work registered in the University of Brighton in the United Kingdom.

I am asking for your agreement to participate in a one to one interview, concerning your individual experience of having chronic low back pain disorder. The purpose of this interview is to explore how you understand and make sense of your condition.

It is anticipated that the interview will last no longer than an hour and a half. I will ask you a set of questions about your experience of having non-specific chronic low back pain disorder. This interview will be carried out at a time convenient for you, in a private room in the health centre where you are being treated. The interview will be audio recorded, however, your identity will remain confidential. Special precautions have been established to protect the confidentiality of your responses. A fictional name will be used in any reference to you and your interview transcript. The data obtained will be referred to by code and will therefore be anonymous. I will send you a written copy of your interview to ask you to review it for accuracy and I will call you to check you are happy with the accuracy of the transcriptions as well as the main themes that I will identify from your interview.

You are free to withdraw from the study at any time and without giving any reason. All information about you will be held in strict confidence. Audiotapes will be preserved until the end of the PhD study at which time they will be destroyed and the written data will be preserved for a maximum of five years after the end of the study.

Please find enclosed an information sheet, which gives you more detailed information about the study.

After reading the information sheet and if you wish to participate in this study, I would like to invite you to fill the form at the bottom of this page and send it back to me using the stamped addressed envelope attached. This will help me in contacting you with an interview date should you agree to participate.

If you have any questions about this study please do not hesitate to contact me on my mobile phone or work number, X or X, or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk. If I am not available when you call, please leave a message and I will call you back.

Thank you very much for reading this letter.

Carmen Caeiro

✂-----

I _____ (name)

accept to be contacted by the researcher on

_____ (mobile phone or telephone

number) to discuss the possibility of participating in this study.

This contact does not implicate any obligation in participating.

Appendix 12: Portuguese version of the invitation letter for participants

Universidade de Brighton, Reino Unido

Centro de Investigação para as Profissões na Área da Saúde

Convite

Para participação num estudo sobre a experiência
dos indivíduos portugueses com dor crónica lombar

Exmo(a) Sr.(a)

O meu nome é Carmen Caeiro e escrevo-lhe para o(a) convidar a participar num estudo sobre a experiência dos indivíduos portugueses com dor crónica lombar. Este estudo faz parte do meu doutoramento, a decorrer na Universidade de Brighton, no Reino Unido.

Venho por este meio convidá-lo(a) a participar numa entrevista individual sobre a sua experiência de dor crónica lombar. O propósito desta entrevista é explorar a forma como compreende e atribui significado à sua condição.

É esperado que esta entrevista não tenha uma duração superior a uma hora e meia. Eu, enquanto investigadora principal, irei colocar-lhe algumas questões sobre a sua experiência de dor crónica lombar. Esta entrevista será conduzida num horário que lhe seja conveniente, numa sala reservada onde ninguém terá acesso no decorrer da entrevista, no centro de saúde onde está a ser acompanhado(a). A entrevista será gravada em formato áudio, contudo, a sua identidade permanecerá confidencial. Neste sentido, são asseguradas um conjunto de precauções com o intuito de garantir a confidencialidade das respostas dadas por si: será utilizado um nome fictício na transcrição da sua entrevista; qualquer informação será divulgada de forma codificada assegurando o seu anonimato. Irei também solicitar-lhe que reveja o texto referente à transcrição da sua entrevista e irei fazer um telefonema para o confirmar. Nesse telefonema irei também apresentar um sumário com os principais temas que identifiquei na sua entrevista e aferir a sua adequabilidade.

É livre de desistir do estudo, em qualquer momento, sem que tenha que apresentar qualquer razão para o fazer. Toda a informação que lhe diga respeito será mantida em confidencialidade. As gravações serão destruídas após a finalização do estudo e a informação escrita será preservada por um período máximo de cinco anos.

Em anexo, pode encontrar uma ficha informativa que lhe oferece informação mais detalhada sobre o estudo. Depois de ler esta ficha, e no caso de ponderar participar no estudo poderá preencher o formulário no final desta página e enviá-lo através do envelope selado também em anexo. Desta forma, poderei contactá-lo(a) mais tarde para conversarmos sobre a possibilidade de participar neste estudo.

Se tiver qualquer questão sobre este estudo, por favor não hesite em contactar-me via telemóvel ou telefone, X ou X, ou através do e-mail, carmen.caeiro@ess.ips.pt ou C.S.FradeCaeiro@brighton.ac.uk.

Se no momento em que o fizer não conseguir contactar-me por favor deixe uma mensagem, para que possa contactá-lo(a) assim que me for possível.

Muito obrigada por ler esta carta.

Os melhores cumprimentos,

Carmen Caeiro

✂-----

Eu _____ (nome)

aceito ser contactado(a) pela investigadora

_____ (telemóvel ou telefone fixo) para

conversar sobre a possibilidade de participar neste estudo.

Este contacto não implica qualquer obrigação da minha parte em participar no estudo.

Appendix 13: Participant information sheet

University of Brighton, Clinical Research Centre for Health Professions

Participant Information Sheet

PhD Study

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

This document includes two parts: part 1 tells you the purpose of this study and what will happen to you if you take part; and, part 2 gives you more detailed information about the conduct of the study.

Ask me if there is anything that is not clear or if you would like any more information. Take time to decide whether or not you wish to take part.

Part 1 | Purpose of the study and what will happen to the participants

What is the purpose of the study?

The purpose of this study is to explore how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition.

Why have I been invited?

You have been invited because your doctor referred you to physiotherapy for your back problem and also because of your particular experience of having chronic low back pain. Your participation will inform the understanding of

individuals` experiences of having chronic low back pain, which may help improve health care provided in Portugal to individuals with similar experiences.

Do I have to take part?

It is up to you to decide. I will describe the study to you and go through this information sheet with you in detail. You will have time to read it and to raise any questions. If you wish to take part I will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving any reason. If you choose to withdraw, this will not affect the standard of care you receive in any way.

What will happen to me if I take part?

You will come to the health centre where you are being treated, to participate in a one to one interview. In this interview I will ask you questions related to your experience of living with chronic low back pain (for example: *“Please tell me about your experience of living with chronic low back pain”*). The interview will take place outside of your normal treatment sessions and will be set up at a convenient time for you and for the researcher. It is anticipated that the interview will last no longer than an hour and a half. You will be interviewed only once, in a private room which no one else can access during the interview time. The interview will be audiotaped.

What will I have to do?

You will be asked questions about your experience of living with chronic low back pain. You have freedom to answer questions as you wish.

What are the possible disadvantages and risks of taking part?

The only disadvantage is that you will need to allocate approximately 1h30 of your time for the interview. Possible risks are concerned with the fact that because you will be invited to talk about your experience of having chronic low back pain this could include sensitive issues for you. If the interview becomes upsetting, I (as an interviewer) will stop the interview immediately as well as audio-recordings and give you the chance to recover and decide if you want to

continue or not. If you continue to feel upset the interview will be stopped out and I will provide you the telephone contact number to access appropriate support after the interview. The detailed information on this is given in Part 2 of this information sheet.

What are the possible benefits of taking part?

You will have the opportunity to be actively listened to by someone who is trying to understand your experience of living with chronic low back pain. The information I get from this study may help inform the management of patients suffering from chronic low back pain with similar experiences.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this information sheet.

Will my taking part in the study be kept confidential?

Yes, the study follow ethical and legal practices and all information about you will be handled in confidence. The details are included in Part 2 of this information sheet.

If the information in Part 1 has interested you and you are considering participating, please read the additional information in Part 2 before making any decision.

Part 2 | Conduct of the study

What will happen if I don't want to carry on with the study?

Your participation is totally voluntary and you are free to withdraw from the study at any time without giving reason. If you withdraw from the study, the audiotape and transcriptions will be destroyed. Therefore, no information about yourself will be used in the study. This will not affect the standard of care you receive.

What if there is a problem?

If you have any concerns about any aspect of this study, ask to speak with me (the researcher) and I will do my best to answer all your questions. You can contact me by mobile phone, work number or by e-mail at carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

If you want any additional information from the University or wish to complain formally you can contact a senior research administrator Mrs Marilia Vasquet-Whittome, by telephone or by e-mail (M.Vasquet-Whittome@brighton.ac.uk). The research administrator speaks fluent Portuguese and will facilitate your contact with an independent senior academic in The School of Health Professions at the University of Brighton.

What if the interview becomes upsetting?

You can contact “SOS Voz Amiga” (SOS Friendly Voice) on 213544545, 912802669 or 963524660. This is a Portuguese centre that gives psychological support. After your first call for identification, the centre will return your call.

Will my taking part in this study be kept confidential?

All information about your identity will be held in strict confidence. The data obtained will be referred to by code and will therefore be anonymous. A fictional name will be used to hide your identity.

What will happen to any information I give?

The information you give will be audio recorded and then analysed. I (the researcher) will store the audio recordings safely, to avoid any possible access by a second party. The recordings will be preserved until the end of the PhD study and the written data will be preserved for a maximum of five years, after the end of the study.

What will happen to the results of the research study?

The results will be used exclusively for academic purposes and may be published in scientific journals. In both situations, verbatim quotations for the

transcriptions will be used without mentioning your identity in any circumstance. In both situations a fictional name will always be used.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Faculty of Health and Social Research Ethics and Governance Committee of the University of Brighton. There have been not identified Ethics Committees in Portugal that have been relevant for this study.

Contact details

Researcher: Carmen Caeiro

Mobile Phone: X

Work Number: X

E-mail: carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

University Senior Research Administrator: Mrs Marilia Vasquet-Whittome

Telephone: X

E-mail: M.Vasquet-Whittome@brighton.ac.uk

SOS Voz Amiga (SOS Friendly Voice)

Mobile Phone: 91 280 26 69 or 963524660

Telephone: 21 354 45 45

Website: <http://www.sosvozamiga.org/>

Thank you very much reading this document,
Carmen Caeiro

Appendix 14: Portuguese version of the participant information sheet

Universidade de Brighton, Reino Unido

Centro de Investigação para as Profissões na Área da Saúde

Ficha Informativa para Participantes

Estudo sobre a forma como os indivíduos portugueses com dor crónica lombar compreendem e atribuem significado à sua condição clínica

Gostaria de convidá-lo(a) a participar neste estudo. Antes de tomar qualquer decisão, é importante que compreenda as razões pelas quais esta investigação está a ser conduzida e o nível de envolvimento que lhe é pedido. Por favor, utilize o tempo que necessitar para ler a informação que se segue. Poderá falar com outras pessoas sobre este estudo, se o desejar.

Este documento inclui duas partes: a parte 1 apresenta-lhe informação sobre o propósito deste estudo e o nível de envolvimento que lhe será pedido; a parte 2 oferece-lhe informação mais detalhada sobre a forma como o estudo será conduzido.

Se algum aspecto não for claro ou se desejar mais informação por favor não hesite em colocar-me as suas questões. Utilize o tempo que necessitar para decidir se deseja ou não participar neste estudo.

Parte 1 | O propósito do estudo e o nível de envolvimento que lhe é pedido

Qual é o propósito deste estudo?

O propósito deste estudo é explorar a forma como os indivíduos portugueses com dor crónica lombar compreendem e atribuem significado à sua condição clínica.

Por que fui convidado(a)?

Depois de referido para a fisioterapia, pelo seu(sua) médico(a) de família, foi convidado(a) para participar neste estudo pela sua experiência de dor crónica lombar. A sua participação irá contribuir para uma melhor compreensão sobre a experiência dos indivíduos com dor crónica lombar e poderá contribuir para melhorar os cuidados de saúde prestados.

Tenho mesmo que participar?

A decisão é sua. Eu irei descrever-lhe o estudo ao longo desta ficha informativa. Terá o tempo que necessitar para a ler e colocar questões. Se decidir participar irei convidá-lo(a) a assinar um consentimento informado, que confirma a sua livre vontade em participar. É livre de desistir do estudo a qualquer momento, sem que tenha que o justificar. Esta decisão não terá qualquer impacto no seu tratamento.

O que acontece, se aceitar participar?

Será convidado para uma entrevista individual, no centro de saúde onde está a ser acompanhado(a). Nesta entrevista, irei colocar-lhe algumas questões sobre a sua experiência de dor crónica lombar (por exemplo: “*Fale-me sobre a sua experiência de dor crónica lombar*”). Esta entrevista sera planeada à parte do seu tratamento e sera marcada num período do dia que lhe seja conveniente. Estima-se que a entrevista tenha uma duração não superior a uma hora e meia. Será entrevistado(a) uma única vez, numa sala do centro de saúde reservada para este efeito, e onde outras pessoas não poderão aceder durante este período.

O que terei que fazer?

Terá que responder a questões sobre a sua experiência de dor crónica lombar. Terá liberdade de responder conforme preferir.

Quais são as possíveis desvantagens ou riscos se aceitar participar?

A única desvantagem é que terá de despende de cerca de 1h30 do seu tempo. Os possíveis riscos estão relacionados com o facto poder algum momento da

entrevista sentir a necessidade de falar sobre aspectos mais sensíveis da sua experiência. Se, por alguma razão, a entrevista se tornar desagradável, a entrevista será imediatamente interrompida e o gravador desligado. Ser-lhe-á dado o tempo que necessitar para se recompor e decidir se deseja continuar a entrevista. Se necessitar, também poderão ser fornecidos contactos telefónicos através dos quais poderá aceder a apoio apropriado depois da entrevista. Na parte 2 deste documento, poderá encontrar mais informação sobre este aspecto.

Quais são as possíveis vantagens em participar?

Terá a oportunidade de ser ouvido por alguém que está realmente interessado em compreender a experiência dos indivíduos Portugueses com dor crónica lombar. A informação obtida a partir deste estudo poderá contribuir para melhor os cuidados de saúde prestados em Portugal a indivíduos com este problema.

E se houver algum problema?

Qualquer queixa que tenha sobre este estudo, sobre a forma como foi abordado(a) ou qualquer dano associado serão considerados. Na parte 2 deste documento, poderá encontrar mais informação sobre este aspecto.

A minha participação neste estudo será confidencial?

Sim. Eu irei seguir um conjunto de princípios éticos e legais de forma a assegurar que a sua participação será mantida em confidencialidade. Na parte 2 deste documento poderá encontrar mais informação sobre este aspecto.

Se a informação disponibilizada na parte 1 lhe despertou interesse em participar, por favor leia a informação adicional apresentada na parte 2 antes de tomar qualquer decisão.

Parte 2 | A forma como estudo será conduzido

O que acontece se eu não aceitar participar no estudo?

A sua participação é totalmente voluntária e é livre de desistir do estudo a qualquer momento, sem que tenha que o justificar. Se desistir do estudo, eu destruirei a gravação e as transcrições. Nessa situação, qualquer informação que lhe diga respeito não será utilizada no estudo. Esta decisão não terá qualquer impacto no tratamento que lhe está a ser prestado no centro de saúde.

E se houver algum problema?

Se tiver alguma queixa sobre qualquer aspecto deste estudo, deverá falar comigo (a investigadora). Nessa situação, farei o meu melhor para responder às suas questões. Poderá contactar-me no meu telemóvel, x, ou no telefone, X, ou ainda através do e-mail, carmen.caeiro@ess.ips.pt ou C.S.FradeCaeiro@brighton.ac.uk.

Se pretende informação adicional da Universidade que suporta esta investigação, ou se desejar fazer uma reclamação poderá contactar uma administrativa da Universidade, a Sra. Marília Vasquet-Whittome, através do telefone (X) ou através do e-mail (M.Vasquet-Whittome@brighton.ac.uk). A pessoa indicada fala português fluentemente, pelo que poderá facilitar o seu contacto com um investigador da Universidade de Brighton.

E se a entrevista se tornar desagradável ou triste para mim?

Poderá contactar o centro “SOS Voz Amiga”, através do telefone 213544545, ou do telemóvel 912802669 ou 963524660. Trata-se de um centro português que oferece apoio psicológico gratuito, via telefone. A primeira chamada é paga e serve apenas para identificação. Imediatamente a seguir o centro devolve-lhe a chamada.

A minha participação neste estudo será confidencial?

Toda a informação relacionada com a sua identidade será mantida em estrita confidencialidade. Toda a informação será mencionada de forma codificada e

será anónima. Será utilizado um nome fictício para esconder a sua verdadeira identidade.

O que irá acontecer às informações que eu der sobre mim?

A informação que transmitir durante a entrevista será gravada em formato áudio com o intuito de ser analisada posteriormente. Eu (a investigadora) encarregar-me-ei de guardar todas as gravações num lugar seguro de forma a impedir o seu acesso por outras pessoas. As gravações serão mantidas até ao final do estudo, a informação escrita será preservada por um período máximo de cinco anos após o término do estudo.

O que irá acontecer com os resultados deste estudo?

Os resultados serão utilizados exclusivamente para fins académicos e poderão ser publicados em revistas científicas na área da saúde. Em qualquer uma das situações, serão utilizadas transcrições do discurso dos participantes, sem que seja mencionada a sua verdadeira identidade em qualquer circunstância. Em qualquer uma das situações será utilizado um nome fictício.

Quem avaliou a adequabilidade deste estudo?

Este estudo foi avaliado positivamente pela comissão de ética da universidade de Brighton, no Reino Unido. Recorreu-se a uma comissão estrangeira pelo facto de não ter sido identificada nenhuma comissão portuguesa para este efeito

Contactos

Investigadora: Carmen Caeiro

Telemóvel: X

Telefone: X

E-mail: carmen.caeiro@ess.ips.pt or C.S.FradeCaeiro@brighton.ac.uk.

Universidade de Brighton | Administrativa: Marilia Vasquet-Whittome

Telefone: X

E-mail: M.Vasquet-Whittome@brighton.ac.uk

SOS Voz Amiga

Telemóvel: 91 280 26 69 or 963524660

Telefone: 21 354 45 45

Sítio na internet: <http://www.sosvozamiga.org/>

Muito obrigada por ler este documento,

Carmen Caeiro

Appendix 15: Participant consent form

UNIVERSITY OF BRIGHTON

Participant Consent Form

An Exploration of how Portuguese Individuals with non-specific chronic low back pain disorder understand and make sense of their condition

- ◆ I agree to take part in this research which is looking at the Portuguese individuals experience of having non-specific chronic low back pain disorder.
- ◆ The researcher has explained to my satisfaction the purpose of the study and the possible risks involved.
- ◆ I have had the procedure explained to me and I have also read the information sheet. I understand the procedures fully.
- ◆ I am aware that I will be required to answer questions about my experience of having non-specific chronic low back pain disorder and my answers will be taped.
- ◆ I understand that any confidential information will normally be seen only by the researchers and will not be revealed to anyone else.
- ◆ I understand that I am free to withdraw from the investigation at any time.

Name (please print).....

Signed

Date

Appendix 16: Portuguese version of participant consent form

UNIVERSIDADE DE BRIGHTON, Reino Unido

Consentimento Informado

Estudo sobre a forma como os indivíduos portugueses com dor crónica lombar compreendem e atribuem significado à sua condição clínica.

- ◆ Eu aceito participar neste estudo que procura explorar as experiências dos indivíduos portugueses com dor crónica lombar.
- ◆ A investigadora explicou-me de forma satisfatória o propósito deste estudo e os possíveis riscos envolvidos.
- ◆ Foram-me explicados todos os procedimentos e li cuidadosamente a ficha informativa que me foi entregue juntamente com o convite para participar neste estudo. Compreendo todos os procedimentos.
- ◆ Sei que me serão colocadas questões sobre a minha experiência de dor crónica lombar e que as minhas respostas serão gravadas em formato áudio e posteriormente transcritas.
- ◆ Compreendi que qualquer informação confidencial que me diga respeito será apenas manuseada pela investigadora e não será revelada a ninguém.
- ◆ Compreendi que sou livre de desistir do estudo, a qualquer momento.

Nome (maiúsculas)

Assinatura.....

Data

Appendix 17: Interview schedule

University of Brighton, Clinical Research Centre for Health Professions

An Exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition

Interview Schedule

Introductory key messages

Thank you very much for accepting my invitation. Your participation will be very important in the development of this study.

As I have already told you, I am very interested in your experience of having chronic low back pain. There are no right or wrong questions. It is all about your ideas, thoughts and feelings about your experience.

Because I am very interested in your experience, I will try to say very little in order to allow you to speak freely. But sometimes I may ask you some questions. Please, take your time in thinking and talking.

Do you have any questions before we start the interview?

Key Questions

- Please tell me about your experience of living with chronic low back pain?

Do you have any experience in particular, which was more important for you?

Can you describe a typical day when you have pain?

How has this pain influenced your life?

Probing Questions

You have talked about... why do you think it is important?

You have mentioned... what are/were your thoughts about this?

Can you describe... in more detail?

Can you give me an example of that?

Is there anything important we haven't talk about?

Appendix 18: Transcript excerpts

In this appendix, excerpts from one participant's interview transcription are provided. This information is divided into 3 sections: the first illustrates the Portuguese transcription; the second represents the translated version; the third illustrates the final table where the transcripts were introduced in order to carry out data analysis.

I. Rita's interview transcript (excerpt) – Portuguese Version

- 61 Investigadora: E achar o contrário, não é?
- 62 Rita: É um trabalho muito ingrato! A pessoa que está por fora e já tem acontecido com colegas
63 minhas que andavam no apoio domiciliário e que depois ficaram lá na cozinha diziam: "ah lá
64 na cozinha não se trabalha, não sei que mais..." E agora já dizem: "não, não! É mais puxado
65 na cozinha, que andar no apoio domiciliário". Porque a pessoa quando está por fora pensa
66 uma coisa e depois quando lá chega é outra! Mas pronto sentia muitas dores na minha coluna,
67 mas pronto agora... agora é dos braços...
- 68 Investigadora: Agora está melhor desta parte, mas não tão bem da outra?
- 69 Rita: Mas pelo menos já estou melhor duma parte! Já não tenho tantas dores! Já me sinto
70 muito melhor. Movimento-me muito melhor... Uma pessoa vai-se baixar começa logo aquela
71 dor, tem que se pôr noutra posição ou têm que fazer assim. Eu tinha muito a mania de me
72 ajoelhar, por exemplo a limpar o pó aquelas as partes assim mais baixas para não me doer
73 tanto ajoelhava-me. Por exemplo, a limpar uma casa de banho ajoelhava-me para limpar a
74 banheira a sanita, aquilo tudo... Agora não, agora faço tudo assim dobrada, porque consigo...
75 E antigamente tinha que fazer, não é? Tinha mais dificuldade e então demorava mais tempo
76 também... fiquei...
- 77 Investigadora: Como é que era esse antigamente? Lembra-se quando é que começou a ter
78 dor?
- 79 Rita: Eu comecei a ter dor muito nova, eu acho que foi logo derivado à minha infância, porque
80 eu infelizmente fiquei sem mãe aos 14 anos e comecei logo a ganhar para a casa. Eu e a
81 minha irmã! Ficámos só duas porque o meu pai não quis saber de nós. O meu pai faleceu há 8
82 anos atrás. Ficamos em casa com ele, só que ele entregou-se à bebida e aquilo foi... Nem é
83 bom pensar nessa parte da adolescência... E então eu não sou daqui, sou do Norte, sou de
84 Ceia daquela encosta de Ceia... E então aquilo era assim: eu trabalhava no campo, a carregar
85 areia, estrume, as uvas, sacos de adubo quando era para ir para o campo... E eu ainda era
86 muito nova, com 14, 15, 16, 17... que eu vim pra cá com 18... A cavar, era... Eu acho que
87 começou logo daí porque eu sempre me lembrou de ter dores nas costas... Eu penso que foi...
88 Depois havia aquelas pessoas que para a gente levar mais qualquer coisa calcavam as coisas
89 que era para a gente levar mais... Uma pessoa para subir um degrau até as pernas tremiam
90 com o peso que aquilo tinha... E eu acho que foi derivado daí. Depois vim do Norte, fui
91 trabalhar para um fábrica de confecções... Trabalhei muitos anos ainda, muitos anos... Se

92 calhar uns 7 ou 8... A pessoa está todo o dia na mesma posição... Senta-se na máquina, só
93 mexe os dois pés que é um para levantar o calcador e outro para cozer, não é? E está todo o
94 dia naquela posição... E eu quando me levantava, nessa altura conseguia ter tantas dores nas
95 costas como agora... Porque quando me levantava da cadeira parecia já uma velhinha
96 "marreca" com a dor que tinha aqui de estar 4 horas ali naquela posição! Só quando a gente ia
97 à casa de banho é que saía dali... Porque depois é assim: aquilo é uma linha da montagem...
98 a senhora já viu na televisão... o meu trabalho passa para a da frente, a da frente passa para a
99 da frente, e se eu parar, por exemplo a minha colega da frente já não tem trabalho. E então a
100 gente ali, tem de estar o dia todo assim. Até que... eu por acaso nunca tive problemas, mas
101 uma irmã minha que também trabalhou muitos anos lá... Até que ela.. como ela era mais fraca
102 do que eu, talvez de osso, não sei... Sei que ela esteve muito tempo de baixa por causa duma
103 dor que tinha aqui no ombro, que ela não conseguia levantar os casacos... Porque é assim...
104 De verão, por exemplo... a gente trabalha ao contrário! De verão, é os casacos de inverno! E
105 de inverno é a roupa de verão... Está um calor como está... e uma pessoa ali com calor... que
106 às vezes até ligava um... aquilo dos incêndios... O alarme dos incêndios com o calor que lá
107 estava... Uma pessoa com um blusão daqueles... pesado... ali a fazer aqueles casacos... Eu
108 por acaso acho que isto tudo tenha sido derivado ao meu trabalho ter sido... Eu gosto da
109 costura, tirei curso de costureira... De cozinheira, não tenho! Mas de costureira tenho o
110 curso... Mas gosto de costurar na minha casa, mas não gosto de costurar nas fábricas!
111 Porque... para já uma pessoa lá não aprende nada! É sempre a mesma coisa, depois é
112 sempre... Se for preciso está 15 dias ou 3 semanas com uma máquina enfiada por exemplo
113 de preto, ou uma linha branca ou amarela... Porque enquanto a gente não fizer aquela
114 quantidade de peças, a linha é sempre... É um trabalho muito monótono! A cozinha, eu gosto
115 muito! Porque por exemplo hoje faz-se uma feijoada, amanhã faz-se um bacalhau à brás,
116 depois de amanhã faz-se um bacalhau espiritual... É monótono porque a gente esta sempre...
117 Acabo... É o almoço da 1 às 2... E às duas começo logo a fazer o jantar, ainda não tenho
118 acabado de fazer a digestão do almoço, acabei de almoçar... já estou a fazer o jantar... Mas é
119 um trabalho que não é tão monótono como a costura. Gosto de fazer e se você me perguntar
120 o que é que eu gosto mais de fazer, é estar na cozinha! Onde eu passo o meu tempo é na
121 cozinha. Eu passa-se semanas e semanas que não me sento no sofá na sala, passo o tempo
122 todo na cozinha, ou faço um bolo ou faço rissóis eu também faço muitos rissóis... Ou quando
123 é de inverno, faço filhoses... o meu canto da casa favorito é a cozinha! Ou a máquina da
124 costura... Mas isso neste momento só costuro para mim, ou para minha irmã, ou para uma
125 pessoa assim... Por exemplo para as minhas colegas, para as fardas novas... Já sei que lhe

126 tenho que fazer a bainha das calças... Mas costurar, como eu costurava aqui há 10/ 15 anos
127 atrás, já não faço! E não faço porque não tenho tempo, mas gosto! Mas lá está, já é umas
128 bainhas hoje ou amanhã é um fecho... Outro dia, já é apertar uma saia... é diferente do que
129 estar ali 15 dias ou 3 semanas... Eu por exemplo na altura não fui para a X, porque eu disse:
130 "não! Enquanto eu arranjar trabalho noutro lado, não vou para a fábrica de confecções!" A
131 fábrica até já fechou, e eu continuo com a mesma ideia... enquanto eu arranjar trabalho noutro
132 lado eu não vou pra uma fábrica de confecções... Não digo que não vou, porque posso
133 precisar, não é? Eu vivo do meu ordenado e mal de mim se o meu ordenado faltar... Lá está,
134 eu tinha aquelas dores todas mas eu nunca faltei ao trabalho! Um dia tomava um *ben-u-ron*,
135 outro dia tomava o *brufene*, outro dia tomava o *moltil* que era para não ser sempre o
136 mesmo... Mas também não tomava todos os dias! Aqueles dias que me doía mais a coluna
137 tomava... A partir daí nunca mais tomei comprimido nenhum... Mas tenho que trabalhar, tenho
138 dois filhos e tenho as minhas coisas para pagar, isso tudo... Mas eu só vou para uma fábrica
139 de confecções se não arranjar noutro lado... De contrário... Se arranjar noutro lado eu não vou
140 pra uma fábrica de confecções!

141 **Investigadora:** Pois ainda lá trabalhou lá quantos anos? 7 anos?

142 **Rita:** 7 ou 8 anos! Porque eu trabalhei ano e meio no Norte! Trabalhei 3 na xxx, não sei se
143 você é aqui de Setúbal... Olhe é ali na estrada do Alentejo, aqui em Setúbal chama-se a
144 estrada do Alentejo... Entretanto essa fábrica fechou, naquela altura em que as fábricas
145 começaram todas a fechar. Depois trabalhei ali na xxx, e também andei 4 anos, entretanto
146 fechou também! Foi quando eu deixei de... por isso trabalhei 8 anos e meio em fábricas... E
147 depois fui trabalhar para uma senhora... que foi ela... só trabalhei com ela 2 anos, mas foi a
148 minha sorte! Ensinou-me muito e eu aprendi muito naqueles 2 anos que trabalhei com ela. Foi
149 ela que me ensinou a fazer os bolos, a fazer os rissóis... Eu já gostava da cozinha, mas não...
150 Ensinou-me a fazer tudo... Por exemplo, eu já tenho dito a continuo a dizer: "eu aprendi mais
151 em 2 anos com aquela senhora, que aprendi em 9 no trabalho onde estou!" Porque ali, para já
152 estive 9 meses ou 8... Eu entrei para lá em Junho, passei a cozinheira em Abril! Naqueles
153 meses todos estive com uma cozinheira e eu era ajudanta. A partir daí passaram-me a
154 cozinheira nunca mais tive outra cozinheira, tenho sido sempre eu! A partir daí nunca aprendi
155 mais nada com ninguém! Vou por exemplo à internet, ou vou a um livro de culinária... à
156 procura de receitas... mas nunca mais aprendi lá nada... tirando aquele tempo com a outra
157 senhora... Naqueles 2 anos eu aprendi tudo! Mas de cozinha nunca aprendi nada porque ela

II. Rita`s interview transcript (excerpt) – English Version

61 "Yeah, there in the kitchen they don't work, and all of that..." But now they say: "no, no, no! It's
62 harder in the kitchen than in home support". Because when someone is on the outside it is one
63 thing, when we get there it's another! But well I used to feel pain in my lower back, but now well...
64 now it's the arms...

65 Researcher: Now you're better on that side, but not as good on the other?

66 Rita: But at least I'm already better on one side! I no longer feel so much pain! I feel much better.
67 I move much better. One tries to bend down and then comes that pain, having to try another
68 position or having to do like this. I used to go on my knees, for example to clean the dust under
69 things so it wouldn't hurt so much I would go on my knees. For example, while cleaning the
70 bathroom I would go on my knees to clean the toilet, the bathtub, all that... Not anymore, now I
71 do everything bending down like this, because I can... And before I had to do it, right? I had more
72 difficulty so I took longer too... I was...

73 Researcher: How was it before? Do you remember how the pain started?

74 Rita: I started having pain when I was very young, I think it was because of my childhood,
75 because unfortunately I lost my mother when I was 14 years old and started working immediately
76 to support the household. My sister and I! We were both alone because my father didn't care
77 about us. My father passed way 8 years ago. We stayed at home with him, but he gave in to
78 alcohol and it was... It's not even good to think of that period of my adolescence... And I'm not
79 from here, I'm from up north, from xxx, from that mountain range of xxx... And it was like this: I
80 worked on the land, carrying sand, manure, grapes, sacks of fertilizer when it was to go to the
81 land... And I was very young, 14, 15, 16, 17... when I came here at 18... Digging, it was... I think
82 it started right there because I remember always having pain in my back... I think it was... Then
83 there were those people who used to repress things so we would take more amount... While
84 climbing a step the legs would shake with the weight I had on me... And I think it was because of
85 that. Then I came from the north and went to work on a clothing factory... I still worked for many
86 years, many years... Maybe 7 or 8... One is all day in the same position... While sitting at the
87 machine, you only move both feet, one to lift the presser and the other to sew, isn't it? And you
88 spend the whole day in that position... And when I got up, at that time, I used to feel as much
89 pain as I do now... Because when I was getting up from the chair I was like an old woman with a
90 hunchback from the pain here for being 4 hours in that position! I would only move out of there to
91 go to the toilet... Because it's like this: that is an assembling line... you must have seen it on
92 TV... my work passes on to the one next to me, then to the next, and if I stop, the colleague next

93 to me will be out of work. So over there we have to go on like this the whole day. Until... actually I
94 never had any problems, one of my sisters who also worked there for many years... Until she...
95 as she was weaker than me, maybe it was the bones, I don't know... I know she was on sick
96 leave for a long time because of a pain on the shoulder that prevented her from lifting the
97 jackets... Because... During the Summer, for example... we work the other way around! During
98 the summer, it's the winter's jackets! And during the winter, it's summer clothes... It's already
99 hot... and someone over there with that heat... sometimes it would even set... that fire thing...
100 the fire alarm off so hot it was... A person with a jacket like that... heavy... making those jackets
101 there... I actually think this is all due to my work being... I like sewing, I took a dressmaker
102 training course... I don't have a cooking one! But I do have dressmaker training... But I like to
103 sew at home, but I don't like to sew at factories! Because... first, we don't learn anything there!
104 It's always the same, then it's always... If necessary, you're 15 days or 3 weeks with a machine
105 for example with black or white or yellow thread... Because until you make a certain number of
106 pieces, the thread is always... It's very monotonous work! Cooking, I like that very much!
107 Because, for example, today you cook beans, tomorrow you cook codfish "à Brás", then the next
108 day another type of codfish... It's monotonous because we are always... I finish... It's lunch from
109 1 till 2... And at 2, I am already starting to prepare dinner, I haven't finished digesting lunch, I've
110 just finished lunch... I'm already preparing dinner... But it's a job that is not as monotonous as
111 sewing. I like to do it and if you ask me what I like most, it's being in the kitchen! I spend most of
112 my time in the kitchen. Weeks pass by and I don't even sit in a couch, I spend my time in the
113 kitchen, either baking a cake or making some pastry, I also make a lot of pastry... Or during the
114 Winter I make "filhoses" (typical Portuguese pastry)... my favourite place at home is the kitchen!
115 Or the sewing machine... But right now I only sew for myself, or for my sister or for someone
116 like... for example for my colleagues, new uniforms... I already know I have to hem the pants...
117 but sewing, like I used to do 10/15 years ago, I no longer do that! And I don't do it, because I
118 don't have the time, but I like it! But I hem some pants today, then sew a zipper tomorrow...
119 Another day I take a skirt in... It's different from being there 15 days or 3 weeks... For example,
120 back then I didn't go to xxx because I said: "no! As long as I get a job somewhere else, I'm not
121 going to the clothing factory!" The factory has already closed and I still have the same idea... as
122 long as I can find a job somewhere else I'm not going to a clothing factory... I'm not saying I will
123 not go, because I may need it, right? I live of my salary and it's my bad luck if it lacks... There it is,
124 I had all those pains but I never missed a day of work! One day I would take "be-nu-ron"
125 (paracetamol), another day "brufene" (ibuprofen), then "nolotil" (metamizole), so it wouldn't
126 always be the same... But I didn't take them every day! Those days my back hurt I would take

127 them... Since then I have never taken a pill... But I have to work, I have two kids and my bills to
128 pay and all that... But I will only go to a clothing factory in case I don't find anything else
129 elsewhere... Otherwise... If I find something somewhere else, I won't go to a clothing factory!

130 Researcher: You still worked there for how long? 7 years?

131 Rita: 7 or 8 years! Because I worked a year and a half up North! I worked 3 in X, I don't know if
132 you're from Setúbal... It's in road to Alentejo, here in Setúbal, it's called Estrada do Alentejo...
133 Meanwhile, that factory closed down, back then when the factories started to close down. Then I
134 worked there in X, also for 4 years, and then it also closed down. That's when I stopped, so I
135 worked 8 years and a half in factories... Then I went to work for a lady... it was her... I only
136 worked 2 years for her, but I was lucky! She taught me a lot during those 2 years I worked for her.
137 She taught me how to bake, how to make pastries... I already liked cooking, but I didn't... She
138 taught me everything... For example, I said and will keep saying: "I learnt more in those 2 years
139 with that lady, than throughout the 9 where I am now!" Because here I've spent... 9 or 8
140 months... I started in June, moved on to being a cook in April! Throughout all those months I was
141 with a cook and I was an assistant. From that moment on, they moved me on to being a cook and
142 they have never had any other cook, it has always been me! I go to the Internet for example, or to
143 a cook book... looking for recipes... but never learnt anything there... except for that time with the
144 other lady... Throughout those 2 years I learnt everything! But about cooking, I didn't learn
145 anything, because she would only do sweet and savouries, I never saw her making a pan of
146 soup... About cooking for a restaurant, I didn't learn anything... but I enjoy much of what I do...

147 Researcher: ... and you have been in that area for quite some time, for quite some years...

148 Rita: For 11... With the 2 years with the lady, it's 11. And then I worked one year in partnership
149 with another lady... Because I'm young, a week from this Saturday I will turn 43... But for
150 example, if it weren't for all these laws... I... for example, in 12 years would be retired, with 40
151 years of deductions, now with all these laws it's out of question... But I... that partnership... that
152 didn't work out well and I ended it and went to where I am now! And now I earn more alone at
153 home than what I earned back then in that partnership... so we keep living... with pains... but
154 now happily, with no pain!

155 Researcher: And what about all these years, from the time you worked in the clothing factory,
156 back then, what were the pains like?

III. Rita`s interview transcript (excerpt) – Table version

Rita's Interview | Data Analysis (Steps 1 to 3)

LN	Exploratory Comments _ Step 2	Original Transcript _ Step 1	Emergent Ideas_ Step 3
110	Nowadays, daily life activities seem to be easier to perform. <i>This is not</i>	One tries to bend down and then comes that pain,	<p>Keep doing daily life activities despite pain</p> <p>The sense of control (control pain – control your daily life routines)</p> <p>Pain and work in childhood</p> <p>Stolen adolescence</p>
111	<i>clear because she mixes present and past tenses.</i>	having to try another position or having to do like this. I	
112		used to go on my knees, for example to clean the dust	
113	<u>Rita could influence the control of pain by altering her movements</u>	under things so it wouldn't hurt so much I would go on	
114	<u>when doing a task.</u>	my knees. For example, while cleaning the bathroom I	
115	<u>There is an underlying sense of control – Rita is in control of her pain</u>	would go on my knees to clean the toilet, the bathtub,	
116	<u>and this seems to mean that she can also control her daily life</u>	all that... Not anymore, now I do everything bending	
117	<u>routines.</u>	down like this, because I can... And before I had to do	
118	<u>"I had more difficulty so I took longer too..." – suggesting that pain has</u>	it, right? I had more difficulty so I took longer too... I	
119	<u>not prevented her from doing these tasks, it just had made them more</u>	was...	
120	<u>difficult or more time consuming.</u>	Researcher: How was it before? Do you remember how	
121		the pain started?	
122		Rita: I started having pain when I was very young, I	
123	Rita introduces a connection between her pain and her childhood.	think it was because of my childhood, because	
124	<i>She uses the expression: "I started having pain when I was very</i>	unfortunately I lost my mother when I was 14 years old	
125	<i>young, I think it was because of my childhood" – suggesting that her</i>	and started working immediately to support the	
126	<i>pain was caused by something that happened in that period of her life.</i>	household. My sister and I! We were both alone	
127	The loss of her mother when she was 14 years old obligated her to	because my father didn't care about us. My father	
128	start working very soon. <u>Does she relate this work with her pain?</u>	passed way 8 years ago. We stayed at home with him,	
129		but he gave in to alcohol and it was... It's not even	
130		good to think of that period of my adolescence...	
131	<u>Rita took adult responsibilities when she was 14. Does Rita think</u>		
	<u>people care about her now? She supports others as a cook now and</u>		

<p>131 132 133 134 135 136 137 138 139 140 141 142 143 144 145 146 147 148 149 150 151 152</p>	<p><u>she supported her sister. What does psychosocial theory tell us about life stages – tasks during adolescence? Did Rita jump/ not complete stage? What could that mean.</u></p> <p><i>She also uses the expression “It’s not even good to think of that period of my adolescence...” after talking about her father. What was the most difficult: the work or the relationship with her father who gave in to alcohol? And, does she relate any of these subjects with her pain?</i></p> <p>Rita is from a small village in the north of Portugal.</p> <p>She describes the work tasks she had to do when she started working.</p> <p><i>“... worked on the land, carrying sand, manure, grapes, sacks of fertilizer when it was to go to the land... And I was very young, 14, 15, 16, 17... when I came here at 18... Digging, it was...”</i> <u>She seems to believe that her pain was caused by these tasks, which were physically demanding.</u></p> <p><i>The use of this sentence “While climbing a step the legs would shake with the weight I had on me...” suggests she had no choice. She had to work in order to support the household, and this meant she had to do demanding tasks (physically).</i></p> <p><u>Or, is she merely complaining about the stolen of her childhood and adolescence?</u></p> <p><u>Rita keeps presenting the story of her life, while she is trying to make her “pain story” clear. Both seem to be deeply connected.</u></p>	<p>And I’m not from here; I’m from up north, from xxx, from that mountain range of xxx... And it was like this: I worked on the land, carrying sand, manure, grapes, sacks of fertilizer when it was to go to the land... And I was very young, 14, 15, 16, 17... when I came here at 18... Digging, it was... I think it started right there because I remember always having pain in my back... I think it was... Then there were those people who used to repress things so we would take more amount... While climbing a step the legs would shake with the weight I had on me... And I think it was because of that. Then I came from the north and went to work on a clothing factory... I still worked for many years, many years... Maybe 7 or 8... One is all day in the same position... While sitting at the machine, you only move both feet, one to lift the presser and the other to sew, isn’t it? And you spend the whole day in that position... And when I got up, at that time, I used to feel as much pain as I do now... Because when I was getting up from the chair I was like an old woman with a hunchback from the pain here for being 4 hours in that position! I would only</p>	<p>Pain and work in childhood</p> <p>Pain as part of the life story</p>
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<p>153 154 155 156 157 158 159 160 161 162 163 164 165 166 167 168 169 170 171 172 173 174</p>	<p>She came to the centre of Portugal (littoral coast) when she was 18. It is not clear why she came. <u>But probably she was looking for better conditions of life (job) – a common migratory movement a couple of decades ago in Portugal.</u></p> <p><u>Feelings of responsibility for others.</u></p> <p>Her new job at a clothing factory (in an assembling line) was also painful. She did not have to carry heavies, but she had to stay all day in the same position, which seemed to be also painful.</p> <p>The use of the expression “<i>I used to feel as much pain as I do now</i>” is contradictory with her discourse in the beginning of the interview. Was she avoiding complaining about pain for any reason?</p> <p>Very powerful metaphor – “<i>I was like an old woman with a hunchback from the pain here for being 4 hours in that position!</i>” – <u>maybe suggesting not only how painful her job was but also how “deteriorating”.</u></p> <p>After describing this job as “painful” and “deteriorating”, she states that she had never had any problems – <u>suggesting that she views herself as a strong person, who “had resisted” to the challenges she was presenting.</u> This is emphasised by the comparison with her younger sister (“<i>as she was weaker than me, maybe it was the bones, I don’t know...</i>”) - <u>Her bones/ herself was stronger.</u></p>	<p>move out of there to go to the toilet... Because it’s like this: that is an assembling line... you must have seen it on TV... my work passes on to the one next to me, then to the next, and if I stop, the colleague next to me will be out of work. So over there we have to go on like this the whole day. Until... actually I never had any problems, one of my sisters who also worked there for many years... Until she... as she was weaker than me, maybe it was the bones, I don’t know... I know she was on sick leave for a long time because of a pain on the shoulder that prevented her from lifting the jackets... Because... During the Summer, for example... we work the other way around! During the Summer, it’s the Winter’s jackets! And during the winter, it’s Summer clothes... It’s already hot... and someone over there with that heat... sometimes it would even set... that fire thing... the fire alarm off so hot it was... A person with a jacket like that... heavy... making those jackets there... I actually think this is all due to my work being... I like sewing, I took a dressmaker training course... I don’t have a cooking one! But I do have dressmaker training...</p>	<p>Another “deteriorating” job</p> <p>Strong enough to bear pain</p> <p>A journey full of challenges</p>
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<p>175 176 177 178 179 180 181 182 183 184 185 186 187 188 189 190 191 192 193 194 195 196</p>	<p>Rita keeps describing the challenges she had to face in that job (sometimes the temperature was so hot in the factory that set the fire alarm). <u>Rita seems to be describing a journey full of difficulties and challenges that she had to deal with. All those difficulties and challenges seem to be on the origin of her pain.</u></p> <p>She took a dressmaker training course, but she doesn't like to sew at factories. <u>One might think that this would be because this job was physically demanding and painful. However, Rita justifies that she does not like to work in factories because it is a monotonous work where one does not learn anything new. Rita seems to take these difficulties for granted and does not seem to care about them. For her these challenges are part of life/ she is used to them.</u></p> <p><u>Hard work for a young person. She had huge responsibilities and she was an adolescent. She had to grow up very soon. Consequences?</u></p> <p><u>At the clothing factory (manual work, but sitting in the same position) – again no control over environment or circumstances.</u></p> <p>She prefers her work as a cook (despite being physically demanding too – as she described in the beginning of this interview).</p> <p>She spends the most part of her day in the kitchen (job and home).</p> <p><u>This suggests that pain has not prevented her to do the tasks she likes to do. Pain seems to be part of her life, but does not seem to play the</u></p>	<p>But I like to sew at home, but I don't like to sew at factories! Because... first, we don't learn anything there! It's always the same, then it's always... If necessary, you're 15 days or 3 weeks with a machine for example with black or white or yellow thread... Because until you make a certain number of pieces, the thread is always... It's very monotonous work! Cooking, I like that very much! Because, for example, today you cook beans, tomorrow you cook codfish "à Brás", then the next day another type of codfish... It's monotonous because we are always... I finish... It's lunch from 1 till 2... And at 2, I am already starting to prepare dinner, I haven't finished digesting lunch, I've just finished lunch... I'm already preparing dinner... But it's a job that is not as monotonous as sewing. I like to do it and if you ask me what I like most, it's being in the kitchen! I spend most of my time in the kitchen. Weeks pass by and I don't even sit in a couch, I spend my time in the kitchen, either baking a cake or making some pastry, I also make a lot of pastry... Or during the Winter I make "filhoses" (typical Portuguese pastry)...</p>	<p>Challenges (where pain is included) as part of life</p> <p>The idea of lack of control</p> <p>Pain as part of life</p>
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197	<u>main role.</u>	my favourite place at home is the kitchen! Or the	
198		sewing machine... But right now I only sew for myself,	
199		or for my sister or for someone like... for example for	
200		my colleagues, new uniforms... I already know I have to	
201		hem the pants... but sewing, like I used to do 10/15	
202		years ago, I no longer do that! And I don't do it,	
203	Don't have time to sew, like she had done in the past.	because I don't have the time, but I like it! But I hem	
204		some pants today, then sew a zipper tomorrow...	
205	<u>She is in control unless "bad luck" strikes</u>	Another day I take a skirt in... It's different from being	
206		there 15 days or 3 weeks... For example, back then I	
207		didn't go to xxx because I said: " no! As long as I get a	
208		job somewhere else, I'm not going to the clothing	
209	As long as she gets a job somewhere else, she does not plan to work	factory!" The factory has already closed and I still have	
210	in a clotting factory. In case she needs it, she would do it.	the same idea... as long as I can find a job somewhere	
211	There seems to be a pattern in her life: she does what has to be done,	else I'm not going to a clothing factory... I'm not saying	
212	no matter how difficult or painful it is.	I will not go, because I may need it, right? I live of	
213		my salary and it's my bad luck if it lacks... There it is, I	To do what needs to be
214	<i>The use of this sentence: "I had all those pains but I never missed a</i>	had all those pains but I never missed a day of	done (no matter the pain)
215	<i>day of work!" suggests again that she sees herself as a strong person,</i>	work! One day I would take "ben-u-ron" (paracetamol),	
216	<i>a person that can resist to pain. Her tone of voice suggests she is</i>	another day "brufene" (ibuprofen), then "nolotil"	
217	<i>proud of herself.</i>	(metamizole), so it wouldn't always be the same... But I	Proud of her strength
218	Sometimes she needs pills.	didn't take them every day! Those days my back hurt I	

219	<u>Once again, her priority seems to be supporting her family. Previously,</u>	would take them... Since then I have never taken a	
220	<u>herself and her sister after their mother's death. Now, her two kids.</u>	pill... But I have to work, I have two kids and my	
221	<u>She seems to be ready for doing any efforts in order to support family.</u>	bills to pay and all that... But I will only go to a	Support family is the
222		clothing factory in case I don't find anything else	priority (pain is part of
223		elsewhere... Otherwise... If I find something	life)
224	She worked for 8 years and a half in clothing factories. Then these	somewhere else, I won't go to a clothing factory!	
225	factories closed (related to economic difficulties in the 90's).	Researcher: You still worked there for how long? 7	
226		years?	
227		Rita: 7 or 8 years! Because I worked a year and a half	
228		up North! I worked 3 in xxx, I don't know if you're from	
229	Then she worked 2 years "for a lady" (housekeeper)	Setúbal... It's in road to Alentejo, here in Setúbal, it's	
230	She enjoyed this job because she learnt a lot (about cooking). She	called Estrada do Alentejo... Meanwhile, that factory	
231	does not relate pain to this job.	closed down, back then when the factories started to	
232		close down. Then I worked there in x, also for 4 years,	
233	This seems to be the job she enjoyed the most (even more than her	and then it also closed down. That's when I stopped,	
234	actual job as a cook), because she was taught and she learnt.	so I worked 8 years and a half in factories... Then I	
235	She taught Rita, the things her mother had not time to teach.	went to work for a lady... it was her... I only worked 2	
236	Nowadays, she searches for new recipes on the internet but she does	years for her, but I was lucky! She taught me a lot	
237	not consider she is learning anything new.	during those 2 years I worked for her. She taught me	Some jobs are not
238		how to bake, how to make pastries... I already liked	painful – Enjoy to learn
239		cooking, but I didn't... She taught me everything...	
240		For example, I said and will keep saying: "I learnt more	

Exploratory comments column

Normal text: descriptive comments; *Italic text*: linguistic comments; Underlined text: conceptual comments; Underlined text: supervisor's comments

Appendix 19: Audit trail

This audit trail presents a record of the procedures included in data analysis and consists of 2 sections. The first presents an overall perspective of these stages. The second provides detailed information on the stages previously presented, while using an interview from one participant as an example.

I. Overall perspective of data analysis

The following procedures were carried out for each individual interview:

1. After the verbatim transcription, the transcript was read several times; this constituted the first stage of data analysis and involved immersing oneself in the data, through reading, re-reading and listening to the recordings. In this first stage, the individual participant was the focus of the analysis.
2. After several readings, the interview data was introduced into a table (word document) that includes 4 columns (fig.1):
 - The first column (from left to right) included the line numbers;
 - The second included the exploratory comments, which represented the second stage of data analysis. This process of initial noting aimed to produce comprehensive and detailed notes and comments on the data. Throughout this process, more complex issues have been gradually examined – firstly, via descriptive comments focused on describing the content, secondly via linguistic comments concerned with the specific use of language, and finally via conceptual comments focused on engaging at a more interrogative and conceptual level. Comments from supervisory team were also integrated;
 - The third column included the original transcript;
 - The fourth column included the initial ideas and represented the first part of the development of emergent themes. The analysis was focused not only on the interview transcript but also on the notes and comments added in the second column. The aim was to

reduce the volume of detail without losing its complexity. This process was orientated by the hermeneutic rule of movement between the parts and the whole: as the analysis was carried out, the original transcript became a set of parts, which then came together in a new whole at the end of this analysis. The ideas emerged at this stage had resulted from a co-construction of meaning, in the sense that they not only included the participant`s words but also the researcher`s interpretation.

Laura`s Interview | Data Analysis (Steps 1 to 3)

LN	Exploratory Comments _ Step 2	Original Transcript _ Step 1	Emergent Ideas_ Step 3	
241		não encaro isso dessa maneira, mas pronto eles é		
242		que são os médicos...		
243	Laura emphasises that her pain could be related to something more	Investigadora: Não encara dessa maneira... qual é que	Hypothesising something serious	
244	serious. Seemingly, she does not understand why the x-ray did not	é a sua explicação para a sua dor ter vindo a...		
245	show any problem. <u>She seems to believe that she has a serious</u>	Laura: Olhe eu às vezes penso que tenho alguma		
246	<u>problem that is not detectable by an x-ray (because the x-ray is not</u>	coisa... às vezes penso! Porque é assim eu fiz rx,		
247	<u>enough accurate).</u>	mas no rx não acusava nada, às vezes penso... às		
248	<i>Simultaneously, she is not happy with her doctor`s words "this is pain!</i>	vezes penso e isso às vezes deixa-me um bocadito		Sad about GP`s approach
249	<i>Nowadays everyone have back pain". She just says "alright" about</i>	mais triste ainda, porque já falei com o médico e ele		
250	<i>this. Her words suggest dissatisfaction with the GP approach, not only</i>	"ah isso não é nada... isso são dores... agora toda a		To deal with the absence of solutions
251	<i>because he does not explore her problems in detail but also because</i>	gente tem dores de costas", "pronto, está bem!"... e		
252	<i>he seems to compare Laura with other people – this seems to make</i>	então não se aprofunda... não se aprofunda o		
253	<i>her perceive her problems as being minimised.</i>	assunto.		
254		Investigadora: E como é que se sente quando isso		
255	<i>Laura`s pause before answering this question (How do you feel about</i>	acontece?		
256	<i>the GP`s words?) seems to suggest that it is difficult to talk about this.</i>	Laura: (Suspiro) É assim: mal! Bastante mal! Daí		
257	<i>Her following words support this idea "Bad. Very bad!" The idea of</i>	que... eu diga que isto vai continuar sempre... e		
258	<i>"having pain forever" seem to be the most difficult to accept for her.</i>	pronto não é agradável... não é agradável nós vemos		
259	<i>She seems to be convinced by her GP`s ideas that there is no solution</i>	que não há grande solução para o nosso problema!		
260	<i>for her pain.</i>	Investigadora: O principal problema aqui... não sei se		

Fig. 1 – Excerpt from data analysis _ Laura`s interview

3. The content of the right hand column of the previous table was manually introduced into the N-Vivo 7 research software. Each emergent idea was converted into a free node that was codified as follows: **e.g. 4_Laura_032_Hipotesising something serious (L.12.245)** (fig.2)

Name	Sources	References	Created	Modified
4_LAURA_028_Pain and physical efforts (L.10.208; L.18.378; L.23.495)	1	3	18-01-2013 19:00	18-01-2013 20:07
4_LAURA_029_Cannot understand the doctor's words (L.10.208)	1	1	18-01-2013 19:01	18-01-2013 19:02
4_LAURA_030_Deblity and pain (L.11.223)	1	1	18-01-2013 19:07	18-01-2013 19:07
4_LAURA_031_Doctor knows more than me (L.11.223)	1	1	18-01-2013 19:08	18-01-2013 19:08
4_LAURA_032_Hipotesising something serious (L.12.245; L.13.263; L.30.638)	1	3	18-01-2013 19:11	18-01-2013 20:32
4_LAURA_033_Sad about the GP's approach (L.12.245)	1	1	18-01-2013 19:12	18-01-2013 19:12
4_LAURA_034_To deal with the absence of solutions (L.12.255)	1	1	18-01-2013 19:14	18-01-2013 19:14
4_LAURA_035_Having a diagnose would give more hope (L.13.263)	1	1	18-01-2013 19:21	18-01-2013 19:59
4_LAURA_036_Am I becoming crazy (L.13.263; L.14.288; L.23.495)	1	3	18-01-2013 19:25	18-01-2013 20:08
4_LAURA_037_I really have pain (L.13.263)	1	1	18-01-2013 19:26	18-01-2013 19:26
4_LAURA_038_Self-questioning (L.14.292)	1	1	18-01-2013 19:28	18-01-2013 19:28
4_LAURA_039_Keep in silence to deal with pain (L.14.306)	1	1	18-01-2013 19:29	18-01-2013 19:30
4_LAURA_040_Lack of support from the others (L.14.306)	1	1	18-01-2013 19:30	18-01-2013 19:31
4_LAURA_041_Am I a weak person (L.14.306)	1	1	18-01-2013 19:31	18-01-2013 19:31
4_LAURA_042_Keep in silence because of the lack of support from the others (L.15.3)	1	1	18-01-2013 19:32	18-01-2013 19:32
4_LAURA_043_They are nice but they do not understand me (L.17.351)	1	1	18-01-2013 19:45	18-01-2013 19:46
4_LAURA_044_Pain and ageing (L.17.357)	1	1	18-01-2013 19:47	18-01-2013 19:47
4_LAURA_045_No limits in the past vs a limited life in the present (L.17.357)	1	1	18-01-2013 19:48	18-01-2013 19:48
4_LAURA_046_Questions about physical efforts and pain (L.18.386)	1	1	18-01-2013 19:50	18-01-2013 19:50
4_LAURA_047_GP advices to not carry heavies (L.19.396; L.27.583)	1	2	18-01-2013 19:54	18-01-2013 20:25
4_LAURA_048_Not following GP's advices (L.19.396)	1	1	18-01-2013 19:54	18-01-2013 19:55
4_LAURA_049_The GP is the expert (L.19.396)	1	1	18-01-2013 19:56	18-01-2013 19:56
4_LAURA_050_Disappointment and resignation about the GP's approach (L.20.425)	1	1	18-01-2013 19:57	18-01-2013 19:57
4_LAURA_051_Disappointed due to unsuccessful attempts to relieve pain (L.21.442)	1	1	18-01-2013 20:02	18-01-2013 20:02
4_LAURA_052_I am convinced that I have to support pain because there are no altern	1	1	18-01-2013 20:03	18-01-2013 20:03
4_LAURA_053_Revolt against the GP's approach (L.21.442)	1	1	18-01-2013 19:54	18-01-2013 19:54
4_LAURA_054_The GPs do not spend time listening to patients (L.22.472)	1	1	18-01-2013 19:55	18-01-2013 19:55
4_LAURA_055_GPs probably do not understand my pain (L.22.482)	1	1	18-01-2013 20:05	18-01-2013 20:05
4_LAURA_056_I do not give up looking for an explanation (private practice) (L.23.503;	1	2	18-01-2013 20:10	18-01-2013 20:28
4_LAURA_057_My pain does not come first (L.23.503)	1	1	18-01-2013 20:11	18-01-2013 20:11
4_LAURA_058_Contradictory explanations about pain (L.25.538; L.25.547)	1	2	18-01-2013 20:14	18-01-2013 20:15
4_LAURA_059_Upset about the GP's explanation about pain (L.26.560)	1	1	18-01-2013 20:17	18-01-2013 20:17
4_LAURA_060_I am not that weak! (L.26.568)	1	1	18-01-2013 20:21	18-01-2013 20:21
4_LAURA_061_Give up on the GP's approach (L.27.583; L.28.600)	1	2	18-01-2013 20:24	18-01-2013 20:27

Fig. 2 – Print screen from N-Vivo, excerpt from the free nodes table.

In the previous code example [4_Laura_032_Hypothesising something serious (L.12.245)] 4 identified the number of the interview (in chronological order), **Laura** the participant's pseudonym, **032**, the number attributed to the emergent idea (in chronological order), **Hypothesising something serious** represented the emergent idea, and **(L.12.245)** represented a code that enabled the excerpt correspondent to the emergent idea in the transcript to be located easily (**L** - first letter of the participant's pseudonym, **12** - table transcription page number, **245** - table transcription line number). This record also helped the researcher to check the correspondence between the first identified ideas and the excerpts from each interview (fig.3).

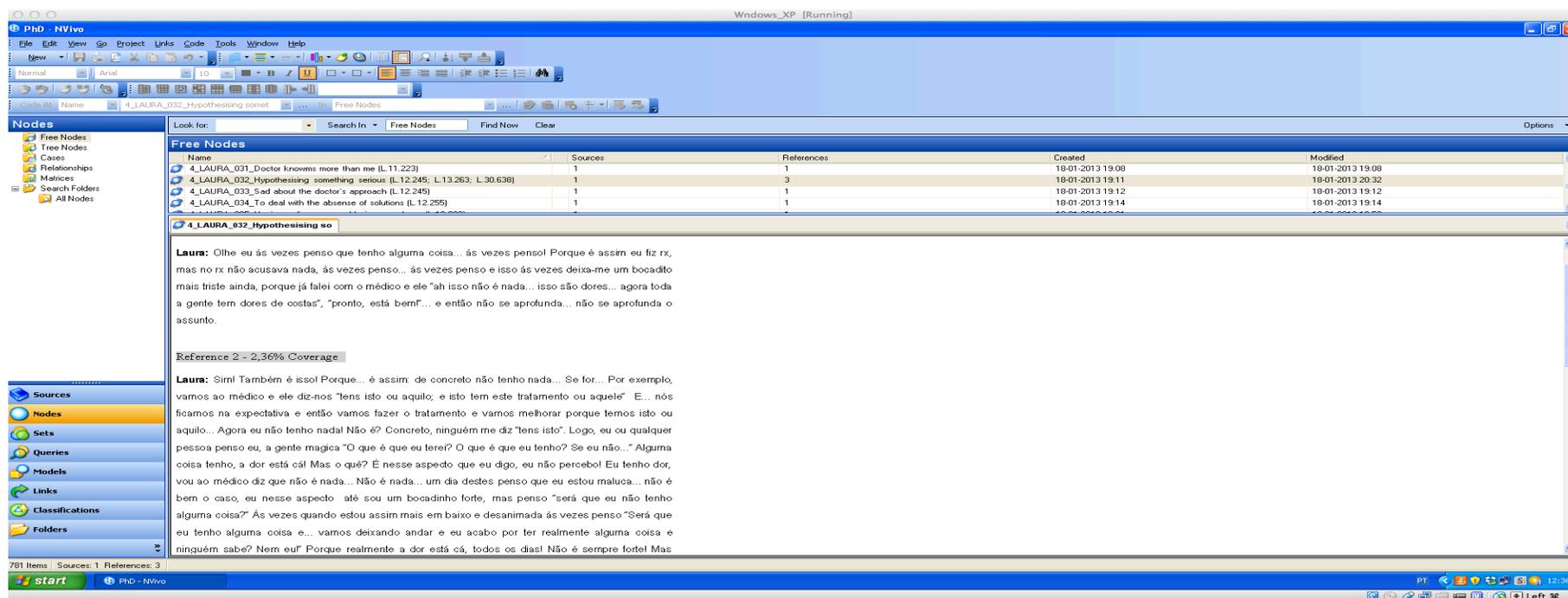


Fig. 3 – Print screen from N-Vivo, excerpt associated to a specific free node

4. The list of free nodes was exported to an excel document, which was used to preserve a detailed record of the development of the emergent themes. The fifth column (from left to right) includes the final themes emerged in the interview as well as the concepts and related excerpts (fig.4).

Laura`s Interview_ Looking for connections across emergent themes (Steps between free nodes and tree nodes_using nvivo) →

Refining emergent themes I (chronological order_ looking for connections using colours)	Refining emergent themes II (looking for connections and grouping emergent themes)	Refining emergent themes III (looking for connections and collapsing emergent themes)	Refining emergent themes IV (grouping emergent themes after collapsing)	Refining emergent themes V (organising themes and superordinated themes - after designing a conceptual map in NVIVO)
Always with pain (L.1.4; L.32.702; L.40.871)	Jobs	Jobs	Jobs	Making sense about pain
Confused about pain (L.1.4)	Pain and physical efforts (L.10.208; L.18.378; L.23.495)	Pain and physical efforts (L.10.208; L.18.378; L.23.495)	Pain and physical efforts (L.10.208; L.18.378; L.23.495)	To deal with the absense of solutions - I am tired of having a non-treatable pain (L.2.42; L.12.255; L.41.898; L.39.856)
The most disturbing is not the pain itself but its constant presence (L.1.4)	<i>Feelings and thoughts about pain</i>	<i>Feelings and thoughts about pain</i>	<i>Feelings and thoughts about pain</i>	Resigned, frustrated and get used to pain (L.2.27; L.9.186)
Resignation (L.2.27)	The most disturbing is not the pain itself but its constant presence (L.1.4)	The most disturbing is not the pain itself but its constant presence (L.1.4)	The most disturbing is not the pain itself but its constant presence (L.1.4)	Pain impact on mood - it is disturbing (L.2.42)
The doctor - there is nothing to do about your pain (H.2.27; L.7.140)	Resignation (L.2.27)	Resigned and get used to pain (L.2.27)	Resigned and get used to pain (L.2.27)	The most disturbing is not the pain itself but its constant presence (L.1.4)
Get used to pain (L.2.27)	Get used to pain (L.2.27)			Disturbed because pain has changed my habits (L.7.140)
Pain is disabling (L.2.27; L.8.161)			Pain impact on mood - it is disturbing (L.2.42)	Upset because pain has decreased my capability to do some tasks (L.8.170)
Pain impact on mood - it is disturbing (L.2.42)	Pain impact on mood - it is disturbing (L.2.42)	Pain impact on mood - it is disturbing (L.2.42)	Disturbed because pain has changed my habits (L.7.140)	Am I becoming crazy - self-questioning (L.13.263; L.14.288; L.14.292; L.23.495)
Tired of pain (L.2.42; L.41.898)	Tired of pain (L.2.42; L.41.898)		Upset because pain has decreased my capability to do some tasks (L.8.170)	It is difficult to deal with the uncertainty about pain (L.5.100; L.30.638)
Isolation (L.2.42; L.34.729; L.35.748)	The inconsistencies (about pain) are disturbing (L.5.100)		Frustration (L.9.186)	
Medication does not work (L.3.53; L.7.140; L.20.432; L.34.742)	Disturbed because pain has changed my habits (L.7.140)	Disturbed because pain has changed my habits (L.7.140)	To deal with the absense of solutions (L.12.255)	Always the same unanswered questions about pain (L.42.908)
Pain is deeply incorporated in the daily life (L.4.68)	Upset because pain has decreased my capability to do some tasks (L.8.170)	Upset because pain has decreased my capability to do some tasks (L.8.170)	Am I becoming crazy - self-questioning (L.13.263; L.14.288; L.14.292; L.23.495)	I cannot understand (L.1.4; L.6.109; L.6.120; L.9.191; L.13.263; L.22.482; L.25.538; L.25.547)
Loss of patience (L.4.68)	Frustration (L.9.186)	Frustration (L.9.186)	It is difficult to deal with the uncertainty about pain (L.5.100; L.30.638)	× Debility and pain (L.11.223)
Some daily activities are like a torture (L.4.76)	To deal with the absense of solutions (L.12.255)	To deal with the absense of solutions (L.12.255)	I am tired of having a non-treatable pain (L.2.42; L.41.898; L.39.856)	× Pain and age aging (L.17.357)
Good support from her husband (L.4.76)	Am I becoming crazy (L.13.263; L.14.288; L.23.495)	Am I becoming crazy - self-questioning (L.13.263; L.14.288; L.14.292; L.23.495)	It is more difficult to be understood than to talk about pain (L.40.876)	× Questions about physical efforts and pain ((L.10.208; L.18.378; L.18.386; L.23.495))

Fig. 4 – Excerpt from data analysis _ Laura`s interview

In the previous figure, the first column (from left to right) included the free nodes exported from n-vivo. At this stage, the ideas that were connected with the same subject were identified via a colour classification. Each colour represented a specific idea and the same code was used in all interviews (for example, yellow was used to identify ideas related to explanations for pain, orange was used to identify ideas related to the contact with health professionals, red was used to identify ideas related to the participant's social network and brown was related to the participant's family).

In the second column, the chronological order (from column 1) was interrupted and information was reorganised according to the colour classification. This column represented the first draft of the emergent themes.

In the third column, each theme was refined, by collapsing similar ideas, without losing the previously selected excerpts.

The fourth column represented the second draft of the emergent themes.

After developing the second draft of the emergent themes, the analysis progressed to another stage and connections across themes were searched. In order to find these connections, several strategies were used such as abstraction (defined as a form of identifying patterns between ideas or concepts and developing a sense of what connect them) and subsumption (when an idea or concept acquired the status of a theme, as it brought together several related ideas or concepts). The aim was to find a way of drawing the emergent themes together and producing a structure that reflected the participant's account. In order to engage in a deeper level of analysis, two main strategies were applied: the development of a conceptual map, which helped the researcher to make sense of how the themes fit together (fig. 5) (using the reflexive journal and N-Vivo 7 research software); and the development of an individual narrative (using the reflexive journal). This narrative integrated both the researcher's interpretation and the participant's selected excerpts (fig. 6). It was certified that all emergent themes were part of this, avoiding the loss of any theme or idea at this stage. The outcomes of this process were represented in the fifth column.

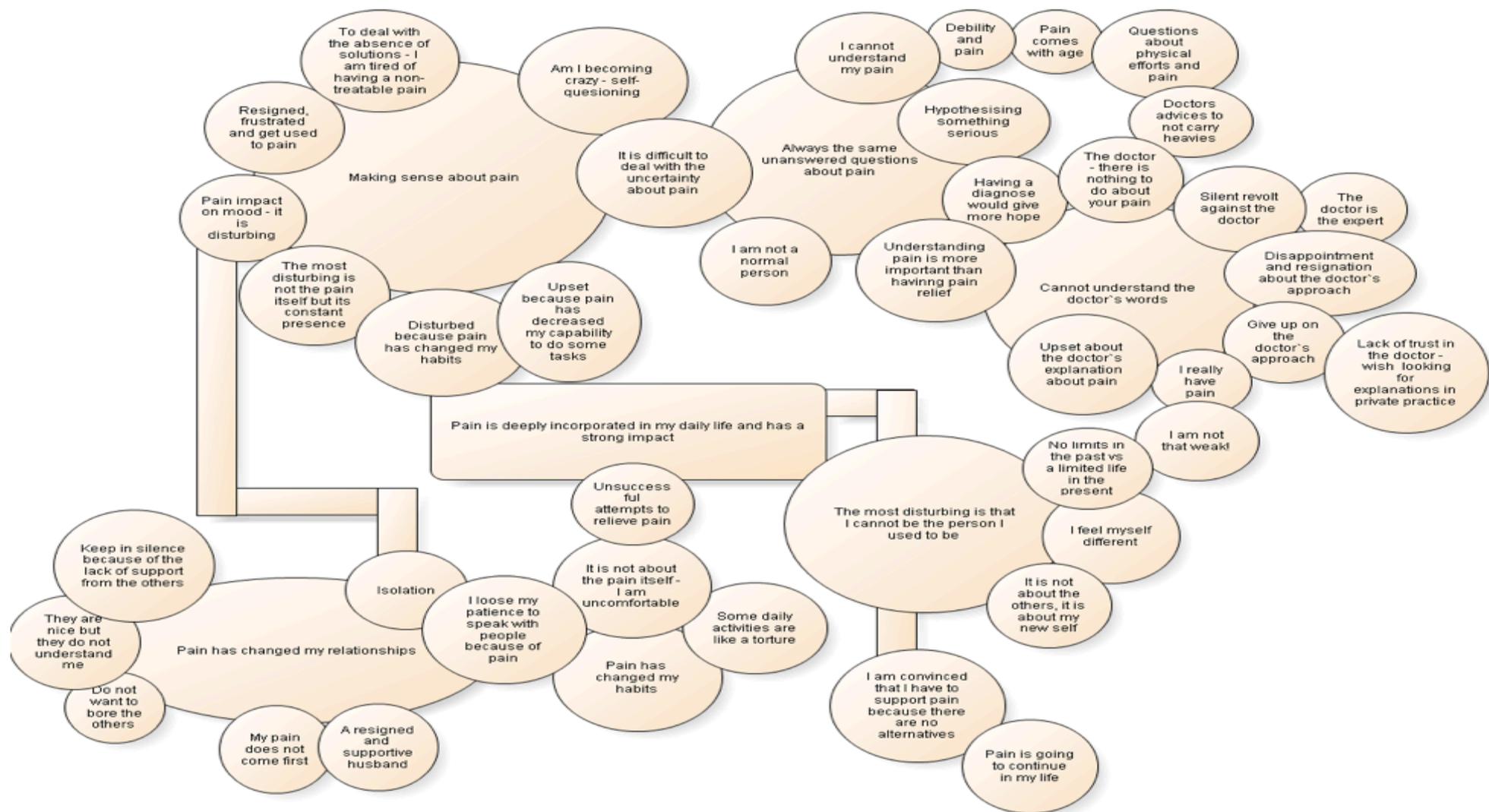


Fig. 5 – Conceptual map _ Laura`s interview

Laura was forty-eight years old and was living with her husband in a small city in the central interior Portugal. (...) She seemed to have been induced by her GP into thinking that psychological issues could explain her pain. Indeed, she associated the beginning of pain to a distressing period of her life. This pain began when her eldest son moved to another city causing her to feel depressed. Although she recognised that both episodes happened simultaneously, she found the GP's association between them strange and difficult to understand. (...) The GP's insistence that her back was in good condition seemed to have reinforced her idea that maybe there was a serious problem in her back. The possibility of having an undiscovered disease made her become worried about her pain and crave a diagnosis, leading her to emphasise that having a diagnosis would be more important than having pain relief. This idea may reveal an apparent difficulty in dealing with the uncertainty associated with the definition of a specific diagnosis.

"The question is always the same: what is this [NSCLBP]? What can I do? These are my doubts! These have been my doubts for so long... And I'm not sure that I'll have answers... These doubts will be with me, at least until I have a concrete answer... I think it'll be like this..." (Laura.42.908-913)

(...) The apparent discrepancy between her GP's words and the way she interpreted pain seemed to be responsible for Laura's struggle to understand the GP's point of view. (...) She held contradictory thoughts about the GP's approach: on one hand she considered the GP to be the expert, but on the other hand she questioned his knowledge because he did not seem to know the origin of her pain. (...). Despite an apparent lack of satisfaction with the GP's explanation and approach, Laura seemed to accept his explanations without asking any questions.

As with Alice, Eva and Helena, there was an underlying sense that the GPs always know more than patients. Their explanations were accepted, even when they did not make sense to the participants. Laura kept following the treatment prescribed by her GP, which consisted of medication although she did not believe she would have any positive results. (...) Laura reproduced her GP's words - "This is pain! Nowadays everyone has back pain" (Laura.12.245) - emphasising her lack of satisfaction. (...)

The apparent lack of trust in her GP seemed to have a major relevance. Laura admitted that she could accept there was no solution to her problem, but this had to be said by a physician in whom she trusted.

"Now, I have nothing! Isn't it? Concretely, I haven't got any problems in my back. (...) No one has said, "you've got this"... And this makes me think, and I think everyone would think the same... What is my problem? What is my problem? If... I must have something wrong because my pain is here! But, what is it? And that's why I say I can't understand! I have pain and my physician says it is nothing... nothing... (...) What if I have a serious problem? Because this pain is here, every single day. It is not a strong pain, it is a dull pain... But it is always here, always, always..." (Laura.13.263-284)(...)

She spent the whole interview emphasising that there must be a reason, associated with a health problem, to justify her pain. However, for some moments she doubted herself by questioning, "Am I going crazy?" (Laura.23.495). She moved quickly from this subject to another, without exploring it in detail, suggesting that this idea was difficult to accept. (...) The recurrent comparisons between her pain and other people's pain, alongside the encouragement to be strong and bear pain like everybody else, made Laura feel accused of being "weak". (...)

Fig. 6 – Excerpt from Laura's narrative

5. In order to keep a record of the decisions undertaken in the previous stage, a tree node was developed using the N-Vivo (fig.7). The tree node included the emergent themes and the ideas/sub-themes included in each theme. The transcript of the interview was revisited and codified in order to associate the participant's excerpts to the correspondent elements of the tree node (fig.8).

Name	Sources	References	Created	Modified
4_Laura Interview	0	0	20-01-2013 14:15	17-06-2014 0:41
Always the same unanswered questions about pain	1	1	20-01-2013 14:18	20-01-2013 19:06
Having a diagnose would give me hope	1	1	20-01-2013 18:48	20-01-2013 19:02
Hypothesising something serious	1	3	20-01-2013 18:48	20-01-2013 19:07
I am not a normal person	1	3	20-01-2013 18:49	20-01-2013 19:06
I cannot understand	1	7	20-01-2013 18:47	20-01-2013 18:55
Disability and pain	1	1	20-01-2013 18:47	20-01-2013 18:56
Pain and aging	1	1	20-01-2013 18:47	20-01-2013 18:56
Questions about physical efforts and pain	1	4	20-01-2013 18:47	20-01-2013 18:58
GP's advices to not carry heavies	1	2	20-01-2013 18:48	20-01-2013 18:59
Understanding pain is more important than having pain relief	1	3	20-01-2013 18:49	20-01-2013 19:04
Cannot understand the GP's words	1	2	20-01-2013 14:19	20-01-2013 19:28
Disappointment and resignation about the GP's approach	1	4	20-01-2013 19:09	20-01-2013 19:22
Give up on the GP's approach	1	2	20-01-2013 19:09	20-01-2013 19:24
I really have pain	1	1	20-01-2013 19:10	20-01-2013 19:26
Lack of trust in the GP - wish looking for explanations in private pr	1	3	20-01-2013 19:10	20-01-2013 19:25
Silent revolt against the GP	1	4	20-01-2013 19:08	20-01-2013 19:16
The GP is the expert	1	2	20-01-2013 19:09	20-01-2013 19:17
The GP said there is nothing to do about my pain	1	2	20-01-2013 19:08	20-01-2013 19:12
Upset about the GP's explanation about pain	1	1	20-01-2013 19:10	20-01-2013 19:26
Expectations about the future	0	0	20-01-2013 14:20	20-01-2013 14:20
I am convinced that I have to support pain because there are no al	1	1	20-01-2013 20:04	20-01-2013 20:05
Pain is going to continue in my life	1	1	20-01-2013 20:04	20-01-2013 20:05
Making sense about pain	0	0	20-01-2013 14:17	20-01-2013 14:17
Am I becoming crazy... Self-questioning	1	4	20-01-2013 18:32	20-01-2013 18:43
Disturbed because pain has changed my habits	1	1	20-01-2013 18:31	20-01-2013 18:40
It is difficult to deal with the uncertainty about pain	1	2	20-01-2013 18:33	20-01-2013 18:45
Pain impact on mood is disturbing	1	1	20-01-2013 18:30	20-01-2013 18:38
Resigned, frustrated and get used to pain	1	2	20-01-2013 18:30	20-01-2013 18:38
The most disturbing is not the pain itself but its constant presence	1	1	20-01-2013 18:31	20-01-2013 18:40
To deal with the absense of solutions - I am tired of having a non t	1	4	20-01-2013 18:28	20-01-2013 18:36

Fig. 7 – Print screen from N-Vivo, excerpt from the tree nodes table.

Windows_XP [Running]

PHD - NVivo

File Edit View Go Project Links Code Tools Window Help

Normal Arial 10

Code At Name Hypothesising something serious ... In Tree Nodes(4_Laura_Interview)Alw ...

Nodes

- Free Nodes
- Tree Nodes
- Cases
- Relationships
- Matrices
- Search Folders
- All Nodes

Look for: Search In Tree Nodes Find Now Clear Options

Tree Nodes

Name	Sources	References	Created	Modified
4_Laura_Interview	0	0	20-01-2013 14:15	17-06-2014 0:41
Always the same unanswered questions about pain	1	1	20-01-2013 14:18	20-01-2013 19:06
Having a diagnose would give me hope	1	1	20-01-2013 18:48	20-01-2013 19:02
Hypothesising something serious	1	3	20-01-2013 18:48	20-01-2013 19:07
I am not a normal person	1	3	20-01-2013 18:49	20-01-2013 19:06
I cannot understand	1	7	20-01-2013 18:47	20-01-2013 18:55
Disability and pain	1	1	20-01-2013 18:47	20-01-2013 18:56
Pain and aging	1	1	20-01-2013 18:47	20-01-2013 18:56
Questions about physical efforts and pain	1	4	20-01-2013 18:47	20-01-2013 18:58

Hypothesising something seriou

Reference 1 - 0,85% Coverage

Laura: Olhe eu às vezes penso que tenho alguma coisa... às vezes pensol Porque é assim eu fiz rx, mas no rx não acusava nada, às vezes penso... às vezes penso e isso às vezes deixa-me um bocadito mais triste ainda, porque já falei com o médico e ele "ah isso não é nada... isso são dores... agora toda a gente tem dores de costas", "pronto, está bem"... e então não se aprofunda... não se aprofunda o assunto.

Reference 2 - 2,36% Coverage

Laura: Sim! Também é issol Porque... é assim: de concreto não tenho nada... Se for... Por exemplo, vamos ao médico e ele diz-nos "tens isto ou aquilo; e isto tem este tratamento ou aquele" E... nós ficamos na expectativa e então vamos fazer o tratamento e vamos melhorar porque temos isto ou aquilo... Agora eu não tenho nada! Não é? Concreto, ninguém me diz "tens isto". Logo, eu ou qualquer pessoa penso eu, a gente magica "O que é que eu terei? O que é que eu tenho? Se eu não..." Alguma coisa tenho, a dor está cá! Mas o quê? É nesse aspeto que eu digo, eu não percebol Eu tenho dor,

431 Items Sources: 1 References: 3

start PhD - NVivo PT 13:47

Fig.8 - Print screen from N-Vivo, excerpt associated to a specific tree node

6. Then the researcher moved to the next interview and repeated the process with each of the interviews.

7. After analysing each interview in detail, the researcher engaged in the searching for patterns across all interviews (fig. 9).

Data Analysis (step 6b) _ Looking for patterns across cases
Themes and Super-ordinate themes of the individual interviews

Alice (11)	Eva (8)	Helen (8)	Laura (7)	Rita (6+1)	Fernanda (6)	João (10)	Marilisa (6+2)
Why do I have pain? Cannot understand pain, but accept it (A.4.83; A.38.824; A.12.251; A.15.321; A.18.380; A.60.1314) Unpredictability and Confusion (A.13.283; A.14.296) Something bad inside (A.56.1217; A.13.283) Pain has coming (A.49.1054; A.18.387)	Efforts to understand pain; looking for explanations to justify pain, every single day (E.5.91; E.23.491; E.25.530; E.63.1373; E.67.1470; E.4.69; E.9.188) Pain and weather (E.2.40; E.4.69; E.42.914) Pain and aging (E.2.40) Pain and postures (E.8.166) Pain and physical efforts (E.9.17; E.34.734) Connections with the car accident (E.21.460; E.2.40; E.28.612; E.31.959; E.62.1344) Pain and mood - questions: are they connected (E.46.991) Refusing any association between pain and anxiety (E.34.734) Refusing any association between mood, thoughts and pain (E.38.819) Cannot associate pain with specific episodes (E.34.734) Cannot understand and explain pain - unpredictability (E.11.237; E.12.253; E.21.460; E.23.491; E.38.831; E.26.558; E.42.921; E.25.529) Struggling with the lack of an explanation (E.67.1470) Struggling to explain pain (E.56.1227)	Trying to live (survive) with this pain (H.1.17; H.7.142; H.41.896; H.43.940; H.44.954; H.45.969; H.48.1053) It is difficult to deal with pain (H.6.116; H.8.153; H.10.208; H.13.274) Trying to keep a positive attitude (H.29.626) Trying to forget pain (H.12.251; H.40.874) Looking for some comfort - to take some rest and use a hot water pack (H.5.108) Pain as part of the daily life A typical day - pain the whole day (H.11.238; H.12.259; H.16.342) Pain limits daily life activities (H.2.24) A mixture of sensations (pain, heat and nervousness) impacts on my job (H.14.288; H.16.334) To survive to support family Putting the others first (H.42.904; H.43.936) To feel accepted and supported only by family (H.17.362; H.19.396; H.19.401; H.34.747; H.46.1000) To be or not to be understood by family (H.18.382) I am the only person who really knows this pain (H.18.382) Family vs The Others I am the only person who really knows this pain (H.18.382) Colleagues tease her (H.26.566; H.28.600) Neighbours pity her (H.32.681) Not being believed because pain is not visible (H.26.566) Lack of acceptance and support at job (H.14.288; H.19.409)	Making sense of pain Dealing with no solutions - I am tired of having a non-treatable pain (L.2.42; L.12.255; L.41.898; L.39.856) Resigned, frustrated and get used to pain (L.2.27; L.9.186) Pain impact on mood - it is disturbing (L.2.42) The most disturbing is not the pain itself but its constant presence (L.1.4) Disturbed because pain has changed my habits (L.7.140) Upset because pain has decreased my capability to do some tasks (L.8.170) Am I becoming crazy - self-questioning (L.13.263; L.14.288; L.14.292; L.23.495) It is difficult to deal with the uncertainty about pain (L.5.100; L.30.638) Always the same unanswered questions about pain (L.42.908) I cannot understand (L.1.4; L.6.109; L.6.120; L.9.191; L.13.263; L.22.482; L.25.538; L.25.547) » Debility and pain (L.11.223) » Pain comes with age (L.17.357) » Questions about physical efforts and pain (L.10.208; L.16.378; L.16.386; L.23.495) » » Doctors advices to not carry heavies (L.19.396; L.27.583) Hypothesising something serious (L.12.245; L.13.263; L.30.638) Having a diagnose would give more hope (L.13.263) Understanding pain is more important than having pain relief (L.28.609; L.36.773; L.42.916) I am not a normal person (L.4.76; L.5.100; L.6.128)	A journey full of challenges where pain is included (R.1.4; R.6.122) Stolen adolescence (R.6.122) Making sense of pain Making sense and dealing with pain influenced by her mother death (R.51.1113) Following the example of her mother to endure pain - being a martyr (R.56.1216; R.57.1237) Fear of not being able to raise children pain is not that important (R.57.1237) Unresolved grief and pain (R.55.1183; R.55.1209) Got used to pain (R.50.1100) Ignore/ Avoid thinking about pain (R.13.272; R.18.387; R.23.485; R.40.873) Keep busy to deal with pain (R.53.1160) Why complain about pain (R.42.924) Cannot complain of anything (R.2.38) Resignation (R.12.258; R.45.972) Pain is not that important (R.12.243; R.12.258; R.28.596) Support family is the priority pain is part of life (R.10.209; R.23.485; R.25.532; R.38.830; R.46.993; R.47.1029; R.49.1066; R.55.1209; R.57.1237; R.62.1357) Focused on being a good mother, pain is not that important (R.32.696) Looking after others (R.44.950; R.46.993; R.49.1066)	Pain as part of life - Pain story and life story Making sense and dealing with pain Resigned to live with this pain (F.22.475; F.24.517) Resigned to live without understanding the pain (F.25.528) Not comfortable with the lack of understanding and solution for her problem (F.22.464) The unpredictability of pain is scary (F.10.202) Anxiety due to the unpredictability of pain (F.26.563; F.27.591) Fear of not being able to keep working (F.26.563; F.27.591) Doctors do not solve our problem (F.13.277) Not comfortable with the lack of understanding and solution for her problem (F.22.464) The GP's explanation (F.8.156; F.21.452) Lack of satisfactory - GP's explanations (F.10.217; F.22.475; F.24.519) No one has ever explained this pain to me (F.10.214) The passive experience of physiotherapy (F.19.411) The treatment is the same for everyone, no matter the problem (F.25.539) Relief vs cure (F.25.539) Nothing wrong with my back (F.26.552) It is very difficult to find an explanation (F.17.368; F.38.822; F.38.836) Nothing wrong with my back (F.26.552)	A fragile column - The weakest link (J.16.330; J.27.582; J.33.714; J.47.1022) Several problems in my column (J.6.129; J.10.201; J.29.618; J.32.691) There is something here (column) that justifies my pain (J.45.980) A column of a man of 60 (when I was 20) (J.32.691) The idea of a fragile column comes from a GP A column of a man of 60 (when I was 20) (J.32.691) Not very encouraging words (J.32.691) Do not question GP's explanation (J.47.1035) The GP does not add anything (J.36.775) Following the recommendations of his GP - doing exercise and taking care of his column (J.36.781) A sum of little episodes that have damaged my column (J.5.105; J.6.118; J.15.318; J.16.336; J.24.518) Detrimental jobs (J.4.70; J.6.123; J.8.156) My jobs have been responsible for the increase of my pain (J.4.67; J.8.156; J.34.741) Physically demanding jobs (J.18.386) Need to develop strategies to keep working despite pain (J.4.79; J.20.425; J.20.434) Surprise a physically demanding job that does not increase pain (J.59.1282) Motorcycle accident - detrimental to my back (J.12.245) A fall - detrimental to my back (J.12.250)	Resigned to live with pain (M.19.414) You have to deal with pain (M.9.180; M.15.327) Strategies to deal with pain (M.1.6; M.3.51; M.5.123; M.8.173; M.9.180; M.16.344) Why complain about pain? (M.10.201; M.20.429; M.22.465) Not thinking about pain makes one feel less pain (M.9.195; M.11.229) Think positive (M.26.563) Pain for several years (M.3.51) Keep going with my life (M.1.6; M.3.51; M.8.161; M.20.429; M.21.460; M.40.872; M.45.981) More advantages in keep doing activities (M.10.209; M.11.220) Dealing with the unpredictability of pain (M.45.976) Resigned to the lack of understanding about pain (M.21.439) Dealing with the unpredictability of pain (M.45.976) Cannot understand why I have pain (M.12.253; M.15.327; M.51.1107) Hypothesis to explain pain (M.25.545) Back problems (?) that cause pain (M.3.51) A curved column (M.5.102) A fall that may have left a mark (M.5.128) I believe my pain is caused by an infection (M.12.241; M.12.259; M.24.524; M.25.535; M.25.545) Pain and anxiety (M.23.496; M.24.524)

Fig. 9 - Excerpt from data analysis _ Main themes and sub-themes emerged from the eight interviews

In the previous figure, each column corresponded to one participant and included the information exported from the fifth column of fig. 4. This strategy helped the researcher to have an individual perspective of all themes and sub-themes that emerged in each interview. Additionally the colour classification also provided a quick visualisation of possible convergence and divergence among the interviews. In the following figure, the sub-themes and excerpts were removed in order to facilitate the visualisation of the information. In addition, the information was divided into two pages (fig. 10 and 11).

Data Analysis _ Looking for patterns across cases
Individual interviews- main themes

Alice	Eva	Helen	Laura
Why do I have pain? Alice explanations The others` explanations The GP`s explanations Experiences with health professionals Making sense of pain	Efforts to understand pain: looking for explanations to justify pain, every single day Experiences with health professionals Living with pain and and making sense of it	Pain explanation - I do not know - I really would like to understand it - keep asking herself several questions Disappointment with health professionals` approach Living with pain and making sense of it	Always the same unanswered questions about pain Cannot understand the GP`s words Making sense of pain
Pain as part of the daily life	Pain as part of the daily the daily life	Pain as part of the daily life	Pain is deeply incorporated and has a strong impact in my daily life
Dealing with pain in the daily life Cannot find a way to relieve pain Pain and other people	Dealing with pain in the daily life Cannot relieve pain Pain and other people	Trying to live (survive) with this pain To survive to support family Family vs Other people Expectations about the future	Pain has changed my relationships Expectations about the future The most disturbing is that I cannot be the person I used to be

Fig.10 - Data analysis _ Main themes emerged from the former four interviews

Data Analysis _ Looking for patterns across cases
 Individual interviews- main themes

Rita	Fernanda	João	Marília
Trying to understand her pain	It is very difficult to find an explanation	Cannot explain my pain in a clear way	Resigned to the lack of understanding about pain
Making sense of pain	Doctors do not solve our problem Making sense and dealing with pain This pain is really strong	The idea of a fragile column - GP A fragile column - The weakest link A sum of little episodes that have damaged my column Need to protect my column Pain impact on daily life Pain story	The GP knows why I have pain Resigned to live with pain Pain is really strong Taking care of myself
Pain as part of life - Pain story and life story To do what needs to be done no matter the pain			
Young carers?			
Strong enough to bear pain Pain is not that important	Have to live with this pain Cannot be sick	The impact of pain interpretation on the expectations about the future A contradictory vision about himself	I am not disabled because of pain Doubting herself Isolation?

Fig.11 - Data analysis _ Main themes emerged from the latter four interviews

At this stage, several strategies, such as conceptual maps or notes in the reflexive journal, were used in order to increase the depth of analysis. In the following figure, an example of one of the conceptual models developed is presented (fig.12).

Data Analysis _ Looking for patterns across cases

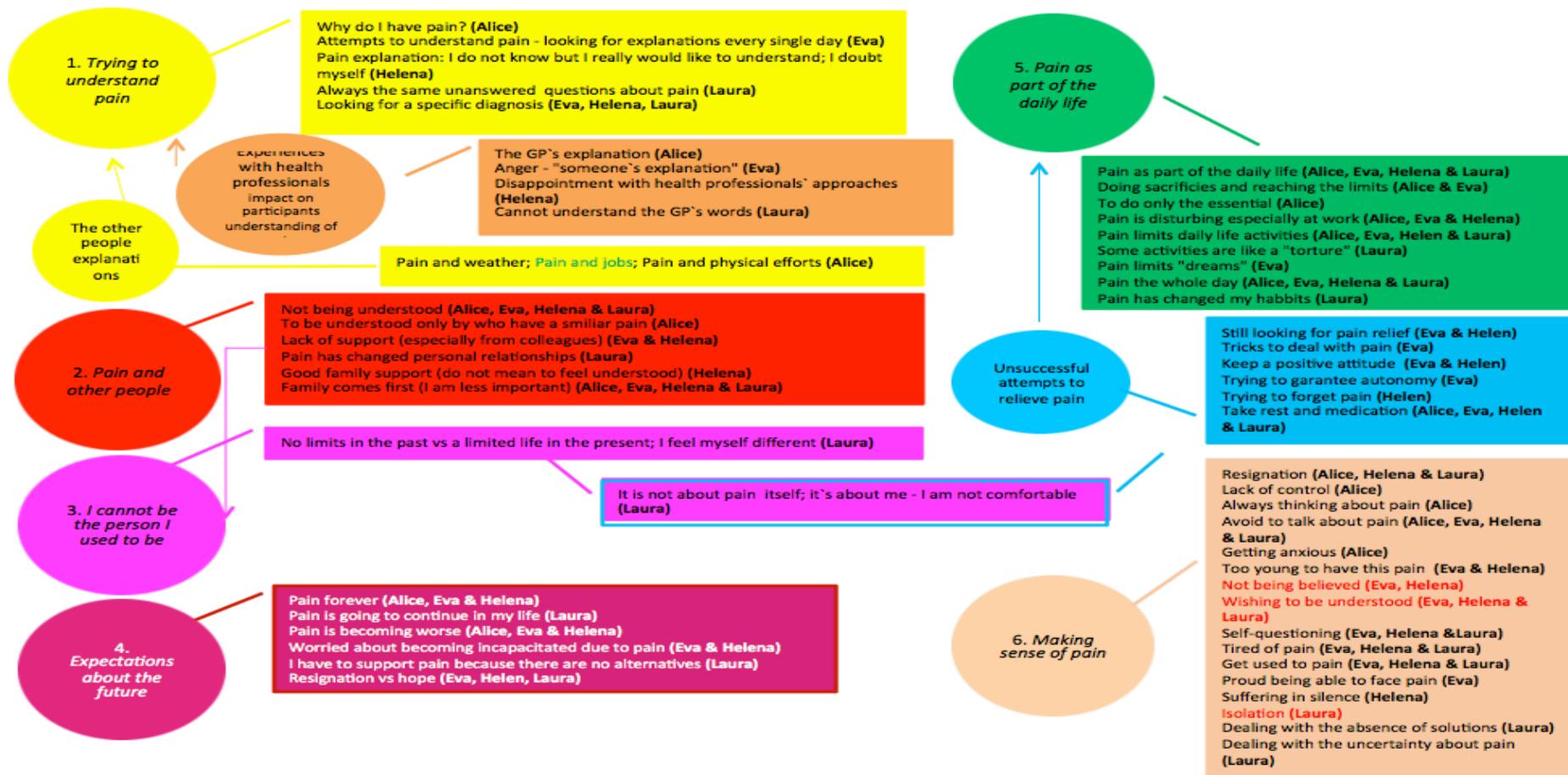


Fig.12 –Conceptual map_ overview of the interrelationship between themes emerged from the former four interviews

II. Detailed information about data analysis – Helena`s interview

In this section, detailed information about the previously presented stages is offered. In order to do so, Helena`s interview is provided as an example.

The following procedures were carried out:

1. Reading, re-reading and listening to the recording.
2. The interview data was introduced into a table of 4 columns (fig. 13). Comprehensive and detailed comments on the data were developed in the second column (from left to right). The first emergent ideas (that precede the first themes) were introduced in the fourth column.
3. Development of free nodes (N-Vivo 7 research software), codified as follow: **e.g. 3_HELENA_020_Sad about the GP`s approach (H.9.183; H.26.551)** (fig. 14)
4. Free nodes were exported to the excel document, which included 5 columns and allowed the researcher to preserve a detailed record of the development of the emergent themes (fig.15). After this, the search for connections across emergent themes was initiated. Several strategies, including the development of a conceptual map as well as an individual narrative, were carried out (fig.16 and 17).
5. Tree nodes (N-Vivo 7 research software) were developed in order to keep a record of the emergent themes, sub-themes and excerpts from Helena`s interview (fig. 18)

The aforementioned figures are presented in the following pages.

Helena's Interview | Data Analysis (Steps 1 to 3)

LN	Exploratory Comments _ Step 2	Original Transcript _ Step 1	Emergent Ideas _ Step 3
175		fui... nunca mais fui... e vim agora porque realmente...	
176		eu vinha mesmo a pensar que ia para a hidroginástica,	
177	Helena seems to be disappointed with the GP's approach – she	porque nunca pensei... que não pudesse fazer...	
178	perceived that her "disease" is not well explored. Is it about the	porque aqui me aconselharam a não fazer! Porque lá	
179	"disease"? Or is it about the impact of the "disease" in her life? <i>The</i>	está isto das costas vai passando, vai passando...	
180	<i>use of the word "sad" may illustrate the emotional impact of this</i>	Investigadora: E o que é que pensa? Quando me diz	Sad about the GP's
181	<i>experience in Helena's life.</i>	que eles lhe dizem esse tipo de coisas, ou que é dos	approach
182	<u>Helena seems to feel that her problems are not carefully considered.</u>	nervos... O que é que pensa sobre isso?	
183	<u>The type of diagnostic tests more frequently required (X-ray) by the GP</u>	Helen: Fico triste. Fico triste porque não exploram	
184	<u>seems to be used as a justification. Helena considers X-ray a basic</u>	bem a nossa doença, porque se a gente se queixa...	
185	<u>test, which does not explore her problems in depth. Does she believe</u>	acho que deviam insistir mais até em fazer certos	
186	<u>that her problems have not been well managed?</u>	exames. Não! É simplesmente a radiografia, às	
187	Helen also feels lack of support – <i>she uses the expression "we should</i>	vezes lá fazem um TAC... mas é como quem diz "faz	Lack of support from
188	<i>be more supported". We? – Who are these people? Is she talking</i>	a fisioterapia, as sessões, e melhoras e pronto"... É	health professionals
189	<i>about herself? Is she talking about other people with the same</i>	isso! Não dizem mais nada! Acho que... devíamos	
190	<i>problems? Have she ever talked to other people with similar</i>	ser mais apoiadas porque é uma dor difícil de	
191	<i>problems? Supported by whom? – Is she talking about GPs? Health</i>	suportar... há dias em que é difícil... a gente quer	
192	<i>professionals in general? This is not clear because she starts this</i>	fazer as coisas e arrasta as pernas... e a dor, aquela	
193	<i>intervention talking about GPs and ends it mentioning the useless of</i>	dor quando dá mais forte... arrastar a perna, custa...	
194	<i>physiotherapy. She seems to associate this lack of support to health</i>	a gente ir a andar, às vezes bem, e de repente... a	
195	<i>professionals in general.</i>	perna fica sem forças e a gente vai coxear um	

Fig. 13 – Excerpt from data analysis _ Helena's interview

Free Nodes

Name	Sources	Reference	Created
 3_HELENA_001_Get used to pain (H.1.6)	1	1	18-11-2012
 3_HELENA_002_Unsuccessful attempts to relieve pain (H.1.12; H.2.35; H.4.70; H.6.26; H.7.136; H.24.518; H.25.539; H.39.85)	1	8	18-11-2012
 3_HELENA_003_Keep living with this pain (H.1.17; H.7.142; H.41.896; H.43.940; H.44.954; H.45.969; H.48.1053)	1	7	22-11-2012
 3_HELENA_004_Pain forever (H.1.17)	1	1	20-11-2012
 3_HELENA_005_Pain limits daily life activities (H.2.24)	1	1	20-11-2012
 3_HELENA_006_Cry because of pain (H.2.35)	1	1	20-11-2012
 3_HELENA_007_Connection between back pain and knee PAIN (H.3.50; H.4.85; H.20.436; H.21.458)	1	4	20-11-2012
 3_HELENA_008_Chocked with the GP's answer (H.3.50)	1	1	20-11-2012
 3_HELENA_009_A knee x-ray legitimates back pain (H.3.63)	1	1	20-11-2012
 3_HELENA_010_Cannot associate a specific moment to the start of back pain (H.4.85)	1	1	20-11-2012
 3_HELENA_011_Symptoms in several body parts - all seems to be connected (H.5.103)	1	1	20-11-2012
 3_HELENA_012_Deal with pain - to take some rest and use a hot water pack (H.5.108)	1	1	20-11-2012
 3_HELENA_013_Shyness and uncomfortable being the centre of attention (H.6.118)	1	1	20-11-2012
 3_HELENA_014_Suffering as a consequence of some bad habits (H.6.116)	1	1	20-11-2012
 3_HELENA_015_Weak pills that cannot relieve pain (H.6.126)	1	1	20-11-2012
 3_HELENA_016_To show a happy face (H.7.142)	1	1	20-11-2012
 3_HELENA_017_Need to be careful (H.8.153)	1	1	20-11-2012
 3_HELENA_018_Doctors do not say anything (H.8.166)	1	1	20-11-2012
 3_HELENA_019_Is pain in my head (H.8.169)	1	1	20-11-2012
 3_HELENA_020_Sad about the GP's approach (H.9.183; H.26.551)	1	2	20-11-2012
 3_HELENA_021_Lack of support from health professionals (H.9.189)	1	1	20-11-2012
 3_HELENA_022_Lack of information from health professionals (H.9.189)	1	1	20-11-2012
 3_HELENA_023_It is difficult to deal with pain (H.10.208)	1	1	20-11-2012
 3_HELENA_024_Pain will become worse (H.10.208)	1	1	20-11-2012
 3_HELENA_025_Give up on health professionals approach (H.10.217)	1	1	20-11-2012
 3_HELENA_026_Looking for an alternative (H.10.217)	1	1	20-11-2012
 3_HELENA_027_Not used to do sports (H.11.228)	1	1	20-11-2012
 3_HELENA_028_A typical day - pain the whole day (H.11.238)	1	1	20-11-2012
 3_HELENA_029_Pain in every single task (H.11.238)	1	1	20-11-2012
 3_HELENA_030_Secretely complain about pain (H.12.251)	1	1	20-11-2012
 3_HELENA_031_Sometimes it is not possible to forget pain (H.12.251)	1	1	20-11-2012
 3_HELENA_032_Pain is always here (H.12.259)	1	1	20-11-2012
 3_HELENA_033_Not used to talk about herself (H.13.269)	1	1	20-11-2012

Free Nodes

Name	Sources	Reference	Created
 3_HELENA_034_Bad postures increase pain (H.13.274)	1	1	20-11-2012
 3_HELENA_035_Suffering in silence (H.13.274; H.15.319)	1	2	20-11-2012
 3_HELENA_036_A mixture of sensations (pain, heat and nervousness) (H.14.288; H.16.334)	1	2	20-11-2012
 3_HELENA_037_A difficult work environment (H.14.288)	1	1	20-11-2012
 3_HELENA_038_Pain impacts on job (H.14.301)	1	1	20-11-2012
 3_HELENA_039_Connection between feeling nervous and having pain (H.14.301; H.15.319)	1	2	20-11-2012
 3_HELENA_040_Pain the whole day (H.16.342)	1	1	20-11-2012
 3_HELENA_041_Good family support (H.17.362; H.46.1000)	1	2	20-11-2012
 3_HELENA_042_A lot of suffering in the past (H.18.373; H.44.960; H.46.1000)	1	1	20-11-2012
 3_HELENA_043_To be or not to be understood by family (H.18.382)	1	1	20-11-2012
 3_HELENA_044_I am the only person who really knows this pain (H.18.382)	1	1	20-11-2012
 3_HELENA_045_To feel accepted and supported by family (H.19.396; H.19.401)	1	2	20-11-2012
 3_HELENA_046_Lack of acceptance and support at job (H.19.409)	1	1	20-11-2012
 3_HELENA_047_A long story of back pain (H.20.425; H.25.539)	1	2	20-11-2012
 3_HELENA_048_Pain explanation - I do not know (H.21.458; H.22.471)	1	2	20-11-2012
 3_HELENA_049_Inadequate approach (from health professionals) (H.22.471)	1	1	20-11-2012
 3_HELENA_050_Not taken seriously (H.22.471)	1	1	20-11-2012
 3_HELENA_051_A problem in several vertebrae (H.22.471)	1	1	20-11-2012
 3_HELENA_052_My back pain was not explored (assessed) (H.22.481)	1	1	20-11-2012
 3_HELENA_053_Always the same (unsuccessful) treatment (H.22.481)	1	1	20-11-2012
 3_HELENA_054_Lack of support (H.22.481)	1	1	20-11-2012
 3_HELENA_055_To doubt herself (H.23.495; H.49.1071)	1	2	20-11-2012
 3_HELENA_056_Pain explanation - to keep asking herself several questions (H.23.495)	1	1	20-11-2012
 3_HELENA_057_Lack of information from health professionals - they do not promote a dialogue (H.24.518)	1	1	20-11-2012
 3_HELENA_058_No expectations about treatment prescribed by the GP (H.24.524)	1	1	20-11-2012
 3_HELENA_059_Poor communication with health professionals - they do not promote dialogue (H.26.551)	1	1	20-11-2012
 3_HELENA_060_Not being believed (H.26.566)	1	1	20-11-2012
 3_HELENA_061_Being teased by colleagues (H.26.566; H.28.600)	1	2	20-11-2012
 3_HELENA_062_Pain is not visible (H.26.566)	1	1	20-11-2012
 3_HELENA_063_You have to support pain (H.26.566)	1	1	20-11-2012
 3_HELENA_064_To be selective - in response of not being believed and being teased (H.29.615)	1	1	20-11-2012
 3_HELENA_065_Trying to keep a positive attitude (H.29.626)	1	1	20-11-2012
 3_HELENA_066_Connection between pain and mood (H.29.636; H.30.646; H.30.656; H.47.1034)	1	4	20-11-2012

Free Nodes			
Name	Sources	Reference	Created
3_HELENA_067_Neighbours feel pity for her (H.32.681)	1	1	20-11-2012
3_HELENA_068_Sad about not being able to do easy tasks (H.32.681; H.33.724)	1	2	20-11-2012
3_HELENA_069_To young to have this disability (H.32.681)	1	1	20-11-2012
3_HELENA_070_Sad about both reactions pity and tease (H.32.681)	1	1	20-11-2012
3_HELENA_071_It is difficult to find the words (H.32.681)	1	1	20-11-2012
3_HELENA_072_It is difficult to accept this incapacity (H.34.740)	1	1	20-11-2012
3_HELENA_073_Supported only by her family (H.34.747)	1	1	20-11-2012
3_HELENA_074_It is not possible to abolish pain vs hope for some relief (H.35.757; H.35.765)	1	2	21-11-2012
3_HELENA_075_It is difficult to express the sensation of pain (H.36.789)	1	1	21-11-2012
3_HELENA_076_Pain and agony (H.37.797)	1	1	21-11-2012
3_HELENA_077_Everything hurts (H.37.802)	1	1	21-11-2012
3_HELENA_078_Cannot understand where pain comes from (H.37.802)	1	1	21-11-2012
3_HELENA_079_The future will be probably in a wheelchair (H.38.816)	1	1	21-11-2012
3_HELENA_080_This pain will damage my body (H.38.824)	1	1	21-11-2012
3_HELENA_081_Become more incapacitated in yhe future (H.38.816)	1	1	21-11-2012
3_HELENA_082_Sometimes I forget pain (H.40.866)	1	1	21-11-2012
3_HELENA_083_It is very important to forget pain sometimes (H.40.874)	1	1	21-11-2012
3_HELENA_084_It is difficult to forget pain (H.40.874)	1	1	21-11-2012
3_HELENA_085_Pain cannot impede me to help and support my family (H.42.904)	1	1	21-11-2012
3_HELENA_086_Becoming in second place (H.43.936)	1	1	21-11-2012
3_HELENA_087_Pain explanation - I really would like to understand it (H.47.1027; H.49.1071; H.50.1097)	1	3	21-11-2012
3_HELENA_088_I do not have an explanation (H.48.1044)	1	1	21-11-2012
3_HELENA_089_Thoughts and pain (H.49.1060)	1	1	21-11-2012
3_HELENA_090_Worried about the lack of pain explanations (H.50.1085)	1	1	21-11-2012
3_HELENA_091_A reserved person (H.52.1127)	1	1	21-11-2012

Fig. 14 – Print screen from N-Nivo, Helena`s free nodes table.

Helena's Interview - Looking for connections across emergent themes (Steps between free nodes and tree nodes_using nvivo)

Refining emergent features (chronological order_ looking for connections using colours)	Refining emergent features II (looking for connections and grouping emergent features into themes)	Refining emergent themes III (looking for connections and collapsing features in emergent themes)	Refining emergent themes IV (grouping emergent features after collapsing)	Refining emergent themes V (organising themes and superordinated themes - after designing a conceptual map in NVIVO)
Get used to pain (H.1.6)	<i>Pain impact in the daily</i>	<i>Pain impact in the daily</i>	<i>Pain impact in the daily</i>	<i>Trying to live (survive) with this pain (H.1.17; H.7.142; H.4.896; H.43.940; H.44.954; H.45.969; H.48.1053)</i>
Unsuccessful attempts to relieve pain (H.1.12; H.2.35; H.4.70; H.6.126; H.7.136; H.24.518; H.25.539; H.39.854)	Pain limits daily life activities (H.2.24)	Pain limits daily life activities (H.2.24)	Pain limits daily life activities (H.2.24)	It is difficult to deal with pain (H.6.116; H.8.153; H.10.208; H.13.274)
Keep living with this pain (H.1.17; H.7.142; H.41.896; H.43.940; H.44.954; H.45.969; H.48.1053)	A typical day - pain the whole day (H.11.238)	A typical day - pain the whole day (H.11.238; H.12.259; H.16.342)	A typical day - pain the whole day (H.11.238; H.12.259; H.16.342)	Trying to keep a positive attitude (H.29.626)
Pain forever (H.1.17)	Pain in every single task (H.11.238)			Trying to forget pain (H.12.251; H.40.874)
Pain limits daily life activities (H.2.24)	Pain is always here (H.12.259)		Jobs	Looking for some comfort - to take some rest and use a hot water pack (H.5.108)
Cry because of pain (H.2.35)	Pain the whole day (H.16.342)		A mixture of sensations (pain, heat and nervousness) impacts on my job (H.14.288; H.14.301; H.16.334)	
Connection between back pain and knee pain (H.3.50; H.4.85; H.20.436; H.21.458)				<i>Pain as part of the daily life</i>
Chocked with the GP's answer (H.3.50)	Jobs	Jobs	Strategies to deal with pain in daily life	A typical day - pain the whole day (H.11.238; H.12.259; H.16.342)
A knee x-ray legitimates back pain (H.3.63)	A mixture of sensations (pain, heat and nervousness) (H.14.288; H.16.334)	A mixture of sensations (pain, heat and nervousness) impacts on my job (H.14.288; H.14.301; H.16.334)	Keep living with this pain (H.1.17; H.7.142; H.41.896; H.43.940; H.44.954; H.45.969; H.48.1053)	Pain limits daily life activities (H.2.24)
Cannot associate a specific moment to the start of back pain (H.4.85)	Pain impacts on job (H.14.301)		Deal with pain - to take some rest and use a hot water pack (H.5.108)	A mixture of sensations (pain, heat and nervousness) impacts on my job (H.14.288; H.16.334)
Symptoms in several body parts - all seems to be connected (H.5.103)			It is difficult to deal with pain (H.6.116; H.8.153; H.10.208; H.13.274)	
Deal with pain - to take some rest and use a hot water pack (H.5.108)	<i>Strategies to deal with pain in daily life</i>	<i>Strategies to deal with pain in daily life</i>	Trying to keep a positive attitude (H.29.626)	To survive to support family
Shy and uncomfortable being the centre of attention (H.6.118)	Keep living with this pain (H.1.17; H.7.142; H.41.896; H.43.940; H.44.954; H.45.969; H.48.1053)	Keep living with this pain (H.1.17; H.7.142; H.41.896; H.43.940; H.44.954; H.45.969; H.48.1053)	Trying to forget pain (H.12.251; H.40.874)	Putting the others first (H.42.904; H.43.936)
Suffering as a consequence of some bad habits (H.6.116)	Deal with pain - to take some rest and use a hot water pack (H.5.108)	Deal with pain - to take some rest and use a hot water pack (H.5.108)		To feel accepted and supported only by family (H.17.362; H.19.396; H.19.401; H.34.747; H.46.1000)
Weak pills that cannot relieve pain (H.6.126)	Suffering as a consequence of some bad habits (H.6.116)		Cannot relieve pain	To be or not to be understood by family (H.18.382)
To show a happy face (H.7.142)	Need to be careful (H.8.153)		Unsuccessful attempts to relieve pain (H.1.12; H.2.35; H.4.70; H.6.126; H.7.136; H.24.518; H.25.539; H.39.854)	I am the only person who really knows this pain (H.18.382)
Need to be careful (H.8.153)	It is difficult to deal with pain (H.10.208)	It is difficult to deal with pain (H.6.116; H.8.153; H.10.208; H.13.274)		<i>Family vs The Others</i>
GPs do not say anything (H.8.166)	Not used to do sports (H.11.228)		<i>Feelings and thoughts about pain</i>	I am the only person who really knows this pain (H.18.382)
Is pain in my head (H.8.169)	Sometimes it is not possible to forget pain (H.12.251)		Get used to pain (H.1.6)	Colleagues tease her (H.26.566; H.28.600)
Sad about the GP's approach (H.9.183; H.26.551)	Bad postures increase pain (H.13.274)		Shy and uncomfortable being the centre of attention (H.6.118; H.13.269; H.52.1127)	Neighbours pity her (H.32.681)
Lack of support from health professionals (H.9.189)	Trying to keep a positive attitude (H.29.626)	Trying to keep a positive attitude (H.29.626)	To show a happy face (H.7.142)	Not being believed because pain is not visible (H.26.566)
Lack of information from health professionals (H.9.189)	Sometimes I forget pain (H.40.866)		Suffering in silence (H.2.35; H.12.251; H.13.274; H.15.319)	Lack of acceptance and support at job (H.14.288; H.19.409)
It is difficult to deal with pain (H.10.208)	It is very important to forget pain sometimes (H.40.874)	Trying to forget pain (H.12.251; H.40.874)	Connection between feeling nervous and having pain (H.14.301; H.15.319; H.37.797; H.49.1060)	You have to support pain (H.26.566)
Pain will become worse (H.10.208)	It is difficult to forget pain (H.40.874)		To doubt herself (H.23.495; H.49.1071)	To be selective - in response of not being believed and being teased (H.29.615)
Give up on health professionals approach (H.10.217)			Sad about not being able to do easy tasks (H.32.681; H.33.724)	
Looking for an alternative (H.10.217)	Cannot relieve pain	Cannot relieve pain	Sad about both reactions pity and tease (H.32.681)	<i>Living with pain and making sense of it</i>
Not used to do sports (H.11.228)	Unsuccessful attempts to relieve pain (H.1.12; H.2.35; H.4.70; H.6.126; H.7.136; H.24.518; H.25.539; H.39.854)	Unsuccessful attempts to relieve pain (H.1.12; H.2.35; H.4.70; H.6.126; H.7.136; H.24.518; H.25.539; H.39.854)	To young to have this disability (H.32.681)	Get used to pain (H.1.6)
A typical day - pain the whole day (H.11.238)	Weak pills that cannot relieve pain (H.6.126)		It is difficult to accept this incapacity (H.34.740)	It is difficult to express her thoughts and feelings about pain (H.32.681; H.36.789)
Pain in every single task (H.11.238)			It is difficult to express her thoughts and feelings about pain (H.32.681; H.36.789)	Shy and uncomfortable being the centre of attention (H.6.118; H.13.269; H.52.1127)
Secretely complain about pain (H.12.251)	<i>Feelings and thoughts about pain</i>	<i>Feelings and thoughts about pain</i>		Connection between feeling nervous and having pain (H.14.301; H.15.319; H.37.797; H.49.1060)
Sometimes it is not possible to forget pain (H.12.251)	Get used to pain (H.1.6)	Get used to pain (H.1.6)	<i>Experiences with health professionals</i>	Suffering in silence (H.2.35; H.12.251; H.13.274; H.15.319)
Pain is always here (H.12.259)	Cry because of pain (H.2.35)		Is pain in my head (H.8.169)	To show a happy face (H.7.142)
Not used to talk about herself (H.13.269)	Shy and uncomfortable being the centre of attention (H.6.118)	Shy and uncomfortable being the centre of attention (H.6.118; H.13.269; H.52.1127)	Disappointment with health professionals approach (H.3.50; H.9.183; H.24.524; H.26.551)	Sadness - sad about the others' reactions (H.32.681)
Bad postures increase pain (H.13.274)	To show a happy face (H.7.142)	To show a happy face (H.7.142)	Lack of support from health professionals (H.9.189; H.22.481)	Sadness - Sad about not being able to do easy tasks (H.32.681; H.33.724)
Suffering in silence (H.13.274; H.15.319)	Secretely complain about pain (H.12.251)		Give up on health professionals approach (H.10.217)	

A mixture of sensations (pain, heat and nervousness) (H.14.288; h.16.334)	Not used to talk about herself (H.13.269)		Inadequate approach (from health professionals) (H.22.471; H.22.481)	It is difficult to accept this incapacity - To young to have this disability (H.32.681; H.34.740)
A difficult work environment (H.14.288)	Suffering in silence (H.13.274; H.15.319)	Suffering in silence (H.2.35; H.12.251; H.13.274; H.15.319)	Not taken seriously (H.22.471)	To doubt herself (H.23.495; H.49.1071)
Pain impacts on job (H.14.301)	Connection between feeling nervous and having pain (H.14.301; H.15.319)	Connection between feeling nervous and having pain (H.14.301; H.15.319; H.37.797; H.49.1060)	Poor communication with health professionals - they do not promote dialogue (H.8.166; H.22.471; H.24.518; H.26.551)	
Connection between feeling nervous and having pain (H.14.301; H.15.319)	To doubt herself (H.23.495; H.49.1071)	To doubt herself (H.23.495; H.49.1071)		Disappointment with health professionals approach (H.3.50; H.9.183; H.24.524; H.26.551)
Pain the whole day (H.16.342)	Sad about not being able to do easy tasks (H.32.681; H.33.724)	Sad about not being able to do easy tasks (H.32.681; H.33.724)	<i>Pain and others</i>	Lack of support and respect from health professionals (H.9.189; H.22.481)
Good family support (H.17.362; H.46.1000)	To young to have this disability (H.32.681)	To young to have this disability (H.32.681)	I am the only person who really knows this pain (H.18.382)	Not taken seriously (H.22.471)
A lot of suffering in the past (H.18.373; H.44.960; H.46.1000)	Sad about both reactions pity and tease (H.32.681)	Sad about both reactions pity and tease (H.32.681)	Lack of acceptance and support at job (H.14.288; H.19.409)	Poor communication with health professionals - they do not promote dialogue (H.8.166; H.22.471; H.24.518; H.26.551)
To be or not to be understood by family (H.18.382)	It is difficult to find the words (H.32.681)		Not being believed because pain is not visible (H.26.566)	Inadequate approach (from health professionals) (H.22.471)
I am the only person who really knows this pain (H.18.382)	It is difficult to accept this incapacity (H.34.740)	It is difficult to accept this incapacity (H.34.740)	Being teased by colleagues (H.26.566; H.28.600)	Unsuccessful attempts to relieve pain (H.1.12; H.2.35; H.4.70; H.6.126; H.7.136; H.24.518; H.25.539; H.39.854)
To feel accepted and supported by family (H.19.396; H.19.401)	It is difficult to express the sensation of pain (H.36.789)	It is difficult to express her thoughts and feelings about pain (H.32.681; H.36.789)	You have to support pain (H.26.566)	Give up on health professionals approach (H.10.217)
Lack of acceptance and support at job (H.19.409)	Pain and agony (H.37.797)		To be selective - in response of not being believed and being teased (H.29.615)	Is pain in my head (H.8.169)
A long story of back pain (H.20.425; H.25.539)	Thoughts and pain (H.49.1060)			Pain explanation - to keep asking herself several questions (H.23.495)
Pain explanation - I do not know (H.21.458; H.22.471)	A reserved person (H.52.1127)		<i>Pain and others (family)</i>	Pain explanation - I do not know - I really would like to understand it - keep asking herself several questions (H.21.458; H.22.471; H.47.1027; H.49.1071; H.50.1097)
Inadequate approach (from health professionals) (H.22.471)			To be or not to be understood by family (H.18.382)	Cannot understand where pain comes from (H.37.802; H.4.85; H.48.1044)
Not taken seriously (H.22.471)	<i>Experiences with health professionals</i>	<i>Experiences with health professionals</i>	To feel accepted and supported only by family (H.17.362; H.19.396; H.19.401; H.34.747; H.46.1000)	Connection between back pain and knee pain (H.3.50; H.4.85; H.20.436; H.21.458)
A problem in several vertebrae (H.22.471)	Choked with the GP's answer (H.3.50)		Neighbours feel pity for her (H.32.681)	Connection between pain and mood (H.29.636; H.30.646; H.30.656; H.47.1034)
My back pain was not explored (assessed) (H.22.481)	A knee x-ray legitimates back pain (H.3.63)	A knee x-ray legitimates back pain (H.3.63)	Becoming in second place (H.42.904; H.43.936)	Symptoms in the whole body - all seems to be connected (H.5.103; H.37.802)
Always the same (unsuccessful) treatment (H.22.481)	GPs do not say anything (H.8.166)			Worried about the lack of pain explanations (H.50.1085)
A common lack of support from health professionals (H.22.481)	Is pain in my head (H.8.169)	Is pain in my head (H.8.169)	<i>Expectations about the future</i>	
To doubt herself (H.23.495; H.49.1071)	Sad about the GP's approach (H.9.183; H.26.551)		It is not possible to abolish pain (pain forever) vs hope for some relief (H.1.7; H.35.757; H.35.765)	<i>Expectations about the future</i>
Pain explanation - to keep asking herself several questions (H.23.495)	Lack of support from health professionals (H.9.189)	Disappointment with health professionals approach (H.3.50; H.9.183; H.24.524; H.26.551)	The future will be probably in a wheelchair (H.38.816)	This pain will damage my body (H.38.824)
Lack of information from health professionals - they do not promote a dialogue (H.24.518)	Lack of information from health professionals (H.9.189)	Lack of support from health professionals (H.9.189; H.22.481)	This pain will damage my body (H.38.824)	Become more incapacitated in the future because pain will become worse (H.10.208; H.38.816)
No expectations about treatment prescribed by GPs (H.24.524)	Give up on health professionals approach (H.10.217)	Give up on health professionals approach (H.10.217)		Pain forever - It is not possible to abolish pain - vs hope for some relief (H.1.17; H.35.757; H.35.765)
Poor communication with health professionals - they do not promote dialogue (H.26.551)	Looking for an alternative (H.10.217)		<i>Understandings about pain</i>	
Not being believed (H.26.566)	Inadequate approach (from health professionals) (H.22.471)	Inadequate approach (from health professionals) (H.22.471; H.22.481)	Connection between back pain and knee pain (H.3.50; H.4.85; H.20.436; H.21.458)	
Being teased by colleagues (H.26.566; H.28.600)	Not taken seriously (H.22.471)	Not taken seriously (H.22.471)	Symptoms in the whole body - all seems to be connected (H.5.103; H.37.802)	
Pain is not visible (H.26.566)	A problem in several vertebrae (H.22.471)		Connection between pain and mood (H.29.636; H.30.646; H.30.656; H.47.1034)	
You have to support pain (H.26.566)	My back pain was not explored (assessed) (H.22.481)		Cannot understand where pain comes from (H.37.802; H.4.85; H.48.1044)	
To be selective - in response of not being believed and being teased (H.29.615)	Always the same (unsuccessful) treatment (H.22.481)		Pain explanation - I do not know - I really would like to understand it - keep asking herself several questions (H.21.458; H.22.471; H.47.1027; H.49.1071; H.50.1097)	
Trying to keep a positive attitude (H.29.626)	A common lack of support from health professionals (H.22.481)		Worried about the lack of pain explanations (H.50.1085)	
Connection between pain and mood (H.29.636; H.30.646; H.30.656; H.47.1034)	Lack of information from health professionals - they do not promote a dialogue (H.24.518)			
Neighbours feel pity for her (H.32.681)	No expectations about treatment prescribed by GPs			

Sad about not being able to do easy tasks (H.32.681; H.33.724)	Poor communication with health professionals - they do not promote dialogue (H.26.551)	Poor communication with health professionals - they do not promote dialogue (H.8.166; H.22.471; H.24.518; H.26.551)
To young to have this disability (H.32.681)		
Sad about both reactions pity and tease (H.32.681)	<i>Pain and others</i>	<i>Pain and others</i>
It is difficult to find the words (H.32.681)	A difficult work environment (H.14.288)	
It is difficult to accept this incapacity (H.34.740)	I am the only person who really knows this pain (H.15.382)	I am the only person who really knows this pain (H.15.382)
Supported only by her family (H.34.747)	Lack of acceptance and support at job (H.19.409)	Lack of acceptance and support at job (H.14.288; H.19.409)
It is not possible to abolish pain vs hope for some relief (H.35.757; H.35.765)	Not being believed (H.26.566)	Not being believed because pain is not visible (H.26.566)
It is difficult to express the sensation of pain (H.36.799)	Being teased by colleagues (H.26.566; H.28.600)	Being teased by colleagues (H.26.566; H.28.600)
Pain and agony (H.37.797)	Pain is not visible (H.26.566)	
Everything hurts (H.37.802)	You have to support pain (H.26.566)	You have to support pain (H.26.566)
Cannot understand where pain comes from (H.37.802)	To be selective - in response of not being believed and being teased (H.29.615)	To be selective - in response of not being believed and being teased (H.29.615)
The future will be probably in a wheelchair (H.38.816)	<i>Pain and others (family)</i>	<i>Pain and others (family)</i>
This pain will damage my body (H.38.824)	Good family support (H.17.362; H.46.1000)	
Become more incapacitated in the future (H.38.816)	To be or not to be understood by family (H.18.382)	To be or not to be understood by family (H.18.382)
Sometimes I forget pain (H.40.866)	To feel accepted and supported by family (H.19.396; H.19.401)	To feel accepted and supported only by family (H.17.362; H.19.396; H.19.401; H.34.747; H.46.1000)
It is very important to forget pain sometimes (H.40.874)	Neighbours feel pity for her (H.32.681)	Neighbours feel pity for her (H.32.681)
It is difficult to forget pain (H.40.874)	Supported only by her family (H.34.747)	
Pain cannot impede me to help and support my family (H.42.904)	Pain cannot impede me to help and support my family (H.42.904)	
Becoming in second place (H.43.936)	Becoming in second place (H.43.936)	Becoming in second place (H.42.904; H.43.936)
Pain explanation - I really would like to understand it (H.47.1027; H.49.1071; H.50.1097)		
I do not have an explanation (H.48.1044)	<i>Expectations about the future</i>	<i>Expectations about the future</i>
Thoughts and pain (H.49.1060)	Pain forever (H.1.17)	
Worried about the lack of pain explanations (H.50.1085)	Pain will become worse (H.10.208)	It is not possible to abolish pain (pain forever) vs hope for some relief (H.1.7; H.35.757; H.35.765)
A reserved person (H.52.1127)	It is not possible to abolish pain vs hope for some relief (H.35.757; H.35.765)	The future will be probably in a wheelchair (H.38.816)
	The future will be probably in a wheelchair (H.38.816)	This pain will damage my body (H.38.824)
	This pain will damage my body (H.38.824)	Become more incapacitated in the future because pain will become worse (H.10.208; H.38.816)
	Become more incapacitated in the future (H.38.816)	
	<i>Understandings about pain</i>	<i>Understandings about pain</i>
	Connection between back pain and knee pain (H.3.50; H.4.85; H.20.436; H.21.459)	Connection between back pain and knee pain (H.3.50; H.4.85; H.20.436; H.21.459)
	Cannot associate a specific moment to the start of back pain (H.4.85)	
	Symptoms in several body parts - all seems to be connected (H.5.103)	Symptoms in several body parts - all seems to be connected (H.5.103; H.37.802)
	Pain explanation - I do not know (H.21.458; H.22.471)	
	Pain explanation - to keep asking herself several questions (H.23.495)	
	Connection between pain and mood (H.29.636; H.30.646; H.30.656; H.47.1034)	Connection between pain and mood (H.29.636; H.30.646; H.30.656; H.47.1034)
	Everything hurts (H.37.802)	
	Cannot understand where pain comes from (H.37.802)	Cannot understand where pain comes from (H.37.802; H.4.85; H.48.1044)
	Pain explanation - I really would like to understand it (H.47.1027; H.49.1071; H.50.1097)	Pain explanation - I do not know - I really would like to understand it - keep asking herself several questions (H.21.458; H.22.471; H.47.1027; H.49.1071; H.50.1097)
	I do not have an explanation (H.48.1044)	
	Worried about the lack of pain explanations (H.50.1085)	Worried about the lack of pain explanations (H.50.1085)
	A lot of suffering in the past (H.18.373; H.44.960; H.46.1000)	

Fig. 15 –Data analysis _ Helena`s interview

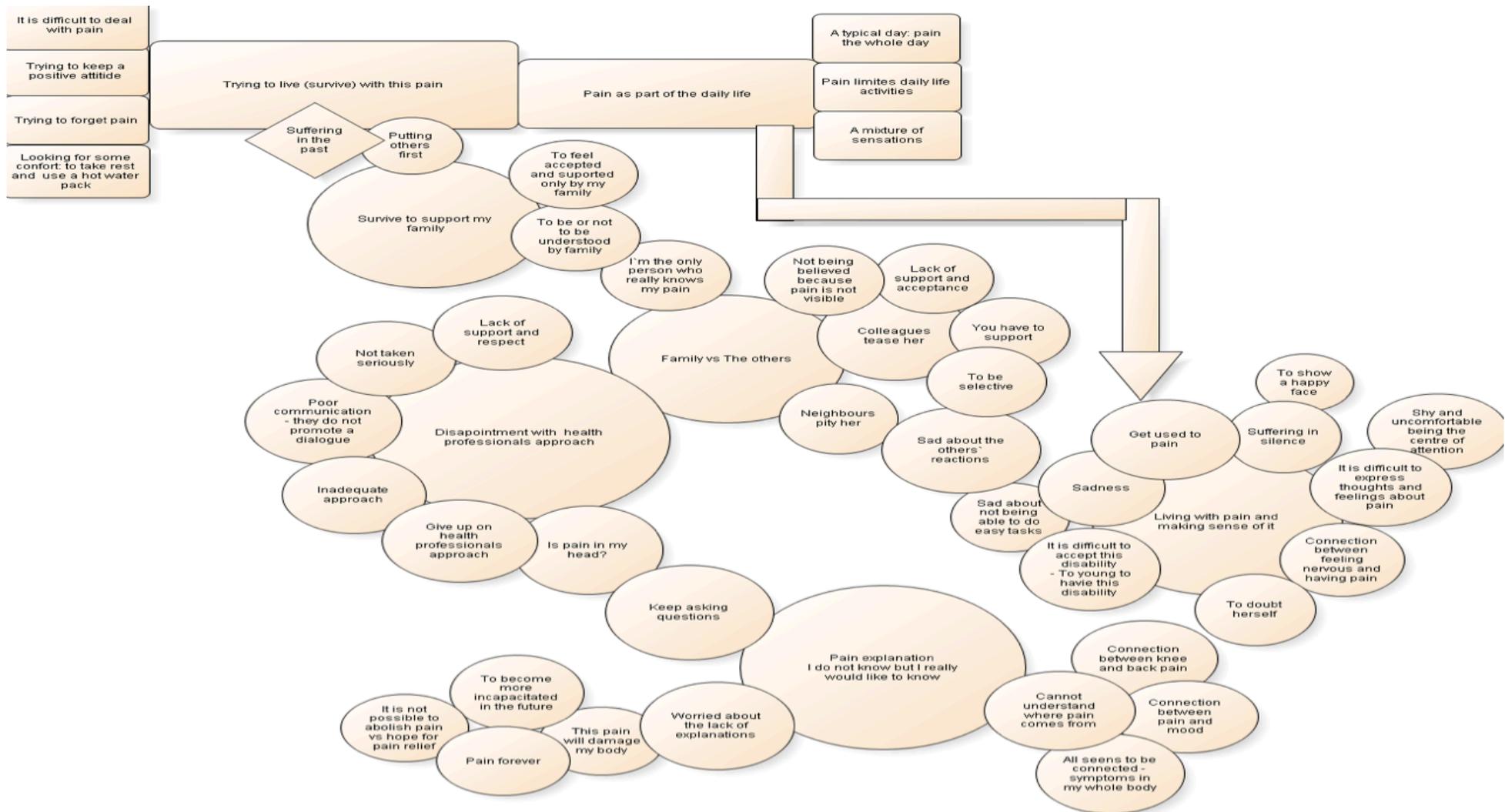


Fig. 16- Conceptual map _ Helena`s interview

Helena`s narrative

Helena was fifty-four years old and was living alone in a small city in central interior Portugal. Despite living alone, she reported having great support from her son and nephews. They all had a close relationship, as they had lived together for many years. She was a civil servant, working as a secretary in an open office space. Her working environment seemed to be uncomfortable for her, as she reported to be teased about her pain. She admitted dealing with the situation by isolating herself. She also explained that it was difficult to talk about her NSCLBP because she was reserved private person. During the interview she appeared to be shy and uncomfortable with being the centre of attention. She did not seem to be used to talking about herself for so long.

Helena had NSCLBP for approximately fifteen years and could not recall a specific incident that may have triggered her NSCLBP. She reported that she had knee pain before having low back pain, but she did not know if there was any connection between the two. Although Helena perceived her NSCLBP as disturbing, she considered that that she had suffered more with the death of close relatives. She repeatedly emphasised that she needed to move on.

“And I`m a single mother... although I`ve got some support from relatives... but this is my main responsibility, right? So, I need to forget this pain, in this situation I need to forget pain because I need to move on, I need to fight for my life, I need to fight... And no matter how painful it is, I need to keep doing my tasks... I can`t sit down complaining – Ow, I`m in pain! My back hurts! I can`t move! I can`t work! – What would happen with my life? So, I needed to move on, needed to fight, needed to work, I still need to work! So, I come in second, or third place, depending on the circumstances, right?” (Helena.41.900- 916)

Although Helena wanted to find an explanation for her pain, she had a completely different attitude regarding this subject when compared to Alice and Eva. She considered that she had been through a lot in her life and because of this she tended to minimise the importance of her back pain. She had experienced more severe pain in her life, which seemed to be related to personal problems. She tried to distinguish this more severe pain by calling it “psychological pain”. Initially, back pain seemed to be a secondary problem in her life. However, its combination with other personal problems made it a disturbing problem in her life.

“I`ve already thought about this... so many times... Why? I do physiotherapy... I avoid physical exertions... My family does things instead of me... Why doesn`t it stop? There is no explanation... There is no explanation...” (Helena.23.495-499)

“Because I don`t know where this pain comes from... Maybe, it started like every kind of

pain... But when you cut your finger, you know that your pain comes from this, right? When you fall and sprain your ankle, you know that your pain comes from this. But this pain, I don't know. I don't know where it comes from!" (Helena.50.1097-1102)

Helena emphasised that understanding her pain would help her to deal with it or to permanently forget it. For her, understanding pain would be helpful in reducing her anxiety. Given that she could not understand her pain, she tended to imagine that something detrimental was possibly happening to her body.

"Understanding pain would possibly help me feel better... Because I would know what it is... That pain comes from there, from the problem I have there... And, by knowing this I would be able to deal with it... Or, completely forget everything... I don't have any problems... and that's that!" (Helena.49.1071-1077)

"I see myself in the future... Maybe using a wheelchair... because day after day, well it isn't day after day, it's year after year... I'm getting worse... worse... and with the passing of time I'll have more pain, for sure. (...) I believe that one day... I'm not sure about the wheelchair... but I'm sure that I'll be disabled... at least in my ability to walk... for sure" (Helena.38.816-824)

Initially, Helena emphasised that she had not an explanation for her pain; it just started many years ago. However, she eventually offered some hypotheses to explain her pain: it might be connected to a previous episode of knee pain or to her mood. According to Helena, pain increased when she was upset or anxious and this seemed to be a natural association for her. She also hypothesised that her pain might be genetic because her mother also had back pain. Despite all of her hypotheses, in due course she emphasised that she did not have an explanation.

She compared her pain to other pains that were relieved by specific treatments (such as pills or surgery) to emphasise that her situation was different. This lack of response to treatment seemed to be responsible for Helena's difficulties in understanding pain.

"I don't know! Was I badly treated? At that time, was the treatment inadequate? I don't know! At that time, when I complained about pain in my leg, my knee... rather than having the X-ray of my knee... I should have done an X-ray of my back, right? But at that time, I only did one of my knee... Then, when I went to physiotherapy... then the physician ordered a CAT-scan..." (Helena.22.471-479)

Helena expressed disappointment and distress about health professionals' approaches. She had visited several physicians, with no pain relief. Besides the lack of support from health professionals, Helena expressed that she was not respected and believed by them because

she perceived to be accused of imagining her pain. She deliberately described in detail her first appointment emphasising that she was “shocked” when the GP started laughing and insinuating that she was exaggerating because there were no reasons for such an intense pain. She did not think that the GP believed her. Although she was in distress about this, she did not completely refute this hypothesis.

“I... I remember that... fifteen years ago, when I was younger... I went to a physiotherapist... a physician... and when I complained about knee pain... I had a really strong pain in my knee, really strong... I went to the appointment and said that I had a strong pain in my knee and had no idea what was causing it... He just started laughing... and I... I was... really shocked... The physician... I mean, I was complaining about pain and he was looking like... doubtful! He said – Oh you`re so young... and all that stuff.... He might have said that to motivate me, or something like that... But, the way he said it... the way he said it... he just didn`t believe me.” (Helena.3.50-63).

Like Alice and Eva, Helena expected GP to be able to tell her what was wrong with her back, or, in other words, why she had pain. However, when she was asked about the answers she had been given, she immediately said “They don`t say anything” (Helena.8.166). Her facial expression and tone of voice seemed to illustrate her lack of satisfaction and disappointment. The explanations ranged from “frail vertebrae” to “it is in your head, you are too nervous” (Helena.8.158). The diversity of explanations seemed to be responsible for Helena`s difficulties in understanding and dealing with her pain.

“They don`t say anything! That`s that! They just say I have to put up with the pain... do some physiotherapy... and that`s that (...) I haven`t done any more physiotherapy because, honestly... I go to the physicians and they always say the same thing...” (Helena.8.166-171)

“I`ve got some frail vertebra... and that`s that... I need to be careful! (...) Honestly, I go to the physicians and it`s always the same thing... sometimes they even tell me that this comes from my mind... that it`s caused by my anxiety... and... no matter how calm I am, they say it`s caused by anxiety... (Helena.8.161-174)

“I don`t know if it comes from my mind, as he said...or not... but no, I don`t think this comes from the mind, because we feel this pain, right? We feel this pain, so it`s not our imagination...” (Helena.23.489-492)

Like Eva, Helena believed that besides explanations for the pain, health professionals should inform patients about the best strategies to self-manage pain.

Helena analysed her GP`s approach with some criticism emphasising that information on how to deal with pain would be more useful than the usual pack of ten sessions of

physiotherapy. When Helena was asked about how she tried to clarify her doubts about pain with her doctor, she admitted that she did not try. The reasons to justify this seemed to be associated to both her personality, which caused her to remain silent, and the GP's approach, which did not appear to promote dialogue. Helena seemed to be resigned to this kind of approach and spoke about it as something normal.

"... If we were prepared to deal with this [pain], with this stuff... It might happen, right? It might happen... this pain... and if we had knowledge about how to deal with it... It would be - I'm going to feel pain... so I need to do this to avoid it... - It would be better... [to have this knowledge], right? Rather than having the usual ten sessions of physiotherapy, ..."
(Helena.9.196-203)

"That's because when you don't know what to do... You just let it go... And, then you... reach a point when you can't walk anymore... actually, you definitely get to a point where you stop being able to walk, right? Meanwhile, we could have had more support... been given more knowledge or... whatever..." (Helena.10.208-215)

Helena seemed to believe that pain would be relieved if the GP were to provide her with adequate information. She seemed to believe that the health professionals' approaches to her problem did not correspond to her needs and that her problem was not taken seriously. Her speech and tone of voice varied from a sense of resignation to exasperation about the health professionals' approaches. Her thoughts of not being respected and believed associated with the diversity of unsuccessful treatments prescribed by her GP, appeared to have contributed to Helena having given up on healthcare. Seemingly, she did not believe that she would have any positive results from the contact with health professionals.

For her, the relationship with her GP seemed to be a problem. Besides this, she also believed that her pain was not well investigated or managed. Helena believed that her doctor did not study her problems in detail, which made it impossible for him to provide a diagnosis and prescribe adequate treatment. For example, she considered the X-ray a basic and insufficient exam and believed that her doctor should prescribe more detailed exams. Additionally, the treatment prescribed was always the same (physiotherapy), which made her lose hope in having any pain relief.

She started speaking about the lack of support in dealing with pain, referring singularly to her GP. However, she finished by using the plural, suggesting that she was talking about health professionals in general.

"I feel disappointed. I feel disappointed because they don't analyse our problem in depth..."

Because if we complain about pain... (...) it's just "do the physiotherapy, you're going to get better and that's that"... It's like this! They don't add anything more! I think... we should have more support because this pain is difficult to deal with..." (Helena.9.183-191)

"I started this [seeking health care] when I was forty... He [the GP] told me – you're too young to feel this pain – But I was in pain... it was the beginning of it... And the pain has got worse... I've never felt any improvement [as a consequence of treatments]... on the contrary... it has got worse..." (Helena.25.539-544)

"I think they should invest more, even do some complementary tests. But, they don't! It's just a simple X-ray, or sometimes a CAT-scan... (Helena.9.185-187)

"Why didn't he prescribe other treatments, I might have got better... Something other than physiotherapy... Because physiotherapy... you feel better during that period... and everyone I talk to says the same... Physiotherapy only helps you while you're having the sessions... At least in my experience... it's just when you're doing it..." (Helena.22.481-488)

"No... That support... I've already given up... As I told you, it's been four years since I've done anything like this... no physiotherapy... nothing..." (Helena.10.217-219)

Helena emphasised that other people did not understand her because her pain was not visible. She was the only person who understood her pain.

"This gives me the impression that some people don't believe in my pain... Others... I don't know... I don't know... (...) They don't know this pain... and when someone doesn't have this pain... they can't believe it... They just believe someone is sick when they are bedridden. There is a popular saying... something like "the upright diseases are not believed!" The upright diseases – if someone is walking and going about their life... They don't believe in our pain... they just believe it if someone is bedridden... That's it!" (Helena.26.566-590)

Her family was very supportive and this seemed to be related to past family bereavements. Her son and nephews visited her regularly and she also had the support of her mother. Seemingly, she had contradictory ideas about her family support. On one hand she thought that they could understand her, but on the other she emphasised that "they understand but...". She did not end this sentence, but gave one example to illustrate her reasoning. Frequently, her son told her that she was always "moaning and groaning" about pain. As a consequence, she avoided talking about this because she knew that if she answered his comments, they would quarrel and end it with a loud "I'm the only person who knows my pain". This expression might complete the first one ("they understand but... I'm the only

person who knows my pain”). Indeed, Helena seemed to feel supported and helped by her family, but she seemed to be (as did the other participants) the only person who really knew her pain. Regardless the intimacy shared with another person, this experience seemed to be perceived as almost impossible to communicate. Contrary to Eva, in Helena`s interview the words “supported” and “understood” seemed to have distinct meanings – despite feeling well supported by her family, it did not necessarily mean that she felt completely understood.

However, apart from her family, no one seemed to give her support to deal with pain. People`s reactions seemed to vary according to the relationship established and the context where it took place. For example, at work she considered that she was teased. Seemingly, she believed that her colleagues perceived her to be consistently complaining. Through some examples, Helena characterised her colleagues` reactions as “bitter jokes”. Her selection of adjectives to speak about this might reveal how intensively and aggressively she perceived her colleagues` words. She rationalised that she should not attach importance to these jokes, because she still needed to keep working with these people every day.

Helena was also upset about neighbours who tended to pity her. When old ladies from the neighbourhood tried to help carrying her bags, she felt grateful but deeply distressed. It seemed that Helena compared herself to those older ladies and felt she was more incapacitated, which in her perspective was not supposed to happen. She considered herself too young to have these difficulties.

When she compared both these behaviours, teasing and pitying, she admitted the last one was more difficult to deal with. She tried to ignore her colleagues` jokes, but her neighbours` pity seemed to generate an internal conflict, where she felt upset and disappointed with herself.

“I`ve had some situations... I think they`re teasing me, they`re teasing me... when someone says “Ow, I can`t...” or “I`m in pain...” or “I`ve got something here”... I think... they`re teasing me, right? I think they... There are people that seem to be teasing me about my pain... It`s like this... (...) And sometimes when I`m getting things off my chest with particular people... I believe they`re teasing us... it`s probable... “She has a pretty face, looks good and complains about pain and complains about this and that”. Yes...” (Helena.27.572-594)

“Because we`re doing our work... like getting a folder and while we`re getting the folder, while we`re getting the folder... because sometimes we have to do this... to say “Ow”... And they, “There`s she goes, she`s complaining again... she`s complaining again”. And I say this because... we`re stuck together for seven hours... Fortunately or unfortunately...” (Helena.28.604-610)

“I feel upset when they make jokes... that joking feeling... when I`m complaining about my pain... but I also get upset when I complain and people realise that I can`t carry a bag full of

groceries and help me... I have principles, of course I'm grateful... Sometimes I say that I'm fine... because I'm a nice person... I'm sometimes grateful because I'm feeling so bad... (...) I feel upset because I'm a young person and I can't carry a bag full of groceries but I also feel upset when they don't believe my pain... I don't know... I can't explain it... I don't know" (Helena.32.681-721)

There were also people whose advice was focused on the need to bear the pain. Helena perceived that according to them she needed to deal with her pain, because everyone did it. Pain and suffering seemed to be viewed as a kind of fate that was inevitable in life. This idea appeared to be connected with Alice's notion of sacrifice.

In general, people's reactions seemed to have a very negative impact on Helena, who became a very selective and lonely person. Helena's speech suggested that she tried to live her life without externalising her pain. She used the expression "you have to put on a happy face" (Helena.7.142), which seemed to demonstrate that she believed that she should avoid complaining about pain. This belief seemed to be a reaction to the perceived accusations from people around her, who tended to give her the idea that she was "whiny" (Helena.7.142).

"You have to put on a happy face because the people around us aren't responsible for our pain... we can't complain all the time... because if we complain, they say we're whiny ... that we're always whining... that we don't want to do anything... It can't be... we need to move forward... basically we need to live with this pain..." (Helena.7.142-149)

Like Eva, Helena justified the lack of support from other people with the lack of visibility of her pain. She seemed to believe that this made it difficult for people around her to believe that she was really in pain. She used a popular saying (literally, "the upright diseases are not believed") meaning that when someone looks good, no one believes they are sick. This seemed to illustrate the strong cultural component of this kind of reaction.

When Helena was asked about what kind of reaction would make her feel comfortable, she immediately answered, "taking my pain away". On one hand, people's reactions seemed to have a major impact on her pain experience, making it more difficult to bear. On the other hand, they did not seem to be that important because in the end pain was still there and no one could help her.

When Helena was prompted for explanations for her pain, she asked herself several questions. For a few moments she doubted herself, questioning if her pain was a product of her imagination. Throughout the interview she restricted her hypotheses to justify pain to two

main options: on the one hand, pain could be caused by a real health problem, which was exacerbated by herself; on the other hand, her pain was exclusively the result of her imagination. The conflict between these two options seemed to be difficult to deal with. Helena seemed to prefer the first explanation, but she was afraid that the second might be the most appropriate.

“Is it [pain] in my head...? If it... but no, it’s not in my head because I feel it. We feel this pain, it is not our imagination!” (Helena.23.489-492)

The recurrent comparisons between her pain and other people’s pain, alongside with the encouragement to be strong and bear pain like everybody else, made Helena to feel accused of being a “weak” person. This seemed to generate a dilemma: on one hand, she seemed to feel upset and disappointed with herself; on the other hand, she seemed to look at this accusation with some criticism. Apparently, she considered that her pain was much more difficult to deal with than other people’s pain, and these people definitely could not understand her experience.

Helena was also tired of pain because she felt pain every day. She admitted that she had had stronger pain in her life, psychological pain, but NSCLBP was distressing because it was constantly limiting her ability to perform daily activities. She emphasised that she had to deal with pain and keep doing her daily activities. When she was alone at home it was easier because she could interrupt her tasks and rest. But in her job, she had to bear her pain without resting, which made it more difficult.

“When I’m in pain... if it’s winter, like now, I get into the warm... go to the sofa or to bed... it depends... with a hot water bottle... and that’s what I used to do! In the summer, it’s warmer... so I just lay down... I just rest...” (Helena.39.854-858)

“Sometimes pain is really strong, really strong... Sometimes, my eyes fill with tears... when I’m doing the housework... cleaning the floor... I’ve got a big terrace and when I’m cleaning the floor... (...) that movement, using the broom... I need to stop several times... I have to! To sit down... stand up... lie down... I have to! This is really painful” (Helena.2.21-31)

Her pain seemed to have a significant impact on her job. She had to remain seated for long periods, which was painful, and avoid getting up because of her colleagues’ criticism. This might explain why she believed that she must deal with pain silently. She fulfilled her responsibilities, however she had to deal with a very hostile working environment where she felt accused of imagining her pain. When looking at how Helena dealt with her working

context, the problem did not seem to be the pain itself but the anxiety generated by her colleagues' comments. Despite the difficulties associated to pain, Helena argued that she needed to keep trying to overcome these challenges and keep going. The need to move on was reinforced several times by Helena. The tone of voice and the repetition of this idea suggested that Helena had questioned why she was still living after the death of some close relatives. She had to undertake the responsibility of taking care of her son on her own and this seemed to motivate her to move forward. These thoughts seemed to help Helena to deal with pain, giving her the courage to face the challenges associated with this experience. Rationally, she tried to keep a positive attitude but she described herself as a sad person due to her life story.

Fig. 17 – Helena`s narrative

Tree Nodes

Name	Sources	References	Created
3_Helena_Interview	0	0	24-11-2012 19:35
Disappointment with health professionals approach	0	0	24-11-2012 20:15
Give up on health professionals approach	1	1	24-11-2012 23:06
Inadequate approach (from health professionals)	1	1	24-11-2012 23:05
Is pain in my head	1	1	24-11-2012 23:06
Lack of support and respect from health professionals	1	2	24-11-2012 23:04
Not taken seriously	1	1	24-11-2012 23:05
Pain explanation - to keep asking herself several questions	1	1	24-11-2012 23:07
Poor communication with health professionals - they do not pr	1	4	24-11-2012 23:05
Unsuccessful attempts to relieve pain	1	8	24-11-2012 23:06
Expectations about the future	0	0	24-11-2012 20:16
Become more incapacitated in the future because pain will be	1	2	24-11-2012 23:20
Pain forever - It is not possible to abolish pain vs hope for so	1	3	24-11-2012 23:21
This pain will damage my body	1	1	24-11-2012 23:20
Family vs The others	0	0	24-11-2012 20:14
Colleagues tease her	1	2	24-11-2012 22:31
I am the only person who really knows my pain	1	1	24-11-2012 22:31
Lack of acceptance and support at job	1	2	24-11-2012 22:33
Neighbours pity her	1	1	24-11-2012 22:33
Not being believed because pain is not visible	1	1	24-11-2012 22:33
To be selective - is response of not being believed and being	1	1	24-11-2012 22:34
You have to support pain	1	1	24-11-2012 22:34
Living with pain and making sense of it	0	0	24-11-2012 20:14
Connection between feeling nervous and having pain	1	4	24-11-2012 22:42
Get used to pain	1	1	24-11-2012 22:41
It is difficult to accept this disability	1	2	24-11-2012 22:44
It is difficult to express her thoughts and feelings about pain	1	2	24-11-2012 22:42
Sadness - Sad about not being able to do basic tasks	1	2	24-11-2012 22:43
Sadness - Sad about the others` reactions	1	1	24-11-2012 22:43
Shy and uncomfortable being the centre of attention	1	3	24-11-2012 22:42

Tree Nodes

Name	Sources	References	Created
Shy and uncomfortable being the centre of attention	1	3	24-11-2012 22:42
Suffering in silence	1	4	24-11-2012 22:42
To doubt herself	1	2	24-11-2012 22:44
To show a happy face	1	1	24-11-2012 22:43
Pain as part of the daily life	0	0	24-11-2012 20:13
A mixture of sensations (pain, heat, nervousness) impacts on	1	2	24-11-2012 20:59
A typical day - pain the whole day	1	3	24-11-2012 20:58
Pain limits daily life activities	1	1	24-11-2012 20:59
Pain explanation - I do not know but I really would like to understand it	1	5	24-11-2012 20:15
Cannot understand where pain comes from	1	3	24-11-2012 23:18
Connection between knee and back pain	1	4	24-11-2012 23:19
Connection between pain and mood	1	4	24-11-2012 23:19
Symptoms in the whole body - all seems to be connected	1	2	24-11-2012 23:19
Worried about the lack of explanations	1	1	24-11-2012 23:20
Survive to support family	0	0	24-11-2012 20:14
I am the only person who really knows my pain	1	1	24-11-2012 22:23
Putting the others first	1	2	24-11-2012 21:11
To be or not to be understood by family	1	1	24-11-2012 21:12
To feel accepted and supported only by my family	1	5	24-11-2012 21:11
Trying to live (survive) with this pain	1	7	24-11-2012 20:41
It is difficult to deal with pain	1	4	24-11-2012 20:46
Looking for some comfort - to take some rest and use a hot w	1	1	24-11-2012 20:49
Trying to forget pain	1	2	24-11-2012 20:49
Trying to keep a positive attitude	1	1	24-11-2012 20:48

Fig. 18 – Print screen from N-Vivo, Helena`s tree nodes table

Appendix 20: Additional excerpts supporting themes and sub-themes

Theme 1: The disruptive nature of NSCLBP

Sub-Theme 1.1: Having no influence on the impact of NSCLBP on everyday life

“... at night, I would be on the couch, usually watching tv... then I used to go to bed... perfectly! And, on the next day I could barely get up! And, on some days I couldn't get up! I would miss work! I really couldn't go, really couldn't!” (Fernanda.15.324-329)

“He [husband] sometimes says why don't I ask for a sick leave for a while... But, this is from the spine, why would I go on leave? If I'm at home I feel pain, if I go to work I feel pain. At least I'm working, getting my full salary and don't think that much about the pain!” (Rita.40.873-877)

Sub-Theme 1.2: Adopting strategies to deal with the impact of NSCLBP

“Sometimes, I'm in a bad mood because I'm so drained... because of not being able to find a comfortable position... I end up in such a bad mood... (...) A day goes by, and then the other... then I take some pills... (...) but it's not worth it... I've already realised that it's not worth it... I don't know what to do...” (Laura.2.43-59)

“When I'm in pain... if it's winter, like now, I get into the warmth... go to the sofa or to bed... it depends... with the hot water bottle... and that's what I used to do! In the summer, it's warmer... so I just lay down... I just rest...” (Helena.39.854-858)

“Sometimes I'm doing a task and I already know... I really know that it will cause me a terrible pain, awful, but I don't stop doing it...” (Eva.50.1111-1114)

“It started when I was forty... forty something... He [the physician] said – You're too young to have this pain – But, I already had it... This was at the beginning and the pain has got worse... It's never got better... on the contrary, it has got worse...” (Helena.25.539-544)

“It worries me a lot! Yes! Worries me a lot... the increase of pain, the frequency of pain, and the limitations that it will cause. I`m going to give you another example... the other day... There are times when I am so demotivated, so demotivated because of pain... it`s such a strong pain and limits me in certain tasks... that day, I was at home and I started seeing where I could pass with a wheelchair... when I stop walking... If I stop walking one day... I was completely demotivated... (...) And on that day I realized... and said to myself: “Silly girl, God!” (Eva.59.1296-1317)

Theme 2: Searching for the meaning of NSCLBP

Sub-Theme 2.1: Needing to understand NSCLBP

“I`ve already thought about this... so many times... Why? I do physiotherapy... I avoid physical efforts... My family do things instead of me... Why doesn`t it stop? There is no explanation... There is no explanation...” (Helena.23.495-499)

Sub-Theme 2.2: Possible explanations for NSCLBP

“... it must be an infection, right? (...) I think it is! Do I have an infection... in my hips? I don`t know...” (Marília.12.243-260)

“Yes... I think it is! Because you know... working in the land is very, very hard! And, at the time [after her mother`s death] (...) I stayed with my father and he made me go to work on the land right away... a child that I... I look at my youngest who is 8, and when the oldest was 6 and 7, I would look at the oldest and think: nowadays a 7 or 8 year old child doesn`t even go to the supermarket to get this or that, because they can`t go out... And me back then, I was already digging holes, working on the land.” (Rita.16.330-346)

“When I was twenty, I had a motorbike and I had an accident when I was going to the mountain, I don`t know if... it damaged anything, I`ve got no idea... I know that I broke my wrist... Once I had a fall, a fall... and during a long time... I don`t know at what level it has affected my back... I can`t remember if it affected my back... But there is always some sort of impact... I think... I don`t know at what level, but...” (João.12.245-252)

“Probably, that fall also aggravated or contributed to something more, do you understand? No... I cannot understand until what point that fall had an impact on the whole process... but it probably had some impact, right?” (João.12.272-276)

“I’ve got colleagues... I’ve got a friend who’s already had surgery... (...) Another friend, as well... Nowadays, I think we all... all of us, being the same age... Maria is a bit older... Manuela is a bit younger than me... Others are the same age... They all have these kinds of problems” (Fernanda.12.259-268)

“And I think that all this is connected to the bones, you see? The curved back, the arthritis... I think everything is due to these things... Bad circulation... I also have it! That I inherited from my mother, I usually say, I only inherited the good stuff! And one goes on living...” (Rita.17.353-358)

“But obviously if we’re doing... a certain movement, we’re creating a muscular tension... or if we’re in a stressful situation, we’re also creating a muscular tension... and if we have a weaker region... the weakest link... pain is to be expected there... It is somewhere back here... I’m not sure exactly where... exactly what...” (João.47.1022-1031)

“I know I can’t sleep in my bed... so, if I sleep on my couch and if I have a heater right in front of me with a blanket covering both the heater and myself... I sleep very well... In my bed... I don’t know if it’s because my leg gets colder... I’ve got no idea... I just know that the problem is right here and that I wake up... wake up in tears because of the pain... I noticed that last weekend it was warmer, and I wasn’t in pain...” (Fernanda.3.57-68)

“No... the pain... the low back pain is... in a specific area... so it’s over here in the lower back... but, I have several problems in my back... and, I believe that depending on the movement I’m doing... or... or... a physical situation... for example lifting... for example, lifting something... sometimes it’s not comfortable... but sometimes... there are situations where this doesn’t happen...” (João.29.618-626)

“Sometimes, it hurts... It’s like I say my whole skeleton hurts... all my back is

in pain... the bones right here... I don't know if it's related or not, but some days especially with this weather, raining... cold, essentially the cold weather... or when there is a sudden decrease in temperature, a sudden change in the temperature... It affects me, my pain increases..." (Eva.4.69-78)

"It [NSCLBP] also can be... a problem... a genetic problem... and why am I saying this? Because, approximately three months ago my mother had a surgery precisely... in her lower back... She had a plate and some screws... she had a surgery there... in more than one place in her lower back... And in these cases, there is always a genetic connection, right? (João.15.318-328)

"... and the people I've talked to [about NSCLBP]... they all say the same... (...) I don't know if there is different information for this..." (Helena.23.485-489)

"... this is what I've realised... I didn't read it anywhere... anywhere... nothing... I don't know... (...) No, this idea... I developed it (...) Exactly, exactly... I didn't read this anywhere and no one told me anything, no..." (João.32.681-693)

Sub-Theme 2.3: Understanding NSCLBP and controlling it

"For example, I don't dust all at once... To start with, I'm not at home all day... Today, I clean my room, tomorrow the kids' room, another day the living room... I clean and wash the floor on the same day, because if we clean the kitchen and don't clean the living room... But the dust is never cleaned on the same day, each day I... I organise things like this..." (Rita.27.581-587)

Theme 3. Clinical encounters that perpetuate the lack of understanding about NSCLBP

Sub-theme 3.1. Expectations of being given the ultimate explanation for NSCLBP

"Because I did an X-ray, but it didn't reveal any problems... Sometimes I think... and sometimes this makes me feel even more disappointed because I've already talked to my GP... And he just said "this is nothing... just pain..."

nowadays everyone has back pain"... Ok, fine! And this subject isn't discussed any further... we don't talk about it..." (Laura.12.246-252)

Sub-theme 3.2. Making sense of the health professionals' explanations for NSCLBP

"I don't know... because my spine might have had... might have had some problems that were not common for... for someone of that age... I assumed... I assumed it... it was because of that... A twenty year old with a spine like that, wasn't normal... So that was my conclusion, right? He said seventy or eighty... but for me... it was an indication... he was trying to give me the idea that the state of my spine was only normal for a seventy year old, after having a range of life experiences... I got his message..." (João.33.714-728)

"I say this because it's what the doctor makes me, makes me... believe... unless ... if it doesn't become worse, I mean if this isn't a hernia that can be operated on, because the L4 links everything... the legs and arms... and muscles and everything... not being operated on, which I think is very good... if it doesn't become worse, I should have some physiotherapy sessions, from time to time... and I'm going to live like this..." (Fernanda.21.452-460)

"I've got some frail vertebra... and that's that... I need to be careful! (...) Honestly, I go to the physicians and it's always the same thing... sometimes they even tell me that this comes from my mind... that it's caused by my anxiety... and... no matter how calm I am, they say it's caused by anxiety... (Helena.8.161-174)

"I know that I've got a problem of some sort... because I'm in pain and no one has pain for no reason, right? I've got a problem of some sort and it's difficult not knowing why and not knowing if there is a solution... I don't know... And, it's difficult to explain this to you... But it's difficult to live with such uncertainty... (...) It's difficult... not being certain... in our minds... we're not sure! I'm not sure!" (Laura.30.638-653)

Sub-theme 3.3. Making sense of the relationship with health professionals

"This makes us think about what we're doing wrong, right? Maybe it's because of this... Maybe it's because of that... Considering what we hear

from... what is said by our GP, or other physicians... They're supposed to support us in this... They're the ones who know, right? They're the experts. We just can only say what they tell us." (Laura.19.407-415)

"I go to the GP... I complain about pain and she just doesn't say anything... She [the GP] doesn't say, it is because of this.... or because of that... And, I... I even asked a professor the meaning of the words in the X-ray report... Because she had spoken in her way... and I hadn't understood anything... And, he told me that it was bone spurs... He said that was my problem.... But, she doesn't say anything... just – take these pills and that's that..." (Alice.17.359-369)

Sub-theme 3.4. Losing hope in health professionals' approaches

"It's the anti-inflammatory... so, I avoid going [to medical appointments]... I avoid going [to medical appointments] because they always prescribe medication and I don't think it solves my problem, so I don't go! The last time I went to the hospital was because I was putting a baby girl down and when I straightened up... I realised that I had done something to it... I even went to the emergency services... because I thought I'd done something really bad to it because I couldn't straighten up... without pain... They took an X-ray and... there weren't any problems... They just told me to avoid carrying heavy things..." (Laura.27.585-595)

"I don't know! Was I badly treated? At that time, was the treatment not adequate? I don't know! At that time, when I complained about pain in my leg, my knee... rather than having the X-ray of my knee... I should have done an X-ray of my back, right? But at that time, I only did one of my knee... Then, when I went to physiotherapy... then the physician ordered a CAT-scan..." (Helena.22.471-479)

"The results I had... They weren't great results, right? Physiotherapy is good, it's good, right? But no one can do physiotherapy forever, right?" (Eva.32.699-702)

“The physician says I have to live with this pain, there is no reason to have surgery because it is not a hernia worth operating on... and when I have more severe pain, I should take a pain killer...” (Fernanda.8.156-161)

“That`s because when you don`t know what to do... You just let it go... And, then you... reach a point when you can`t walk anymore... actually, you definitely get to a point where you stop being able to walk, right? Meanwhile, we could have had more support... been given more knowledge or... whatever...” (Helena.10.208-215)

Theme 4. Reshaping social interactions according to the meaning of NSCLBP

Sub-theme 4.1. Needing to legitimate and validate NSCLBP

“It [pain] isn`t visible! I can`t show anyone my pain! I can`t.... I can`t tell other people this is my pain and show it... And they can`t see it... they don`t have to... it isn`t about what people have to do... We can`t see what we don`t know... I don`t blame anyone... Do you understand what I`m saying? It just bugs me because... some days I`d like to be a little better understood, that I would! So, I don`t blame anyone because they can`t see what they`ve never experienced or imagined anything like it in their lives! This pain isn`t real... it isn`t real for them... they don`t have this experience...” (Eva.57.1253-1267)

“If people can appreciate my pain? No! I don`t think they appreciate it at all! I don`t think so! No, I don`t think so, I don`t think so!” (Eva.18.377-379)

“Because we`re doing our work... like getting a folder and while we`re getting the folder, while we`re getting the folder... because sometimes we have to do this... to say “Ow”... And they, “There`s she goes, she`s complaining again... she`s complaining again”. And I say this because... we`re stuck together for seven hours... Fortunately or unfortunately...” (Helena.28.604-610)

Sub-theme 4.2. Isolation and alienation

“Do you really understand what I`m saying? (...) How can I explain this to anyone? To say that this is pain... and it overlaps with another pain... They

can't understand! How can they understand? It's like we're speaking Chinese... If I heard anyone talking like this, I would think that the person was speaking Chinese...(...) No! I've never had this conversation with anyone!" (Eva.27.571-587)

"I think that when we're given an example we can understand things better than with a detailed description... so it's like... "it's life... it's life with niggling pain, niggling pain..." It's what we say to people... just for them to... it's complicated... life is complicated in this way..." (Eva.59.1284-1291)

"Yes sometimes I speak about it... because it's like... there is also a need of saying it... I'm in pain, right? And sometimes I think I speak more than I should... I wish I could speak less than I do... because... I don't think they understand it... No!" (Eva.18.384-389)

"... usually I don't talk about my pain because people immediately answer "I also have pain... nowadays everyone has pain..." so, I don't say anything (...) No! No! Because they say "so what? I also have pain! You're complaining... I also have pain, but I don't complain". Then, most of the times I prefer to remain silent." (Laura.15.314-325)

"Sometimes... sometimes... sometimes I'm in pain, full stop. I'm in pain and... and... I know that it will end up going away... take half an hour, or a day... it will eventually go away. Other times... others.... I'm in pain when I get up so... they immediately notice... I limp more or something like that... so... do you understand? So, there are signs they already recognise... even though I don't say anything.... they know that I... Or I unconsciously put my hand here and massage it... They know... they know that I'm in pain... I don't need to say that I'm in pain, right? Sometimes they don't realise that I'm in pain because I don't give off any signs that... that they notice that... that I'm in pain... this also happens... I'm not the type of person to be in pain and say "Oh, I'm in pain..." it's not my style, at all (João.56.1232-1252)

Sub-theme 4.3. Trying to put NSCLBP in second place

“I lose my patience... I can't handle it ... even my husband, he comes up to me, wanting to talk... and he wants to go here and there... And I... I'm not... Sometimes I just can't take it...” (Laura.4.72-76)

“If needs be, she [the daughter] helps me! But I... I do what it takes so that this isn't necessary... I do more to help her because at the end of the day she also needs it. (...) But, yes I like doing things! And I need to do things! But, if needs be she... or if there's anything I ask for... anything... she's there for me! But I don't put things on her, obviously!” (Eva.55.1209-1217)

“Well, let's see! That's why I told him last year, that he should learn how to make the dough, because of that... Because the course he plans to take doesn't exist here in Setúbal [name of the city]! Either he has to go to Lisbon or to Beja or Évora or... So, he has to go... and for me to afford a room... He knows my situation, right? And we see on TV that I'm not the only one... To pay a room, tuition, travelling, food... it's not enough for everything! And if he eats at home, you already save a lot of money! To cook some rice or some pasta... it's not that hard. If he comes every week, he can take food for 5 days... even on Friday he can eat a pizza. You can eat a pizza once a week, it's not... Well, we'll see... he may even learn how to cook fish...” (Rita.47.1029-1042)

“So my idea was, as a grandmother, to be able to take care of my grandchildren! Because by the time I'm 57, my eldest will be 30! My idea... I might be a grandmother in 4 or 5 years, you never know, right? But if he becomes a dad at my age, there will still be 3 years before my retirement! But my idea was that when I became a grandmother, I would take care of my grandchildren until they were 3 and then we would see! And to retire at 57! When that law [about retirement age] came out, I'm honest... I don't see myself working until I'm 65 years old, but... Look, we'll see what will happen to me... Because if I keep on having pain in my heels, pain in my back and all that... Maybe when my salary is no longer needed to support them... maybe I'll ask for sick leave, work for a while, I don't know... Right now I

don't have any plans for the future, I live one day at a time..." (Rita.46.993-1011)

Theme 5. Defining the self through the meaning of NSCLBP

Sub-theme 5.1. Being questioned and self-questioning

"If I'm at home, for example, I feel more pain when I'm at home than when I'm out. Because when you're at home you don't... Unless I have a lot of patties to make, then it doesn't hurt... But on those days you're more relaxed, not having that much to do... when you don't have to count the hours, it would hurt more! You're more relaxed then, right? It's like it makes you think about it more, I don't know, maybe it's also psychological..." (Rita.41.880-888)

"... it [pain] might be related to stressful situations... emotional stress, let's imagine that... we get... our muscles get... stuck, isn't it? Because it can also be related to... to stressful situations... a psychosomatic situation, let's say that..." (João.30.656-662)

"Honestly last year was... it was crazy! The pain was horrible! And I've already given birth! I've already had a broken leg! I've already had kidney stones! I've been through all of this... I had a broken leg for ten days, waiting for surgery... I've been through a lot, but this pain... it was... it was horrible! I mean we just value pain when we have it... but this pain was equivalent... It wasn't one of the worst pains, but it was close to... it was the same!" (Fernanda.14.286-296)

"I have to have a normal life, right? I can't just lie in bed all day! Because I have a sister who has pain... she'll go straight to the couch to lie down! And she has pain! Even though she takes whatever she takes, she still has pain! Because she thinks she has pain, so she has pain, so then she lies down. I have pain, too! But why am I going to lie down? I have to keep going!" (Marília.10.215-221)

"Because I was a young mum... I had to deal with things... it wasn't that I didn't have any help from my sisters but... if I needed help ... My mother

wasn't, my mum was hindered, she'd had a stroke and was bed-ridden but apart from that... If I ... had to wash my daughter, had to feed my daughter, make the food... I wouldn't know, right? When I got married I didn't know... I had to make the food, I had to deal with it, right?" (Marília.43.936-945)

"I know what a strong pain is! What kidney pain is! Pain! I really know what it is! I can distinguish, when it is a light pain, I don't pay (attention)..."
(Eva.42.903-906)

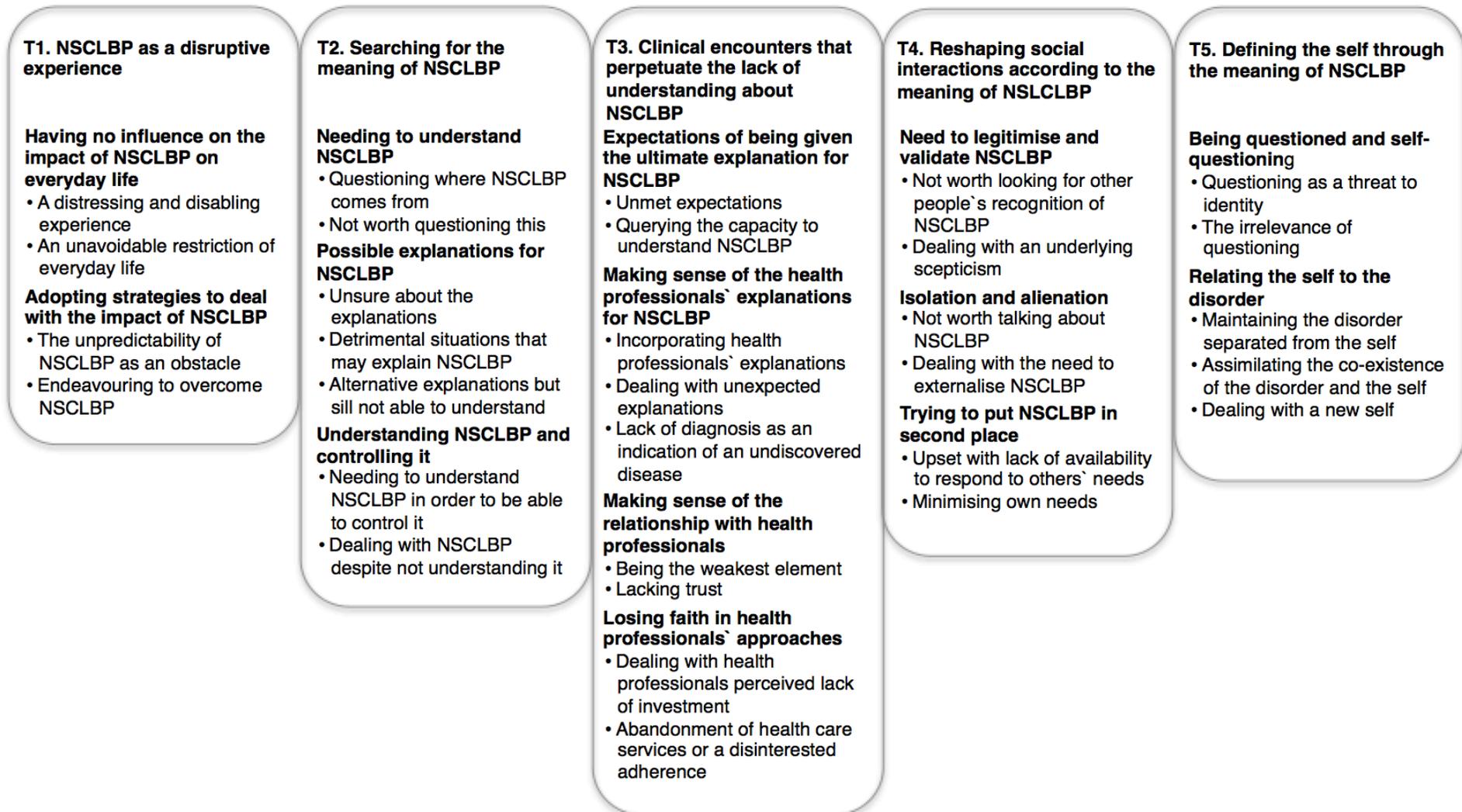
"... he's really whiny. So I say to him "if I complained about the pain I have, you wouldn't sleep a wink all night". He's always complaining about the knee which was operated on "ow, ow, ow, this hurts, this is because of the weather, it's the weather" (Marília.20.418-422)

"Because at work, I think everyone feels more pain than I do. Because one goes on sick leave one day, then the other goes on sick leave. Then another misses work... Some of those poor souls are sick! I see things from both sides! For example, right now one is on sick leave and I think she should be on sick leave! Another one is on sick leave but I think she would be better at work – this is how I feel! Because due to the diseases they have, right? For example... so why should I complain? It's not worth it! The one who is in the kitchen with me for example, I can't carry weights, she can't carry weights, neither of us can. I have to carry everything by myself... who will?"
(Rita.42.924-937)

Sub-theme 5.2. Relating the self to the disorder

"I wish I could be different, but if I haven't changed until now... I don't think it will happen... no, but I ask myself about this a lot, and I've also asked my doctor... to avoid being so nervous... but I don't know how to control myself... I don't know how to do it! That's it, I don't know... some things wouldn't be necessary... but for me... (...) When you're nervous everything hurts..." (Alice.31.677-698)

Appendix 21: Master table of themes, sub-themes and concepts



Appendix 22: Dissemination

The work in progress has been presented annually at the Brighton Doctoral College Postgraduate Research Student Conference. Additionally, abstracts of these presentations have been published in the abstract booklets of this conference (2011-2015).

Caeiro, C. (2011) An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition, *In* PhD & Professional Doctorate Students Annual Conference - Abstract Booklet, Eastbourne.

Caeiro, C. (2012) An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition - preliminary findings", *In* Doctoral College PhD and Professional Doctorate Student Conference - Abstract Booklet, Eastbourne.

Caeiro, C. (2013) An exploration of how Portuguese individuals with non-specific chronic low back pain disorder understand and make sense of their condition - Findings, *In* Doctoral College MPhil/ PhD and Professional Doctorate Student Conference - Abstract Booklet, Eastbourne.

Caeiro, C. (2014) An exploration of the experiences and perceptions of Portuguese individuals with non-specific chronic low back pain, *In* Doctoral College PhD and Professional Doctorate Student Conference - Abstract Booklet, Falmer.

Caeiro, C. (2015) Experiences of Portuguese individuals with non-specific chronic low back pain disorder, *In* Doctoral College PhD and Professional Doctorate Student Conference - Abstract Booklet, Eastbourne.

Additionally, the research process and findings were presented at a research seminar entitled "Making use of qualitative research to better understand our patients", carried out in Setúbal-Portugal in March 2014. An abstract of this presentation was published in the abstract booklet of this event.

Caeiro, C., Moore, A., Price, L. (2014) An exploration of the experiences and perceptions of Portuguese individuals with non-specific chronic low back pain disorder, *In* Friday Evenings Research Seminars - Making use of qualitative research to better understand our patients - Abstract Booklet, Setúbal.

This study's findings are to be presented at International Federation of Orthopaedic Manipulative Physical Therapists (IFOMPT) Conference 2016, carried out in Glasgow-The United Kingdom in July 2016.

Caeiro, C., Moore, A., Price, L. (2016) Portuguese individuals' experiences and perspectives of non-specific chronic low back pain: an interpretative phenomenological analysis. (abstract accepted)

Furthermore, other allied physiotherapy conferences and peer-reviewed journals will be approached in order to promote the disseminations of this study's findings.