

**THE LIVED EXPERIENCE OF ACTIVE CHARCOT
FOOT IN DIABETES MELLITUS**

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Abstract

Charcot foot is a rare but potentially devastating complication of diabetes that can result in foot deformities, ulceration and potentially amputation. Offloading via non-removable cast for an average of nine months is the only known effective treatment. The impact of a clinical diagnosis of active Charcot foot and its management on patient's quality of life has not been well studied. The aim of this research was to enhance the understanding of the lived experience of individuals diagnosed with active Charcot foot.

A novel method of photo elicitation and qualitative interviews using Interpretive Phenomenological Analysis (IPA) was used for the study. Participants were asked to bring in three to five of their own photographs to demonstrate how the diagnosis and management of active Charcot foot had affected their lives. These photographs were used as the basis of a discussion in a semi-structured, tape-recorded interview. Eight interviews were carried out with diabetic foot patients recently diagnosed with acute Charcot foot presenting to one clinical centre and undergoing treatment with casting therapy (six males and two females; two with type 1 and six with type 2 diabetes). The mean age was 59 years and the mean duration of diabetes was 16 years. Time from symptom onset to diagnosis ranged from three days to six months. Duration of casting therapy prior to the interviews ranged from three to seven months.

Patients identified several areas of concern including alterations to their experience of lived time, lived space and a loss of their sense of self. These have been explored through the following three master themes: the life journey interrupted, the hindered body in places and spaces and the diminishing self in a restricted lifeworld. It has therefore been recommended that practitioners take a more holistic approach to assessing and treating this patient group in line with both the results of this research and current government and NHS guidelines. This is the first study known to have explored the patient's perspective of the lived experience of an active Charcot foot. It has demonstrated that both the diagnosis of an active Charcot foot and its management has a more severe impact on patient's perceived quality of life and sense of well-being than has been suggested in previous research.

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List of abbreviations

ADL – Activities of daily living

CAIPE – Centre for the advancement of interprofessional education

CN – Charcot neuropathic osteoarthropathy

COREQ - Consolidated criteria for reporting qualitative research tool

CROW – Charcot restraint orthotic walker

DFU – Diabetic foot ulcer

DSPN – Diabetic sensory peripheral neuropathy

EBP – Evidence based practice

GP – General practitioner

HCP – Health care practitioner

ICF – International classification of functioning, disability and health

IPA – Interpretive phenomenological analysis

IPQ-R - Revised illness perception questionnaire

MRI – Magnetic resonance imaging

NASS – North American Spinal Society

NICE – National institute for health and care excellence

NSF – National service framework

PAIS - Psychosocial adjustment to illness scale

PIN – Patient interpretation of neuropathy questionnaire

PPI – Patient public involvement

QoL – Quality of life

RA – Rheumatoid arthritis

RCT – Randomised control trial

SMFA - Short Musculoskeletal Functional Assessment

TCC – Total contact cast

WHO - World Health Organisation

WHO-FIC – World Health Organisation family of international classifications

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Declaration of Authorship

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:

Date:

Chapter 1. Introduction

This chapter outlines the background to the subject area of the thesis and the context and rationale for the research. It explains why the study was so important to me, the political climate in which it took place and the influences that led to its development. A rationale is provided for the setting in which the research was undertaken and the structure of the document as a whole is outlined. The concept of reflexivity and why this is so central to this study is explained. Reflexive accounts are provided throughout the thesis, the first of which closes this chapter.

1.1. Overview of the study

The central aim of this thesis is to improve our understanding of what it is like to be diagnosed and live with the management of active Charcot foot. Charcot foot is a rare but serious complication of distal, sensory neuropathy, most frequently associated with diabetes (Game et al., 2012). Characterised by bone and joint fragmentation and destruction, it can result in severe foot deformities and frequently leads to ulceration and potentially amputation (Smith, Kumar, & Causby, 2007). Offloading via a knee length, non-removable plaster cast for an average of nine months is the gold standard treatment (Game et al., 2012). Several terms are used to refer to this pathology. However, it was recommended by a specialist task force in 2011 that the nomenclature should be standardised to Charcot neuropathic osteoarthropathy (CN) or the Charcot foot (Rogers et al., 2011). For consistency and ease of reading, the term Charcot foot will be used throughout the thesis. This study concentrates on the patient with active Charcot foot, indicating that there is ongoing bone and joint disruption.

There is limited research regarding the impact of Charcot foot on patients' lives. All previous work used quantitative measures to explore quality of life (QoL) or psychological states such as depression (Chapman, Huber, & Brady, 2011; Chapman, Shuttleworth, & Huber, 2014; Dhawan et al., 2005; Kroin, Chaharbakhshi, Schiff, & Pinzur, 2018; Pakarinen, Laine, Mäenpää, Mattila, & Lahtela, 2009; Pinzur & Evans, 2003; Raspovic & Wukich, 2014; Raspovic, Hobizal, Rosario, & Wukich, 2015; Sochocki et al., 2008; Srivastava, Younis, & Kurdy, 2016; Vileikyte et al., 2008; Willrich, Pinzur, McNeil, Juknelis, & Lavery, 2005). Each study attempted to explore the health-related QoL of patients with Charcot foot by utilising objective measures and validated questionnaires. Regarding the studies investigating the patients' experience of Charcot foot, five utilised the Short-Form 36 questionnaire (SF-36) (Raspovic & Wukich, 2014; Raspovic et al., 2015; Sochocki et al., 2008; Srivastava et al., 2016; Willrich et al., 2005) and Vileikyte et al. (2008) used the shortened version, the SF-12. Pinzur and Evans (2003) also undertook long-term follow up with the SF-36 alongside the American Academy of Orthopaedic Surgeons' (AAOS) foot and ankle outcome measure (American Academy of Orthopaedic Surgeons, 2001). Other research used more condition specific tools such as the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) and the Neuro-QoL (Vileikyte et al., 2003). Two studies utilised the Foot and Ankle Ability Measure (FAAM) (Martin, Irrang, Burdett, Conti, & Swearington, 2005) as a more region-specific tool (Raspovic & Wukich, 2014; Raspovic et al., 2015). The American Orthopaedic Foot and Ankle Society (AOFAS) Diabetic Foot Questionnaire was also tested as a disease specific instrument (Dhawan et al., 2005). However, its use is not currently recommended (Pinsker & Daniels, 2011). All of these measures are discussed in more detail alongside the results of the studies in relation to Charcot foot in the literature review (Section 2.11).

Health status measures, in which patients are asked to rate different aspects of their life, are perhaps the simplest means of measuring health related QoL (Wee et al., 2008). However, the use of these instruments restricts participants' responses within pre-defined limitations. Such restrictions prevent the findings from directly reflecting the patients' experiences and concerns. A gap is then left between the experience of Charcot foot as abstractly defined and the patients' perspective and experience, which is essential for framing effective interventions (Vileikyte, 2008).

The nature of illness can give people a different perspective on life (Morse, 2011). Those affected by any illness can experience a changed sense of self and may also experience social changes such as alterations to their employment and financial status, increasing dependency on others and restrictions to the activities of their day-to-day living (Morse, 2011). Undertaking detailed assessment of patients' experiences can help to gain a deeper understanding of their personal issues, determine priorities for quality improvement, provide a framework for approaching patients' problems holistically and aid health care practitioners (HCPs) in uncovering new approaches to care (Coulter & Ellins, 2006; Greenhalgh & Hurwitz, 1999). The overall aim of this study was therefore to gain a deeper understanding of the experience of living with the diagnosis and management of active Charcot foot as a complication of diabetes mellitus.

The current study is located in the interpretivist paradigm and rooted within a constructionist epistemology and critical realist ontology. Interpretive phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009) using photo elicitation was identified as the most appropriate methodology for this research. The phenomenological emphasis on the experiences and concerns of participants lies at the heart of all IPA research (Larkin,

Watts, & Clifton, 2006). Its commitment to the examination of how people make sense of their major life experiences made it appropriate for this exploratory study which details the patient experience of Charcot foot. Photo elicitation is a visual method based on the simple principle of inserting a photograph into a research interview (Harper, 2002) during which the participant interprets and explains the meaning behind the image (Close, 2007). The photographs are a reference point during the interview and can be used to acquire rich verbal data (Frith & Harcourt, 2007). A detailed discussion of both IPA (Section 3.7) and photo elicitation (Section 3.13.1) can be found in the methodology chapter.

Eight patients presenting to one specialist clinical centre in London for management of active Charcot foot were interviewed. Participants were asked to bring in three to five of their own photographs to demonstrate how the diagnosis and management of active Charcot foot had affected their lives. These photographs were used as the basis of a discussion in a semi-structured, tape-recorded interview. The data were then transcribed and analysed following IPA guidelines (Smith et al., 2009). Whilst it is acknowledged that each patient's experience of the diagnosis and management of active Charcot foot was unique to themselves, common themes were identified. These themes, alongside their related sub-themes, are presented and discussed in this thesis. These areas are then examined against the background of existing literature and implications for practice and future research are identified. Many new insights into the patient's experience of active Charcot foot came to light, revealing that the impact on health related QoL and well-being may be more severe than had been previously recognized in quantitative literature. It is hoped that the findings can be used to help inform the practice of any HCP coming into contact with people undergoing management of active Charcot foot and that the improved knowledge of the patient's experience will assist in improving patient centred care for this vulnerable patient group.

1.2. Study context and rationale

The central focus of this thesis was to explore the lived experience and the significance of active Charcot foot in the lives of those given this diagnosis. There is a paucity of available literature exploring patients' experiences of living with Charcot foot. Those studies identified are almost exclusively quantitative by design. Research aiming to identify and acknowledge patients' experiences and concerns from their own perspectives was felt to be both timely and important for the reasons now discussed.

The research was conceptualised at a time when person centred care was being highlighted in government agendas (Darzi, 2008; Department of Health, 2010; Department of Health, 2013). The Darzi report (Darzi, 2008) recommended a change in focus of NHS services, towards a locally led, patient-centred and clinically driven service where high quality care is the primary concern. Darzi's report, 'High Quality Care for All', advocated quality at the heart of everything, with health care to be understood from the perspective of patients and improvements made by analysing and understanding patient satisfaction with their own experiences (Darzi, 2008). Subsequent to this, the white paper, *Equity and Excellence: Liberating the NHS*, was published in 2010. This document called for greater patient choice, personalised care that reflects the individual's needs, and a strong patient voice, using the slogan; '*no decision about me without me*' (Department of Health, 2010).

More recently the Francis report (Department of Health, 2013) made 290 recommendations designed to create a common patient centred approach across the NHS with values of care and respect at its core. Clearly, if personalised care reflecting patient need is the aim of public health care services, it is vital to explore that need in a

considered and methodical way. Given the current paucity of qualitative research in diabetic foot complications, and in Charcot foot in particular, this only serves to highlight the need for and importance of the present research.

For more than a decade there has also been an increased focus in government and health service policy, highlighting the importance of recognising and dealing with improvement of both diabetes care and the psychosocial aspects of long-term illnesses. The National Service Framework (NSF) (Department of Health, 2001) for diabetes set out to improve care by outlining twelve standards designed to reduce the burden of diabetes and its associated health inequalities by 2013. The aims were to provide diabetes services that are person centred, developed in partnership with the patient, equitable, integrated and outcome oriented. The need to understand the experience of living with diabetes and diabetes care was acknowledged (Department of Health, 2001).

The improvements in diabetes services since the publication of the framework have been variable, and in 2016 the Public Accounts Committee reported an unhealthy picture of diabetes services in England. Performance in delivering the recommended nine care processes and achieving the three treatment standards, which help to minimise the risk of diabetes patients developing complications in the future, were also reported to have stalled (House of Commons Committee of Public Accounts, 2016). Unfortunately, while some signs of progress have been noted since the conception of the NSF, there remains a long way to go before everyone with diabetes receives high quality care (Diabetes UK, 2016). The National Diabetes Audit and National Diabetes Foot Care Audit continue to provide a comprehensive view of care in England and Wales by measuring the effectiveness of healthcare received against National Institute for Health and Care

Excellence (NICE) clinical guidelines and NICE quality standards in England and Wales (Health & Social Care Information Centre, 2016a, 2016b). These audits are ongoing and the results are reviewed and disseminated annually.

In 2004, the Quality and Outcomes Framework (QOF) (NHS England Gateway, 2014) was introduced, to help standardise improvements in the delivery of primary medical services. In diabetes care, incentives encourage GPs to examine patients' feet and stratify them into risk categories as part of the recommended annual diabetes review (NHS England Gateway, 2014). The foot review should include bare foot examination for neuropathy, ischemia, callus, infection, deformity, gangrene and Charcot foot (NICE, 2015). Patients classified as being at moderate or high risk of developing diabetic foot problems should then be referred to a foot protection service led by a HCP with specialist training in diabetic foot problems and access to the wider multidisciplinary team (NICE, 2015). More than 400,000 people with diabetes in England are still not having an annual foot check, despite these being important for preventing diabetes-related amputation, (Diabetes UK, 2015). The figures estimate that 414,784 people with diabetes in England are not getting the check, which equates to 27.7 per cent of people with Type 1 diabetes and 13.3 per cent of people with Type 2 diabetes (Diabetes UK, 2015).

Current national health policies aim to foster a common culture throughout the whole health service by putting the patient first (Francis, 2010). It is recognised that people with long-term physical health conditions often have psychological and emotional needs, resulting from the burden of illness-related symptoms, the disability associated with the physical illness, and the impact of living with more than one physical condition at any time (NHS Confederation, 2012). The focus in the face of multi-morbidities is on

personalised care planning using a collaborative approach and calls have been made for a well-coordinated and collaborative patient journey between physical, psychological and mental health components of disease specific pathways (NHS Confederation, 2012). The NICE guidelines (2012) also highlight the importance of improving the experience of care for people using adult NHS services, knowing the patient as an individual, and recognising that patients may potentially need psychological and emotional support. More specifically still, the most recent NICE guidelines for the diabetic foot suggest that further research is required into several aspects of Charcot foot, including health related QoL (NICE, 2015). Clearly, given the government and health service focus on individuals, understanding experience, and patient centered care, it is important to comprehend the perspectives of the patients treated in the health service, providing further justification for the current study.

1.3. Definitions of health and evidence-based practice

The idea of health emerges from an array of different influences and social processes, many of which operate at levels beyond the physical body with which we experience life (Yuill, Crinson, & Duncan, 2012). It may be defined differently between people, between patients and their doctors and at different places and times (Blaxter, 2010). The World Health Organisation (WHO) describes health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, a definition that has remained unchanged since 1948 (World Health Organisation, 1948). However, most medically related thought remains concerned with disease states and illness (Bury, 2005). Within Western health care, the continued dominance of the biomedical model is reflected in the day-to-day rational and scientific practices associated with the work of doctors within hospital and clinical settings (Yuill et al., 2012). Whilst this biomedical model primarily equates health with the absence of disease, drawing upon biochemical

parameters of ill health as the basis for treatment and intervention (Yuill et al., 2012), other models offer alternative suggestions. The social model for example views health as a positive state of wholeness and well-being, associated with, but not entirely explained by, the absence of illness, disease and physical or mental impairment (Blaxter, 2010). These definitions tend to reflect the ontological and epistemological orientations of those who subscribe to them.

The way HCPs think about health and disease determines their behaviours during clinical encounters with patients to a considerable extent (Rosenbaum & Stewart, 2004). The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) is a framework for describing and organising information on functioning and disability, providing a conceptual basis for the definition and measurement of health and disability. It recognises that a common definition of disability is crucial to understanding and improving outcomes for people with disabilities and is a reference member of the WHO Family of International Classifications (WHO-FIC) (World Health Organisation, 2001). Several formal consensus process meetings to integrate evidence and expert opinion based on the ICF classification and framework, led to the development and definition of ICF core sets for several pathologies, of which diabetes mellitus is one (Ruof et al., 2004). Almost 45% of the adult disease burden is now attributable to non-communicable diseases, and the ageing population has accelerated this burden in many developing countries. Collecting information on health state and health outcomes has therefore become of primary interest to all countries (Cerniauskaite et al., 2011).

Health care practice and policy is based around evidence-based practice (EBP) and makes use of a variety of research and information. Evidence is assessed to demonstrate that interventions have been robustly tested and that public health practice is supported by research or tested pathways. This is used to ensure that care is clinically and cost effective, that high standards are maintained, that care is provided based on the best evidence possible and that the best outcomes for people are achieved (Department of Health, 2013). Research is most commonly assessed by the GRADE (Grading of Recommendations Assessment, Development and Evaluation) system (Dijkers, 2013), which is used to assess the quality of scientific evidence that can then be used to develop recommendations and guidelines. GRADE was developed by an international panel, and has been adopted all over the world, including by the Cochrane Collaboration and NICE, as a way of rating the quality of research on which to base their recommendations. In the GRADE approach, randomised controlled trials (RCTs) start as high-quality evidence and observational studies as low-quality evidence, to support estimates of intervention effects (Dijkers, 2013). By its very nature, this prioritises scientific quantitative research over the more patient-centred qualitative approaches. Whilst few would disagree with the notion of delivering care based on evidence and information about the efficacy of treatment, the use of a broader evidence base should be considered when trying to implement patient-centred care (Rycroft-Malone, 2004).

The nature of illness and its impact is complex and is capable of invoking physical, psychological and social changes. When illness is not part of life, we often take the relationship between our bodies and ourselves for granted (Freund & McGuire, 1995). Serious and chronic illnesses can undermine the unity between body and self and force identity changes (Charmaz, 1995). This is especially damaging to the self when experienced as unpredictable, uncontrollable and overwhelming as it paralyses the

person's ability to plan and manage their life (Freund & McGuire, 1995). For this reason, it is important that HCPs study and understand the impact of illness on patients and utilise this understanding within their clinical practice (Dobbie & Mellor, 2008).

1.4. Setting

This research was undertaken at a specialist diabetic foot clinic in London. The clinic is a centre of excellence and a tertiary referral centre for complex foot pathologies that result from diabetes. It runs five days a week and has daily access to an extensive multidisciplinary team. Referrals into the clinic are taken from other hospitals, general practitioners (GPs) and other HCPs. Where swift action is required or in emergency situations, such as a suspected active Charcot foot, patients are seen on the same or following working day. Many investigations such as blood tests and x-rays can be accessed on the same day. Provision of Aircast boots and total contact cast (TCC) manufacture occur within the foot clinic and are arranged by the podiatrists. All of the participants in this study were referred to the foot clinic as new patients for a current episode of active Charcot foot.

1.5. Why this research is relevant to me

This study is relevant to me primarily because of my role as a podiatrist in a hospital setting where I manage patients with active Charcot foot. As a clinician working in a tertiary referral centre for the diabetic foot, I have had the opportunity to work with many patients diagnosed with Charcot foot in both the active and chronic stages. Sadly, being a relatively rare pathology, many patients are initially misdiagnosed. Consequently, late presentation is common. I have had the chance to view first-hand how distressing it can

be when patients either do not understand or feel they have no control over what is happening to them. Conversely, I have also witnessed the practitioner's frustrations in trying to relay the appropriate information to patients and to divulge the gravity of the pathology and its management in an acceptable way.

I feel that the present research is of genuine importance given the current paucity of available information. It aims to formally recognise those adverse effects and quality of life changes that may be noted anecdotally during clinical sessions but remain unrecognised in currently existing literature. It also allows me as both a researcher and practitioner to focus on the issue in a patient centred, holistic manner rather than simply addressing the Charcot foot. Dissemination of the findings could make a substantial difference to the experience of both those being diagnosed with Charcot foot and the holistic understanding of the professionals treating those receiving this diagnosis. By gaining insight into the real-life concerns of those receiving management of active Charcot foot as people, practitioners could have a much clearer understanding of the issues on which to focus discussion in future consultations. This should result in better patient-centred care for the patients of the future and could lead to further important research in this area.

1.6. Structure of the thesis

Chapter 1. This initial chapter introduces the study and the thesis.

The remaining chapters are designed to guide the reader through the research process.

Chapter 2. This chapter provides a critical review of the literature surrounding Charcot foot and similar related pathologies, giving a background to the study. Diabetes mellitus, Charcot foot, psychosocial elements of diabetes and its complications and biographical disruption are all presented.

Chapter 3. This chapter provides a justification of the theoretical underpinnings of the research and associated ontological and epistemological positions. An exploration of IPA is provided and the novel use of photo elicitation is discussed. The chapter provides details of the practical issues surrounding data collection and the selection of participants, during both the planning of the research and the data generation. Details regarding the sample size and population, ethical and quality considerations are also given. Operational considerations and ethical issues surrounding each area of the study are also discussed. Details are also given of how the data were analysed and how the final themes were identified.

Chapter 4. This chapter provides details of the findings, discussing each of the three identified master themes, followed by their associated sub-themes. The three themes presented are: life journey interrupted, the hindered body in places and spaces and the diminishing self in a restricted lifeworld.

Chapter 5. This chapter presents a discussion of the findings in comparison to existing literature and phenomenological philosophy. It follows the structure of Ashworth's (2003) fractions of the lifeworld. This is then followed by a discussion of the implications

for practice, a critical evaluation of the strengths and limitations of the study and suggestions for further research and for clinical practice.

Chapter 6. This chapter concludes the thesis and considers the unique contribution to knowledge that this research has made.

Each chapter, including this one, will conclude with a reflexive statement.

1.7. Reflexivity

It is now commonplace to acknowledge that the values and experiences of the researcher can potentially influence what they see and how they understand the data they collect (Doyle, 2013). Researchers are an inevitable part of what is being researched. This is particularly pertinent to this study due to the dual role of practitioner and researcher. It is viewed as inevitable that the researcher will bring their subjective selves into the research along with their preconceptions. This can both blinker the researcher and enable insight (Finlay, 2011). Good qualitative research should always show the hand of the researcher (Altheide & Johnson, 2011), and since many areas of qualitative research assume that the researcher will influence the study, reflexivity is an important part of its transparency (Yardley, 2008).

Reflexivity in a study can be defined as both the acknowledgment and identification of the researcher's place and presence in the investigation, and the process of using these insights to critically examine the entire research process (Underwood, Satterthwait, & Bartlett, 2010). This can be achieved by openly describing features of the study that may

have influenced the data or the interpretations, such as the researcher's background or interests. It can also be appropriate to include a reflexive analysis of how these features could have influenced the conclusions reached (Yardley, 2008). Reflexivity is not simply an awareness-raising activity that we engage in prior to and during data collection; rather it should be viewed as a vital component to each stage of the research journey (Shaw, 2010). At the outset of a project, the researcher's own ideas and concerns are influenced by their preconceptions, which in turn are shaped by their experiences and expertise (Smith, 2007). It is therefore essential that the researcher acknowledge their preconceptions prior to their encounter with their study participants. Whilst such fore-structures may ontologically precede a person's encounters during their research, renewed understanding may also move from the subject being researched to the fore-structure (Smith, 2007), thereby altering our understandings as the process progresses. Consequently, continued reflexive practice is essential throughout the research process.

Our motivations, thoughts and perceptions are all in part subconscious. Therefore, we may not be fully aware of them (Clancy, 2013). By initiating statements of positionality, or keeping a reflexive diary, researchers can begin to unpack the stances adopted in their research that could later form the basis of a reflexive account (Clancy, 2013). A reflexive diary was kept throughout this research process as a record of assumptions and a platform to question those assumptions and justify decisions. The reflexivity sections at the end of each chapter help to explain to the reader, throughout the research process, the fore-structures, thoughts and decision-making processes. As reflexivity involves a critical gaze towards oneself (Finlay, 2003b), all reflexive statements appearing at the end of each chapter are written as first-person accounts.

1.8. Reflexive statement

In the first of my reflexive statements I aim to explain my own position relative to the research project. As noted in Section 1.5, I am an experienced podiatrist specialising in high risk foot complaints, in particular issues relating to the complications of diabetes mellitus. My interest in diabetes and high-risk foot complaints began with my first job in a London based community podiatry team. However, my practical experience of dealing with Charcot foot in the early stages of my career was minimal due to its relative rarity and requirement for treatment in secondary care. My particular interest in Charcot foot was stimulated later, when I began working in the specialist diabetic foot clinic where I have now worked for the past 7 years.

In spite of my now relatively extensive experience in treating and researching those diagnosed with active Charcot foot, I still find that the condition is one of the more difficult pathologies to explain and for patients to understand. It is well accepted in the clinic where I work that many repeated conversations are often required with this subset of patients, in order to explain what is happening to them and why their particular management plans have been recommended. We are very lucky within the clinic to have a number of doctors, surgeons and clinicians who are renowned experts in this field and even they often appear to struggle to help patients to understand Charcot foot and the implications of this diagnosis. Working in such a highly specialised and pressurised environment has helped me to establish a strong sense of professional identity as a specialist in the area. I have completed my post graduate diploma in podiatry with diabetes and also had the opportunity to teach undergraduates clinical skills at a university prior to starting my PhD. Each of these experiences further cemented my confidence in my growing knowledge base and identity as a specialist.

My situated knowledge base was very much concentrated around the medical model of thinking that I had developed since my undergraduate training, focusing on gold standard, objective, randomised controlled trials, longitudinal studies and guidelines. As such, I spent a lot of my time in the foot clinic trying to convince patients to adhere to my management plans. I felt proud of the high rate of patient concordance with TCC therapy, as the gold standard treatment of the active Charcot foot, which we as a clinic managed to achieve. In this regard I naively believed that I, as the experienced practitioner, ultimately knew what was best for the patient when it came to treatments such as casting. Such treatment plans for me were simple and logical – the application of a TCC is the very best option to retain optimal foot structure and functionality for the future of those with Charcot foot. Thus, I would go out of my way to persuade patients to comply with this treatment plan. It puzzled me that so many patients wanted so desperately to be out of the TCC when the alternatives of deformity and ulceration and increased risks of amputation seemed so obvious. I questioned “what was a few months in a cast compared with the rest of their lives struggling against the outcomes of suboptimal treatment?”

As I became increasingly familiar with the distress that Charcot foot management caused for some and the harsh reality of this diagnosis for the patient, I wanted to increase my understanding of their experience. I was also keen to unpack the concerns over their management plans and the ways in which their lives were affected. In so doing, I hoped not only to be able to improve my patients’ experiences but also to solve some of my own frustration at repeatedly answering the same questions and never really knowing whether my patients understood what I was saying. Therefore, when I first committed to undertaking this research, I felt quite certain about what I was setting out to achieve and the reason for doing so. I wished to find out more about what my patients understood concerning Charcot foot, what their main issues were and to find a way to provide them

with suitable educational tools to improve their lot and to encourage compliance with my treatment plans. It was not until someone asked me how did I know that educational tools were needed, without having any evidence to suggest that this was the case, or that a lack of education was indeed a key issue in terms of compliance, that I first stepped back and realised how my position and preconceptions were forcing both my research and professional practice down a very specific path.

As a working podiatrist in a busy clinic I also felt that completing research with my own patients would be ideal, but again I was surprised when someone else questioned the ethics and possible compromises of doing so, because of issues such as coercion and power imbalance. Following these discussions, I again took a step back and began a dialogue with my supervisors to dismantle and rethink the research until it transformed into the current thesis. The issues of my dual role were a major concern and have been dealt with more fully in the methodology chapter (Section 3.10.3). However, dealing with such issues early in the research process solidified my belief in the importance of reflexivity and transparency within my research.

Whilst my background experience of treating people with a diagnosis of Charcot foot has given me an invaluable understanding of many of its complexities, it has also left me with various preconceived ideas and ‘fore-understandings’ (Shaw, 2010) which I have tried to confront throughout this research. I feel that in some ways my prior experience and sense of professional identity led to fore-understandings which were superficial, as I unwittingly made my own perspectives superior to those of my patients. Oddly, I had always perceived one of my strengths as a practitioner to be the rapport and understanding that I built with my patients. However, in standing back to examine my

unconscious perspectives, I found that my own experience and belief in the medical model was blinding me to the patients' perspectives even as I tried to plan my research. This was something that I worked hard to overcome through the methodology and ethical considerations which are discussed later in the thesis.

Despite my extensive clinical experience I was a novice researcher, with only minimal prior experience at undergraduate level. This also affected how I approached the research, having to learn a new language and concepts, often unintentionally defaulting to the concepts and language of quantitative research with which my medical background had made me more familiar. Such a shift in perspective was at times very difficult. However, I have retained my steadfast belief in the importance of this work to both patients and HCPs and this has kept me going.

I have been fortunate in that my family has been blessed with good health, so I do not have first-hand experience of myself or a close family member living through major or chronic illness. I have never experienced a patient's role, only that of practitioner. This again may alter and potentially limit my fore-understandings in such areas.

My training, prior professional and personal experiences and current position have all affected every area of this research. This influenced literature review, the methodology chosen, the focus of my interpretations and lines of questioning. I believe that my pre-existing experience, beliefs and assumptions have all been important in helping me to interpret and make sense of the data gathered, and that the study participants and I have together co-constructed the understanding presented in this thesis. I have tried to explore

this in the reflexive statements at the end of every section and hope that the thesis will make this explicit. I believe that this research has important implications for both patients with Charcot foot and practitioners like myself who work with them, and hope that this document will highlight its value.

Chapter 2. Literature review

This chapter provides a critical review of the current literature surrounding Charcot foot in diabetes mellitus. It will also explore the published work on the QoL and psychological impact of those diagnosed with diabetes, Charcot foot, and diabetic foot ulceration (DFU). The review will highlight current gaps in knowledge and literature that led to the development of this research. The research questions, aims and objectives are presented and the chapter concludes with a reflexive statement.

2.1. Search strategy

The search strategy employed for this study is shown in Figure 1. The electronic databases were searched using the search tool One Search. Boolean logic was used, for example: Diabet* AND quality of life AND Charcot. Google Scholar was also searched using a similar strategy, and where possible papers were identified. These were searched for again direct from the journal. No date restrictions were applied but only papers written in the English language were included. All papers found were free to download. Papers referring to Charcot foot as a complication of pathologies other than diabetes were excluded. The reference lists of suitable publications and background reading were also examined for further potentially relevant papers and any which were found were searched for individually. Published conference abstracts were searched for by hand and were included due to the scarcity of available published papers.

Figure 1. PRISMA diagram to show selection of publications.



Using this strategy, 12 possible publications pertaining to the patient's experience of Charcot foot with a background of diabetes mellitus were found. Two were conference poster abstracts (Chapman et al., 2011; Vileikyte et al., 2008) and ten were full articles (Chapman et al., 2014; Dhawan et al., 2005; Kroin et al., 2018; Pakarinen et al., 2009; Pinzur & Evans, 2003; Raspovic & Wukich, 2014; Raspovic et al., 2015; Sochocki et al., 2008; Srivastava et al., 2016; Willrich et al., 2005). None were rejected. All used quantitative measures to explore patients' QoL and the psychosocial impact of the disease. Sample sizes were generally small and all concluded that further research was necessary. Few found significant psychological impact and most postulated that the tools used to assess QoL were not sensitive enough to identify patient perception accurately. A detailed analysis of these studies can be found in Section 2.11.

2.2. Background – Diabetes Mellitus

The current research focuses on the experience of people with active Charcot foot as a complication of diabetes mellitus. Therefore, this literature review will start with a brief overview of diabetes and its complications (Sections 2.2-2.6). Diabetes mellitus is a clinical syndrome characterised by abnormally high glucose levels in the blood. This is known as hyperglycaemia and is due to either an absolute or relative insulin deficiency (Frier & Fisher, 2006). This chronic condition is associated with reduced life expectancy and significant morbidity due to specific diabetes related microvascular complications, increased risk of macrovascular complications and diminished QoL (World Health Organisation, 2006). Diabetes is one of the most common chronic diseases worldwide and both its significance and the number of those diagnosed with this condition are increasing (Shaw, Sicree, & Zimmet, 2010).

2.3. Prevalence and costs

Diabetes is becoming far more common, with a predicted increase of 69% in developing countries and 20% increase in developed countries between 2010 and 2030, equating to 439 million adults worldwide by 2030 (Shaw et al., 2009). In the UK the percentage of the population diagnosed with diabetes is rising by 4.8% per year (House of Commons Committee of Public Accounts Department of Health, 2016). According to analysis by Diabetes UK (2018), the number of people diagnosed with diabetes in the UK has more than doubled in the last twenty years with almost 3.7 million people in the UK now living with this diagnosis. This equates to an increase of 1.9 million since 1998. With such increases in the prevalence of diabetes, it is reasonable to expect that this will also lead to increases in the prevalence of its complications (Diabetes UK, 2018).

Diabetes is recognised as a major public health problem with far-reaching consequences, not only for its adverse impact on the health of people affected by the condition, but also for the economic burden it places on the healthcare system (Meetoo, 2014). The total cost (including direct care and indirect costs) associated with diabetes in the UK has been estimated at £23.7 billion and is predicted to rise to £39.8 billion by 2035-36 (Diabetes UK, 2016). The projected increase in the diabetic population could have a significant impact on NHS resources, particularly since an estimated 80% of diabetes costs in the NHS are attributable to the treatment and management of avoidable diabetic complications (House of Commons Committee of Public Accounts, 2016). Charcot foot is an example of one such complication. In order to try to reduce these escalating costs, it is imperative that diabetes management aims to achieve optimal glucose control to minimise the risk of long-term complications and maintain the QoL of those with diabetes (Meetoo, 2014). Continued increases in health care costs and expenditure will lead to increased

clinical and public health significance as the incidence of diabetes soars (Lin, Carolyn, & Wayne, 2010).

2.4. Aetiology

The National Collaborating Centre for Chronic Conditions (2008) defines diabetes as a group of disorders of which the two most common types are:

- Type 1 Diabetes;
- Type 2 Diabetes.

Type 1 diabetes accounts for only about 5-10% of all diabetes cases (Daneman, 2006). It is caused by autoimmune beta-cell destruction in the pancreas and is characterised by a lack of insulin production (Deshpande, Harris-Hayes, & Schootman, 2008). Previously termed 'insulin dependent diabetes mellitus', people with type 1 diabetes invariably require insulin replacement therapy (Frier & Fisher, 2006). The disorder has a strong genetic component, but the factors that trigger the onset of clinical disease remain largely unknown (Daneman, 2006). Hormone replacement with insulin therapy is generally suboptimal, and despite the implementation of lifestyle and disease management measures, acute and long-term complications are endemic (National Collaborating Centre for Chronic Conditions, 2004).

Type 2 diabetes is a progressive disease with insidious onset (Phillips, 2005) and is generally viewed as a more complex condition than type 1 diabetes (Frier & Fisher, 2006). Type 2 diabetes develops when there is an abnormal increased resistance to the action of insulin and the body cannot produce enough insulin to overcome it (Chatterjee, Khunti, & Davies, 2017). This resistance is also accompanied by beta-cell deficiency

leading to decreased insulin production (Deshpande et al., 2008). Development of type 2 diabetes is associated with several known risk factors including: genetic predisposition, ethnicity, (South Asian, African or Afro-Caribbean decent), obesity, deprivation and a history of gestational diabetes (Diabetes UK, 2010).

Treatment of type 2 diabetes often initially involves lifestyle modification such as controlling diet and increasing exercise levels. Failure to control blood glucose levels requires initiation of drug therapy, with medications designed to increase beta cell function in the pancreas, modify glucose output, reduce rates of glucose absorption and improve sensitivity to insulin. In some patients where obesity is an issue, bariatric surgery or very low calorie diets may be considered. Replacement insulin therapy may ultimately be required (Chatterjee et al., 2017). As the insulin deficiency is progressive, the high glucose levels usually worsen over a timescale of years, requiring continued escalation of blood glucose lowering therapy and a greater risk of complications (National Collaborating Centre for Chronic Conditions, 2008).

2.5. Long-term complications of diabetes mellitus

Current treatment targets recommend supporting patients to maintain their HbA1c (glycated haemoglobin) blood test level at around 48-53mmol/mol (6.5-7%) (NICE, 2015). However, they also recognise the importance of an individualised approach to diabetes care that is tailored to the needs and circumstances of adults with diabetes (NICE, 2015). The inability to maintain blood glucose levels within a normal range can result in chronic hyperglycaemia (Meetoo, 2014), which can affect many different organ systems and over time can lead to serious complications (Deshpande et al., 2008). The latter can have a devastating physical impact on individuals and on their families and is

the leading cause of blindness in people of working age, the largest single cause of end stage renal failure, and, excluding trauma, the biggest cause of lower limb amputation (Department of Health, 2001).

The development of the classic clinical syndromes of diabetic nephropathy, neuropathy, retinopathy and increased atherosclerosis is thought to be the result of local response to vascular injury (Frier & Fisher, 2006). Complications from diabetes can then be classified as microvascular or macrovascular (Deshpande et al., 2008) (Table 1).

Table 1. Microvascular and macrovascular complications of diabetes mellitus.

Micro / Macro-vascular	Complication	Effect
Microvascular	Retinopathy/cataracts	Impaired vision
	Nephropathy	Renal failure
	Peripheral neuropathy	Sensory loss, neuropathic pain, muscle weakness
	Autonomic neuropathy	Postural hypotension, gastrointestinal problems
	Foot disease	Ulceration, Charcot foot
Macrovascular	Coronary circulation	Myocardial ischemia / infarction
	Cerebral circulation	Transient ischemic attack, stroke
	Peripheral circulation	Claudication, ischemia

(Frier & Fisher, 2006).

Two landmark studies, the Diabetes Control and Complications Trial (DCCT) (The Diabetes Control and Complications Trial Research Group, 1996) and the UK Prospective Diabetes Study (UKPDS) (UKPDS Group, 1999), have shown that people with both type 1 diabetes (DCCT) and type 2 diabetes (UKPDS Group, 1999) who received tight glycaemic control, demonstrated a significant reduction in any diabetes related end point, with the most prominent effect being a reduction in microvascular disease (King, Peacock, & Donnelly, 1999). Follow up studies found that prior intensive glycaemic control led to a continued reduction in microvascular risk (Martin et al., 2006; Holman, Paul, Bethel, Matthews, & Neil, 2008).

Both the DCCT and UKPDS trials acknowledged the potential QoL implications and measured them with a variety of validated quantitative measures. Both studies concluded that patients undergoing intensive diabetes treatment did not face deterioration in their QoL, even while the rigour of their diabetes care was increased (The Diabetes Control and Complications Trial Research Group, 1996). However, the UKPDS noted that the complications of diabetes did affect QoL but could not discern whether frequent hypoglycemic episodes had any affect (UKPDS Group, 1999).

Management of diabetes places a heavy emphasis on control of blood sugar levels and food consumption in order to maintain optimal health (Broom & Whittaker, 2004). While the health benefits of self-management and care are clear, people with diabetes need the knowledge, skills and motivation to assess their risks, in order to understand what they will gain from changing their behaviour or lifestyle (Department of Health, 2001). Although the previously mentioned studies (The Diabetes Control and Complications Trial Research Group, 1996; UKPDS Group, 1999) did not note a deterioration in the

QoL of those undergoing intensive diabetes management, negative feelings have been noted when people with diabetes are unable to achieve and maintain recommended blood glucose levels. Feelings of failure, blame and guilt are prevalent in the diabetic population, particularly amongst those with type 2 diabetes embarking on insulin therapy (Phillips, 2005; Schabert, Browne, Mosely, & Speight, 2013), who feel it is an indicator that they have been a 'bad diabetic', or that they are 'not good enough' at their diabetes control (Archer, 2014, p. 102). In the diabetes awareness, wishes and needs (DAWN) study, 40% of participants felt that the need to start insulin meant that they had not followed treatment recommendations properly, leading to feelings of self-blame (Peyrot et al., 2005). Such feelings can mean that people avoid taking their insulin in public places in order to avoid the stigma and negative reactions of others, causing a further negative impact on their control (Phillips, 2005; Browne, Ventura, Mosely, & Speight, 2013). Studies about the fear of developing DFUs have also reported feelings of self-blame and guilt; manifestations of the perception that such complications are a punishment for historically poor diabetes control (Beattie, Campbell, & Vedhara, 2012). Similar reactions may potentially be noted in the Charcot foot population as a late stage consequence of diabetic neuropathy. However, no research has been found which has explored this area.

2.6. Neuropathy

The focus of the current research is on the impact of the Charcot foot (which is a complication of neuropathy) on patients' lives and well-being. Therefore, it is important to understand the underlying aetiology and pathogenesis of neuropathy as a debilitating condition. Diabetes can predispose people to a variety of neurological syndromes (Cameron, Eaton, Cotter, & Tesfaye, 2001) which involve the sensory, motor and autonomic nervous systems (Frier & Fisher, 2006). Neuropathy is one of the most

common long-term complications of diabetes, affecting approximately half of the diabetic population (Boulton & Vileikyte, 2009). Diabetic peripheral sensory neuropathy (DSPN), with or without neuropathic pain, presents in a symmetrical and distal distribution (Hartemann et al., 2011). This sensory neuropathy, which usually begins with a sensory loss and numbness, starting in the toes, spreads proximally in a stocking and glove distribution (Cameron et al., 2001). It develops insidiously and may affect both large myelinated sensory fibres that transmit touch and vibration and the small unmyelinated C fibres that transmit thermal perception and sympathetic function (Buchman, 2006).

Insensate feet can predispose people to further injury such as Charcot foot, DFUs and even amputation through unperceived trauma and foot deformities causing high pressure areas (Vileikyte, Crews, & Reeves, 2017). Sensory loss is considered to be the most important clinical precursor to DFU, which in turn is the most common cause of hospital admission in diabetic patients and the leading cause of non-traumatic lower limb amputation (Cameron et al., 2001). The progression of nerve injury is gradual and leads to the loss of a protective pain threshold or the ability to detect small objects (Buchman, 2006) and often remains unnoticed. The importance of pain is frequently underestimated and if protective pain sensation is lost, so too is the awareness of problems leading to delays in seeking help (Foster, 2006).

Approximately 50% of patients with DSPN are asymptomatic (Boulton & Vileikyte, 2009). People who remain undiagnosed and who are unaware of this issue will be at even higher risk of injury to their insensate feet, when preventative foot care is not implemented (Pop-Busui et al., 2017). Indeed, as many patients with DSPN do not have symptoms, their first presentation may be with a problem such as ulceration or a Charcot

foot (Tesfaye, 2006). For this reason, NICE guidelines (2015) recommend an annual diabetes foot review, to include testing with a 10g monofilament to assess for individual risk status. Those with evidence of DSPN after assessment are deemed at moderate risk of developing a diabetic foot problem, which consequently requires referral to a foot protection service. Evidence of sensory neuropathy alongside another known risk factor such as ischaemia, callus and/or deformity, places the person in a high-risk category. High-risk status requires reviews between 1 week and 2 months with the foot protection team, depending on the presence of any immediate clinical concerns (NICE, 2015). There are currently no approved therapies for asymptomatic DSPN. Therefore, prevention is a key component of diabetes care (Pop-Busui et al., 2017).

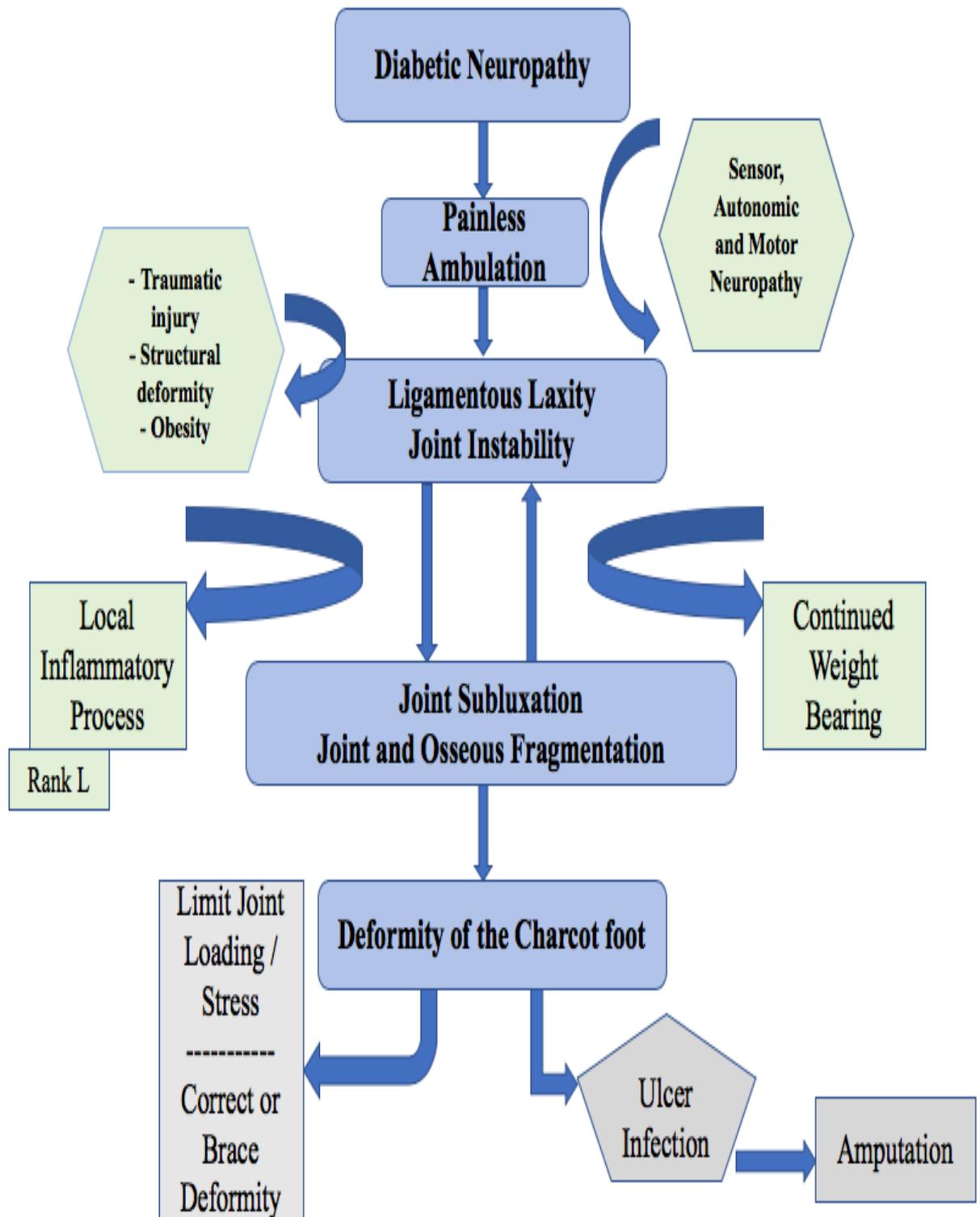
2.7. The Charcot foot

The French physician Jean-Martin Charcot first described what was called ‘Charcot’s disease’ as a complication of tabes dorsalis in 1881. However, it was not until 1936 that William Reilly Jordan described the first link between neuropathic joint disease and diabetes (Bevilacqua, Bowling, & Armstrong, 2010). Charcot foot is an uncommon complication seen in DSPN (Game et al., 2011). It has been associated with a range of conditions, including leprosy, multiple sclerosis, HIV, congenital neuropathy, poliomyelitis, syphilis, and traumatic injury, but it is diabetic neuropathy that has now become its most common aetiology (Wukich & Sung, 2009). Charcot foot has most frequently been reported to affect less than 1% of the overall diabetes population (Frykberg & Belczyk, 2008). Whilst it is not a common problem, it is potentially one of the most disabling conditions encountered by people with diabetes (Pakarinen et al., 2009).

2.8. Aetiology

The active Charcot foot is characterised by a pronounced inflammatory reaction (Jeffcoate, Game, & Cavanagh, 2005) with trauma being the most common aetiological factor in its pathogenesis (Kaynak, Birsal, Fatih Güven, & Ögüt, 2013). It has been suggested that an initial insult, which may or may not be detected due to DSPN, could be sufficient to trigger an inflammatory cascade (Jeffcoate et al., 2005) and a lack of required immobilisation could up-regulate the inflammatory cycle (Kaynak et al., 2013). The exact aetiology of Charcot foot remains undetermined, but the current belief is that once the disease is triggered in a susceptible individual, it is driven by a process of uncontrolled, cytokine-mediated inflammation in the foot (Rogers et al., 2011). This inflammation leads to osteolysis as the co-existent autonomic neuropathy causes an increase in blood flow to the bone, accelerating the bone reabsorption rate (Kaynak et al., 2013). This process of uncontrolled inflammation is indirectly responsible for the progressive fracture and dislocation that characterises its presentation (Rogers et al., 2011). Figure 2 highlights the potential pathways to Charcot foot:

Figure 2. A diagram depicting the pathogenesis of Charcot foot.



(Adapted from Fryberg et al., 2006).

Clinically, the Charcot foot is characterised by bone and joint fragmentation and destruction that can result in severe deformity and can frequently lead to DFU, gangrene, infection, hospital admission and foot amputation (Smith et al., 2007). In 1966 Eichenholtz developed a system of grading Charcot foot according to three well-defined radiographic stages (Table 2).

Table 2. Eichenholtz stages of Charcot foot.

Stage	Phase	Foot presentation	Radiological features
1	Development	Localised warmth, marked swelling and redness	Bony debris, fragmentation of subchondral bone, peri-articular fracture, subluxation and/or dislocation.
2	Coalescence	Continued but decreased warmth swelling and redness	Absorption of fine debris, new bone formation, coalescence of fragments, fusion of joints (ankylosis), and/or sclerosis of bone ends
3	Remodeling	Marked decrease of absence of warmth, swelling and redness, physically enlarged fixed ('healing') deformity	Remodeled and new bone formation, decreased sclerosis, and/or possible gross residual deformity.

(Wukich & Sung, 2009)

In 1990 Tohru Shibata added stage 0 in order to acknowledge the prodromal clinical stage where clinical signs are present but radiographic evidence may be absent or minimal (Sanders, 2010). At stage 0, the foot will present as inflamed, swollen and warm with a typical temperature >2 degrees warmer than the contralateral foot. Pain or discomfort

may also be reported in spite of profound peripheral neuropathy. A history of trauma may or may not be recalled (Jude, 2006).

The images below show the clinical appearance of an active Charcot foot.



Figure 3. Clinical picture of a patient with a red, hot and swollen forefoot and midfoot. It shows the typical active Charcot foot presentation.



Figure 4. Active Charcot foot of the midfoot with a rocker bottom foot deformity.

2.9. Presentation and the issues of misdiagnosis

Charcot foot is rare and is therefore often overlooked at initial presentation (Botek et al., 2010). The condition is frequently misdiagnosed by practitioners who seldom see a patient with diabetes (Johnson, 2010). The diagnosis of Charcot foot in its earliest manifestation is largely dependent on pattern recognition by an experienced clinician and relies on the presence of unexplained inflammation in a foot affected by DSPN (Johnson, 2010) (Figure 2). This can occur with or without fracture or dislocation of the bones and joints and an x-ray (Figure 5), bone scan (Figure 6), or MRI scan (Figure 7) may be required to confirm the diagnosis (Game et al., 2012; NICE, 2015).

A



B



Figure 5. Normal foot x-ray of a patient not showing any bone and joint abnormality (A). Foot x-ray of a patient presenting with a hot swollen foot. The x-ray reveals soft tissue swelling and dislocation at the hindfoot indicative of an advanced Charcot foot deformity (B).

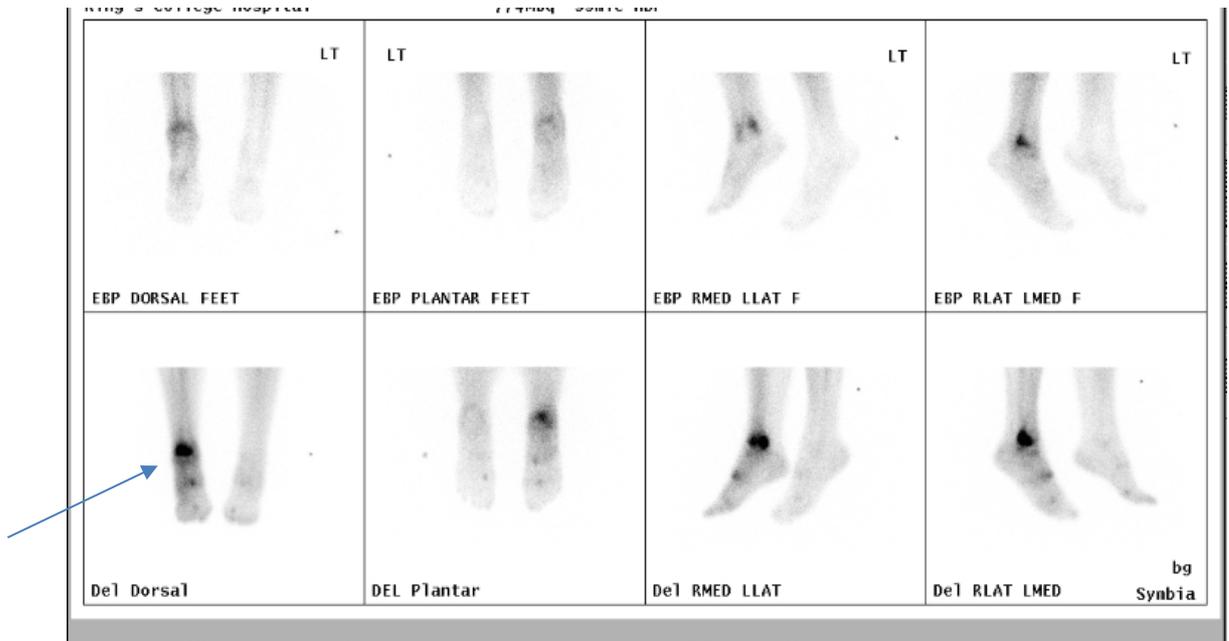


Figure 6. A technetium diphosphonate bone scan of a patient presenting with a suspected Charcot foot. The scan shows a 'hot spot' in the hindfoot as a result of increased osteoblastic activity indicative of bone damage and early presentation of an active Charcot foot.



Figure 7. MRI scan shows extensive bone marrow oedema of the calcaneum, talus, cuneiforms and the 1st, 2nd and 3rd metatarsal bases (arrows) indicating an active Charcot foot at the midfoot and hindfoot areas.

It is well recognised that immediate referral to a foot and ankle specialist and avoidance of weight bearing are of paramount importance to the overall outcome of this condition (Botek et al., 2010). Misdiagnosis can result in improper treatment. When patients continue to weight bear on the injured foot, the disorder continues to progress (Foltz, Fallat, & Schwartz, 2004). Chantelau (2005) compared clinical outcomes in patients with early versus delayed detection and treatment of incipient Charcot foot fracture. No statistically significant differences were found due to the small sample size. However, whilst only one of the eleven in the early treatment group progressed to fracture and deformity, twelve of the thirteen control cases with existing fractures on initial assessment progressed to gross deformity. Such deformity places the patient at far higher risk of suffering future complications such as DFU and amputation, owing to the profound deformity complicated by significant neuropathy. Increased awareness is

essential to enable early diagnosis and the start of appropriate treatment, thereby minimising severe deformity and disability (Johnson, 2010). Early recognition and referral results in better outcomes for patients (Chantelau, 2005).

Charcot foot occurs almost exclusively in the foot and ankle (Wukich & Sung, 2009) and its hallmark deformity is the rocker bottom foot caused by midfoot collapse (Rogers et al., 2011) (Figure 4). It is well known that the presence of DSPN and foot deformity renders a patient at high risk of DFU (NICE, 2015) and that ulceration over high pressure areas can take a very long time to heal. In a study by Sohn et al. (2010) 34% of patients experienced ulceration as a complication of Charcot foot. They concluded that Charcot foot alone does not pose a serious amputation risk when the clinical and radiographic relationship of the forefoot and rear foot remain linear. However, those with Charcot foot deformity complicated by an ulcer had a twelve times higher risk of amputation than the controls.

2.10. Management

Offloading with a TCC is widely regarded as the gold standard treatment for Charcot foot (Foster, 2006) and is often recommended with periods of immobilisation of at least a ten week period (Wukich & Sung, 2009). However, there is no clear evidence to indicate whether non-weight bearing cast immobilisation is superior to a weight bearing TCC (Petrova & Edmonds, 2012). As studies that directly compare TCC management with other modalities are lacking, this recommendation is primarily based on single cohort studies (Frykberg & Enroth, 2010). NICE guidelines (2015) also recommend that non-removable devices should be offered as management for active Charcot foot where a non-removable device is not advisable either for clinical reasons or due to the person's circumstances.

A web-based audit of acute Charcot's disease in the UK, known as the CDUK survey, confirmed a shorter time to resolution in non-removable compared with removable casts from a total of 288 cases from 76 centres (Game et al., 2012). This is most likely because patients who were able to remove their devices were subjected to periods of unprotected ambulation. It is self-evident that even the most effective devices cannot be successful if they are not worn (Bus et al., 2008). Armstrong, Lavery, Kimbriel, Nixon, and Boulton (2003) found that patients using a protective removable cast walker for the offloading of DFU used the devices for only 28% of their total daily activity. Whilst 30% of the patients in the study recorded more daily activity wearing the device, this subset still only wore the device for a total of 60% of their total daily activity. This study concluded that less easily removable devices might increase the prevalence of healing (Armstrong et al., 2003).

Although the importance of adequate offloading is well recognised for Charcot foot, the understanding of the patients' experiences of treatment with TCC or removable devices remains minimal. Awareness of patients' experiences and satisfaction with treatment modalities is essential if holistic, patient-centred care is to be provided, and this may improve concordance with treatment plans.

The images overleaf illustrate some of the more widely available offloading options:



Figure 8. A typical TCC used in the management of active Charcot foot. These are typically manufactured by podiatrists within their clinical setting. However, in some centres these may be manufactured in a hospital plaster room.



Figure 9. A removable TCC, often manufactured for patients rehabilitating out of a non-removable TCC and into footwear once the Charcot foot process has settled into the non-active chronic stage. This type of device may also be manufactured if a patient is unable to tolerate a non-removable TCC.



Figure 10. An Aircast boot. A removable device which is held in stock in many hospitals and is quick and simple to issue. This device may not be suitable for patients who have existing deformity associated with the later stages of Charcot foot.



Figure 11. A Charcot Restraint Orthotic Walker (CROW) boot. This is also a removable device. It can be made to measure by an orthotist and can accommodate the deformities of a late stage Charcot foot.

The duration of management with a TCC varies from an average of nine weeks to a median of eleven months (Petrova & Edmonds, 2012). Table 3 highlights the results of the different studies that explore this:

Table 3. Duration of management with a TCC in patients with active Charcot foot.

Study	Patients	Duration of casting
Armstrong et al. (1997)	55 patients	Average 18.5 weeks (4-56 weeks)
Pinzur et al. (2006)	10 patients	Average 9.2 weeks (8-16 weeks)
Bates et al. (2006)	46 patients	Median 11 months (8-17 months)
de Souza (2008)	27 patients	Average 14 weeks (4-20 weeks)
Game et al. (2012)	219 patients	Median 10 months (2-29 months)

(Adapted from a table by Petrova & Edmonds, 2012)

The overall aim of management with a TCC is to maintain a plantigrade foot that will eventually allow weight bearing in a shoe or brace (Petrova & Edmonds, 2012). However, this does nothing to modify the natural history of the condition or arrest the underlying bone resorption (Jude, 2006). Bisphosphonates are potent inhibitors of bone resorption (osteoclastic activity) and are currently used in other diseases which are characterised by abnormal bone turnover, such as osteoporosis (Frykberg & Enroath, 2010). Several studies have been undertaken on both intravenous and oral bisphosphonates (Anderson, Woelffer, Holtzman, & Jacobs, 2004; Guis et al., 1999; Jude et al., 2001; Pitocco et al., 2005; Selby, Young, & Boulton, 1994). However, none indicated that they have any effect on the final outcome of achieving a stable, healed plantigrade foot, or on the time to return to unrestrained walking (Frykberg & Enroath, 2010). Consequently, NICE guidelines (2015) categorically state that treatment with bisphosphonates should not be offered for active Charcot foot. This is important to note from the perspective of the current research, as it highlights the lack of treatment options for this patient group.

When the Charcot foot is no longer in the active stage, the patient must be rehabilitated and gradually moved from cast treatment to suitable footwear, which is also a lengthy process taking several months. Physiotherapy may be required and the HCP must remain aware of the dangers of reactivating the bony destruction phase by excessively rapid mobilisation (Petrova & Edmonds, 2008). Reconstructive surgery may also be required where attempts at conservative care have failed to prevent major deformities (Baglioni, Malik, & Okosieme, 2012).

2.11. Patient impact – existing knowledge base

It is generally accepted that diagnosis of Charcot foot reduces QoL (Wukich & Sung, 2009). However, only a small collection of studies, undertaken to assess the psychological and emotional impact and health related QoL of people suffering from Charcot foot, was found during the literature review (Chapman et al., 2011; Chapman et al., 2014; Dhawan et al., 2005; Kroin et al., 2018; Pakarinen et al., 2009; Pinzur & Evans, 2003; Raspovic & Wukich, 2014; Raspovic et al., 2015; Sochocki et al., 2008; Srivastava et al., 2016; Vileikyte et al., 2008; Willrich et al., 2005). Each study attempts to explore health related QoL by utilising objective measures and validated questionnaires rather than considering the lived experience of the patient from a qualitative perspective. Table 4 highlights details from these studies. Each study will subsequently be reviewed in turn.

Table 4. Studies comparing published articles exploring Charcot foot and QoL.

Author	Outcome measure	Patients	Key findings
Chapman et al. (2011)	HADS	100 patients, 50 with Charcot foot, 50 without	Anxiety but not depression is higher in patients with Charcot foot than those without.
Chapman et al. (2014)	HADS	50 patients with Charcot foot compared to separate study with 1,456 controls with diabetes	High levels of anxiety and depression in patients with Charcot foot compared with controls. Suggests prevalence risk for depression in Charcot foot approx. double that of general diabetes sample.
Dhawan et al. (2005)	AOFAS	57 patients with Charcot foot	Lower PCS* score on enrolment than follow up. Further studies recommended for tool validation.
Kroin et al. (2018)	SMFA	25 patients with Charcot foot undergoing midfoot surgical reconstruction prior to surgery & subsequently 1-year post surgery	Significant improvements were demonstrated in the standardised functional score, the standardised bother index, the standardised daily activity index and the standardised emotion index of the SMFA post-surgery when compared with pre surgical scores.
Pakarinen et al. (2009)	AOFAS & SF-36	41 patients with Charcot foot	PCS* scores reduced for Charcot foot patients, diagnosis within 3 months resulted in better function and walking distance using AOFAS.
Pinzur & Evans (2003)	AAOS instrument & SF-36	18 patients with Chronic Charcot foot (13 underwent surgical reconstruction, 5 footwear & orthoses only)	Reduction in PCS* and physical role components only, Charcot foot contributes to early retirement and disability.
Rasovic & Wukich (2014)	SF- 36 & FAAM	50 patients with diabetes and Charcot foot, 56 controls with diabetes and no pedal complaints	PCS* notably lower in Charcot foot patients, no difference in MCS**. Lower activity of daily living (ADL) and sport scores for Charcot foot patients using FAAM.

Raspovic et al. (2015)	SF-36 & FAAM	35 patients with midfoot Charcot only, 22 patients with Charcot foot and concomitant ulceration	No significant difference between the two groups using either outcome measure.
Sochocki et al. (2008)	SF-36	60 patients with Charcot foot	Survey found to be sensitive to PCS* but not MCS**
Srivastava et al. (2016)	SF-36	118 patients, 64 without diabetic foot complications, 39 with peripheral neuropathy, 25 with Charcot foot	PCS* and MCS** significantly reduced for Charcot foot compared with the peripheral neuropathy group and control group combined. No significant difference between Charcot foot group and neuropathy group. No significant difference between Charcot foot group and controls.
Vileikyte et al. (2008)	SF-12 & HADS & Neuro-QoL	489 high risk patients, 67 with Charcot foot	Charcot foot was an independent predictor of emotional burden, poorer foot related QoL with the Neuro-QoL and PCS* with the SF-12.
Willrich et al. (2005)	SF-36 & Zung depression scale	20 patients with Charcot foot or DFU, 20 with lower limb amputation and 20 neuropathic controls	PCS* significantly reduced in both Charcot/ulcer group and amputees compared to controls but no difference between the groups. No evidence of depression or cognitive impairment in either group,

*Physical component score (PCS). **Mental component score (MCS).

Of the studies found investigating patients' experience of Charcot foot, five utilised the SF-36 (Raspovic & Wukich, 2014; Raspovic et al., 2015; Sochocki et al., 2008; Srivastava et al., 2016; Willrich et al., 2005) whereas Vileikyte et al. (2008) used the shortened version, the SF-12. The SF-36 is perhaps the most commonly used measure of QoL research (Wee et al., 2008). It is a multipurpose, short-form health survey containing 36 questions and yielding an eight-scale profile of scores and mental and physical health summary measures (Ware, 2000). The SF-12 is a shortened version using only 12 questions to measure functional health and well-being from the patient's perspective (Busija et al., 2011). All studies except one (Srivastava et al., 2016) confirmed a significant decrease in physical component scores (PCS) but not in mental component scores (MCS) in their findings (Raspovic & Wukich, 2014; Raspovic et al., 2015; Sochocki et al., 2008; Vileikyte et al., 2008; Willrich et al., 2005). The study by Srivastava et al. (2016) was the only study using the SF-36 to find a significant decrease in both the PCS and the MCS. However, rather than most of these studies simply indicating that the diagnosis of Charcot foot has no impact on mental functioning, it has been suggested that such generic questionnaires do not adequately capture specific emotional distress of foot problems (Vileikyte, 2008). Each of these studies will now be explored in more detail.

Willrich et al. (2005) recruited sixty participants and split them into subsets as follows: 20 control participants with DSPN, 20 participants receiving treatment for either DFU or Charcot foot, and 20 amputees, with amputations ranging from digital to trans-tibial. No information was given on the stage of the Charcot foot, type of treatment or the grading and management of the DFUs. This study found no differences in MCS between the groups but reported that the PCS was significantly lower for the Charcot foot/ulcer group and the amputee group, than for the control group or the general U.S population using the

SF-36. In addition to the SF-36, they also used two screening tools for cognitive function (the mini mental exam and the clock-drawing test) and the Zung self-rating depression scale to screen for depression. No significant differences in either cognitive impairment or depression were noted between any of the groups. This study concluded that the negative impact of suffering from Charcot foot on health related QoL may be as severe as undergoing lower extremity amputation. However, this conclusion may be misleading on two counts. Firstly, Charcot foot and DFU patients were surveyed together as one group without any distinction being made with regard to the severity of the ulcers or stage of the Charcot foot. Therefore, either group may have influenced the result more than the other. Secondly, the control group had evidence of diabetes and peripheral neuropathy, both of which have a recognised negative impact on QoL (Vileikyte et al., 2005) and may have affected the overall result.

Sochocki et al. (2008) also recruited 60 participants, in the state of Manitoba, Canada, in a study that aimed to identify risk factors that may contribute to a poorer QoL in those with Charcot foot. This was part of a larger project exploring QoL with all diabetic foot problems. They hypothesised that QoL may be poorer for those living in rural areas and for the aboriginal population due to limited timely access to health care. Of the total research population only eleven were of aboriginal origin, and 23 lived in rural areas. The participants were at different stages of Charcot foot management with seven (12%) classified as being at Eichenholtz stage one, 17 (28%) at stage two, 33 (55%) at stage three, and for three (5%) of whom the stage was unknown. Results were similar to the findings of Willrich et al. (2005), in which mean PCS scores were significantly lower than those of the general population in the United States but no difference was noted in the mean MCS. Neither the PCS nor MCS were affected by gender, ethnicity, Charcot foot staging or residence in either urban or rural areas. Nonetheless, they did note that

those who were unemployed or retired, and those who did not drink alcohol had significantly worse PCS scores. No possible explanations were offered for this correlation. The paper concluded that the presence of Charcot foot had a major negative effect on QoL but that the SF-36 was not sensitive to the mental health effects of Charcot foot (Sochocki et al., 2008). In addition, the sample was too small to allow for comparative evaluation of potentially important variables such as the treatment methods for Charcot foot which would have varied given the differing disease stages of the participants and may have affected the results. The presence of other complications or co-morbidities was not controlled for, which may have further influenced the results.

Srivastava et al. (2016) aimed to establish whether people with diabetes and Charcot foot experienced a reduced QoL compared with those who had DSPN and those with diabetes but no evidence of foot disease. The study also used a questionnaire to investigate whether any other demographic variables, such as age, gender, body mass index (BMI), type of diabetes, and diabetic control, were associated with a poorer QoL. Of the 118 patients in the study, there were only 39 in the Charcot foot group, 26 men and 13 women. In slight contrast to the earlier studies, they concluded that both PCS and MCS were significantly lower in the Charcot foot group when compared with all controls (the diabetic control population with no pedal complications together with group with DSPN). However, there were no significant differences in either PCS or MCS when the DSPN group were compared with controls or with the Charcot foot group separately. Nonetheless, they concluded that both the mental and physical health of patients with Charcot foot was significantly poorer than of those with DSPN alone and also of controls with no complications, which may be slightly misleading. Whilst information on the statistical testing is given, details regarding the severity of the peripheral neuropathy and how this was assessed, as well as the stage of the Charcot foot, were absent. When

exploring the results in relation to demographic variables, the paper suggested that the women with Charcot foot reported poorer mental health than the men and that there was a weak correlation between increasing BMI and poorer MCS. Larger scale studies may be required to confirm these associations between gender, BMI and Charcot foot.

Pinzur and Evans (2003) attempted to explore the observational impact of Charcot foot with the SF-36 alongside the American Academy of Orthopaedic Surgeons (AAOS) foot and ankle outcome measure (American Academy of Orthopaedic Surgeons, 2001). The AAOS foot and ankle measure is one of 11 functional outcome assessment measurement instruments for populations with specific musculoskeletal disorders (Hunsaker, Cioffi, Amadio, Wright, & Caughlin, 2002). The foot and ankle module consists of a lower limb core scale containing nine items regarding symptoms and functional status, a global foot and ankle scale containing 20 items pertaining to pain, function, stiffness, swelling and giving way, and a shoe comfort scale containing five items that assess the ability to comfortably wear different shoe types (Martin & Irrgang, 2007). The Academy holds normative data for each of the questionnaires and documentation on how to use this data for comparison (American Academy of Orthopaedic Surgeons, 2001). Evidence for the validity and reliability of the tool was demonstrated as part of a larger study (Johanson, Liang, Daltroy, Rudicel, & Richmond, 2004).

Using the SF-36, Pinzur and Evans (2003) replicated the findings that only physical functioning was significantly reduced in a study of 18 patients. Using the AAOS measure, most felt that Charcot foot greatly interfered with their lives. Participants reported appreciable physical disability with four participants using wheelchairs as their primary mode of ambulation and ten relying upon sticks or crutches. This study concluded that the

diagnosis of Charcot foot decreased general health and physical functioning leading to disability and premature retirement from the workforce. However, mental health, emotional illness and pain were again not found to have a major health related impact. The finding that pain was not felt to play an important role in the impact of the disease could be expected given the background of DSPN. As such, a scale specifically related to this may not be entirely appropriate for this subset of patients. Also, none of the participants in this study were being treated for active Charcot foot at the time of the research. All were in the chronic stage and successfully rehabilitated into custom footwear. Thirteen had undergone surgery to correct Charcot foot deformity prior to the study, which would have likely impacted the results and perceived levels of disability. However, the number of study participants was insufficient to explore the differences between those who received surgical versus accommodative management.

Dhawan et al. (2005) tried to develop and test a disease specific instrument designed to evaluate health related QoL in diabetic foot disease, for use with patients with Charcot foot. The American Orthopaedic Foot and Ankle Society (AOFAS) Diabetic Foot Questionnaire (Dhawan et al., 2005) used several sections from the SF-36 and was designed to compute scores in six domains (general health, physicality, emotion, worry, foot status and care). Eighty-nine participants with active Charcot foot completed the self-administered questionnaire. Fifty-seven completed it again at a three month follow up. HCPs completed an observational survey. Overall, and in line with other studies, participants were found to have a significantly lower PCS on enrolment when compared to the reported norms for other diseases. On evaluation, the tool was found to have moderate to high internal consistency. However, many of the scales showed either low ceiling or high floor effects (Dhawan et al., 2005), meaning that these scales provided little room for change (improvement or deterioration) for participants scoring at or close

to the mean scores for the relevant sections. The questionnaire remained unvalidated for this particular use following the research. The American Orthopaedic Foot and Ankle Society has since concluded that the AOFAS clinical rating systems are neither valid nor reliable. Therefore, their continued use has not been recommended (Pinsker & Daniels, 2011).

Pakarinen et al. (2009) used the AOFAS hindfoot and ankle measure (Kitaoka et al., 1994) alongside the SF-36 as part of their cross sectional follow up study of 41 patients, referred to one clinical centre in Finland with Charcot foot between 1991 and 2002. All patients were diagnosed and treated with below knee casts and advised to remain non-weight bearing whilst the disease was active, followed by a period in a fixed ankle foot orthosis and finally bespoke footwear. Follow up was undertaken in 2007, by which point 12 patients had died. Therefore, 29 people (one with bilateral involvement) formed the study population. Between diagnosis and follow up, 67% of participants suffered at least one episode of DFU, with 40% ulcerating more than once. Fifty percent had also undergone surgical management due to recurrent plantar DFUs, life threatening systemic infection or gross instability as a consequence of their Charcot foot. Surgical procedures ranged from exostectomy, wound revision and arthrodesis to below knee amputation. None of the patients had active DFUs at the point of follow up. The SF-36 scores were compared to those for the Finnish general population and chronically ill population standards. In keeping with the majority of the previous studies, Pakarinen et al. (2009) concluded that mental health was not affected by the presence of Charcot foot. They did conclude that the reduction in physical functioning had long lasting effects, particularly in the components of physical function, role-physical function and social function, which were felt to reflect the restriction in participants' ADLs and narrowed social networks. Interestingly, they found that a delay in diagnosis of more than three months adversely

affected longer-term functional ability and QoL. Ultimately, all patients diagnosed within three months of symptom onset were able to wear commercial footwear compared with 23% who had experienced a longer delay to diagnosis. Moreover, whilst all patients diagnosed within three months could also walk more than 1km, only 54% of those who had experienced diagnostic delay could walk the same distance. However, the long-term nature of this study and incidence of DFU and surgical procedures may skew the results and make them difficult to compare with those of other studies. The lack of AOFAS validation (Pinsker & Daniels, 2011) may also render the results unreliable.

Raspovic and Wukich (2014) and Raspovic et al. (2015) used a very specific, regional measure alongside the SF-36 in their studies. They stated that a region-specific measure, such as the Foot and Ankle Ability Measure (FAAM) (Martin et al., 2005), would provide useful information on the lower extremity function of Charcot foot patients, to supplement the findings of more generic instruments such as the SF-36. Such results could be used to compare other populations (Raspovic & Wukich, 2014). The FAAM consists of a 21-item ADL subscale and an 8-item Sports subscale and is used to evaluate changes in self-reported physical function for individuals with leg, ankle, and foot musculoskeletal disorders (Martin et al., 2005). Each activity has a set choice of responses: no difficulty (four points), slight difficulty (three points), moderate difficulty (two points), extreme difficulty (one point) or unable to perform (no points). Total scores are then calculated and converted to a percentage. Evidence for the validity of the FAAM as an outcome instrument to measure physical function and responsiveness to change in individuals with diabetes and foot and/or ankle related disorders has been demonstrated (Martin, Hutt, & Wukich, 2009; Kivlan, Martin, & Wukich, 2011).

Raspovic and Wukich (2014) recruited 50 patients with intact Charcot foot (23 of whom had required surgical intervention) and 57 controls with diabetes but no foot complaints from the database of a single surgeon at a University foot and ankle centre between 2006-2012. Results from the SF-36 were consistent with previous studies, reporting that the PCS scores were significantly reduced in the Charcot foot group, but that there was no significant difference in the MCS. This study also found that patients with Charcot foot reported reduced mean FAAM ADL scores two standard deviations below those of the control group, and sports scores that were one standard deviation lower than the control group. Such findings may be logical given the non weight bearing treatment regimen and requirement to wear an offloading device during the active stage of the disease (only four patients in this cohort), or during recovery from orthopaedic surgery. However, no details were offered regarding the type of footwear or offloading used at the time of data collection, the time elapsed since the participants' surgery, nor the type of surgery carried out in this cohort. Such information would be useful when trying to critically assess the findings. It was also noted that the group of participants with Charcot foot were more likely to have type 1 diabetes, have a longer duration of diabetes and had higher incidence of neuropathy, each of which may impact the results. Similarly, the incidence of other complications of diabetes or comorbidities were not reported or considered which may have also affected the findings.

Their later study (Raspovic et al., 2015) also used the SF-36 and the FAAM to explore QoL in 35 diabetic patients with intact Charcot foot compared with 22 diabetic patients with Charcot foot and concomitant ulceration. This study found no significant difference in self-reported QoL between the two groups which they postulated was due to the presence of peripheral neuropathy, meaning that the concomitant ulceration did not cause further pain (Raspovic et al., 2015). No information is offered regarding the treatment

plans for either patient group, how often they were reviewed, the type of offloading used nor the historical presence of ulceration. Similar to the previous study (Raspovic & Wukich, 2014), comorbidities and further complications of diabetes were not controlled for. Again, such variables could all have had an influence on the findings.

Vileikyte et al. (2008) utilised the SF-12 alongside the hospital anxiety and depression scale (HADS) (Zigmond & Snaith, 1983) in their research. HADS is a brief, self-administered questionnaire designed to assess physically ill patients for the presence and severity of anxiety and depression. It consists of two 7-item scales, one measuring anxiety and the other depression. The total scores are then used to classify individuals as anxious or depressed (Straat, Andries, & Sijtsma, 2012). In the same study, Vileikyte et al. (2008) also used the Neuro-QoL (Vileikyte et al., 2003) outcome measure, as a more condition specific tool. The 43-item instrument was designed to assess diabetic peripheral neuropathy-related symptoms and psychosocial functioning in several domains: painful symptoms and paresthesia, symptoms of reduced/lost feeling in the feet, diffuse sensory motor symptoms such as unsteadiness when walking, limitations in daily activities, interpersonal issues such as physical or emotional dependence on others and emotional burden (Vileikyte et al., 2003). The Neuro-QoL has been shown to be a reliable and valid measure that allows insights into, and demonstrated stronger associations with, the clinical indicators of neuropathy than the SF-12 (Vileikyte et al., 2003). All three tools were used in a split-site trial of 489 people at high risk of neuropathic DFUs in the UK and USA. Of the participants in this study, 16% had active DFUs and 36% had a past history of DFUs. Sixty-seven patients, who had clinical and radiological mid-foot deformity, characteristic of Charcot foot, were identified and participated in the study. Results were analysed using multivariate regression analysis to control for demographic characteristics, disease, neuropathy severity and active ulceration. When compared to the

high-risk population, the Charcot foot sample showed diminished PCS but not MCS using the SF-12. No significant association between Charcot foot and either anxiety or depression was identified using the HADS. However, using the Neuro-QoL, Charcot foot was found to be a significant independent predictor of emotional burden which highlighted a detrimental effect on functioning. This study maintains that the Neuro-QoL is able to identify emotional effects because it is a condition specific measure, emphasising the importance of such tools when assessing the emotional state of patients with Charcot foot (Vileikyte et al., 2008). Research such as the current study may also be of use when developing or evaluating similar condition specific quantitative research tools given the as yet unknown, in-depth knowledge of the patient experience.

The HADS was used again in later research (Chapman et al., 2011; Chapman et al., 2014). In 2011, Chapman et al. undertook a cross sectional questionnaire survey comparing anxiety and depression levels in people with type 2 diabetes with and without Charcot foot. They recruited a cohort of 100 participants, 50 with Charcot foot and 50 control participants with no history of Charcot foot, from a single foot clinic in South London. No details were offered regarding the stage of Charcot foot and how many were active or chronic, but variables were reduced by excluding those with concomitant DFU, amputation or receiving psychoactive drugs or psychiatric medication. This research was published as an abstract and, due to the lack of detail, the results are not entirely clear. However, they concluded that anxiety but not depression was greater in people with Charcot foot than those without.

In their later publication, Chapman et al. (2014) used the data from the 50 Charcot foot patients in the 2011 research, but not the 50 controls without Charcot foot. This study

concluded that both anxiety and depression levels were higher in this cohort, when compared with a major study on patients with diabetes in Ireland also using the HADS (Collins, Corcoran, & Perry, 2009). Following this comparison, Chapman et al. (2014) suggest that depression risk is approximately 20% higher in their cohort than in the general diabetes population. Similar to the findings by Srivastava et al. (2016), Chapman et al. (2014) also concluded that females experienced significantly higher levels of both anxiety and depression. Unemployed members of black minority ethnic (BME) groups also experienced significantly higher levels of depression but not anxiety. No information is offered regarding the stage of the Charcot foot pathology, although it is noted that the mean duration of Charcot foot was five years ($SD = 3.4$). Therefore it may reasonably be assumed that the majority were in the chronic stage (Eichenholtz stage 3) (Table 2). No information was recorded regarding the type of offloading (TCC, Aircast, bespoke footwear or orthoses) or any ongoing treatment. Whilst it is stated that existing DFU was an exclusion criterion at the point of data collection, no information is offered about the history of DFUs, the extent of any Charcot foot deformity or on-going pedal problems. There is no evidence that comorbidities or other foot complaints had been controlled or accounted for in analysis. Such omissions make it difficult to assess the reliability of the findings as a consequence of Charcot foot alone.

Kroin et al. (2018) used the Short Musculoskeletal Functional Assessment (SMFA) (Martin, Engelberg, Agel, Snapp, & Swiontkowski, 1996) to assess whether successful surgical correction of Charcot foot deformity was associated with a corresponding improvement in patient reported outcomes. The SMFA is a 46 item, self-reported health status questionnaire. It consists of two parts (a dysfunction index and a bother index), and four subscales (daily activities, emotional status, arm and hand function and mobility). The dysfunction index has 34 questions and a set choice of responses: not at all difficult

(one point), a little difficult (two points), moderately difficult (three points), very difficult (four points) or unable to do (five points). The bother index has 12 questions designed to assess how bothered a patient is by problems in functional areas and responses are categorized as follows: not at all bothered (one point); a little bothered (two points); moderately bothered (three points); very bothered (four points) or extremely bothered (five points). Total scores are then calculated, with higher scores indicating poorer function. Evidence for the validity, reliability and responsiveness of the instrument have been demonstrated (Martin et al., 1996; Martin, Engelberg, Agel, & Swiontkowski, 1997).

Of the 25 participants enrolled in their study, Kroin et al. (2018) reported that 18 patients achieved an excellent clinical outcome one year following surgery (remaining intact, infection free and in commercially available footwear), three achieved a good outcome (remaining intact and infection free, but requiring either alterations to custom footwear or short custom orthoses) and three had a poor outcome (residual ulceration, a whole or partial foot amputation or requiring a CROW walker or ankle foot orthoses). One participant died of unrelated causes prior to follow up. Statistical analyses of the results from the SMFA instrument revealed that there was a significant improvement in the self-reported QoL of patients in the dysfunction index ($p=0.01$), the bother index ($p=0.02$), the standardised daily activities index ($p=0.002$) and the emotional status index ($p=0.004$). No significant differences were found in the hand/arm index, nor in the mobility index. The authors concluded that successful correction of the acquired deformity of Charcot foot as a consequence of diabetes, is likely to substantially reverse the negative impact on health related QoL. There is the suggestion that this may be due to the ability to walk in commercially available footwear once again if a good outcome is achieved.

The selection of 25 participants for this research was arbitrary and no power calculations were performed regarding how many participants would be required to accept the authors' hypothesis that successful correction would improve QoL in this patient group. Therefore, larger scale studies may be required if they wish to advocate an increase in surgical reconstruction for a patient population with such a high rate of comorbidities and complications. In addition, only those with midfoot deformity were included and further research should therefore be considered in those with potentially more complex joint involvement and deformity such as in those with ankle involvement.

This small collection of studies highlights the difficulty of attempting to quantify the impact of a disease state on the individual, or a collective group of individuals, with a diagnosis such as Charcot foot, in which studies often conclude that the research tool is insufficiently sensitive for this purpose. Even where research has used the same outcome measures, the exploration of people at different stages of Charcot foot makes it difficult to compare the results. The studies simultaneously explored patients at all stages of Charcot foot, from active to post reconstruction, and some included people with concomitant ulceration. However, it may be reasonable to suppose that people at different stages of this disease may differ in their emotional responses. No studies were found which focused solely on patients with active Charcot foot. This may be due to the relative rarity of the disease and the difficulty of obtaining sufficient participants to obtain statistically significant results. Most studies also observed relatively small patient populations with Charcot foot and no information was given with regard to power calculations and the ability to make generalisable results from their findings, which is often a concern in quantitative research. It should also be noted that people presenting with the complications of diabetes will often have multiple comorbidities, which may be difficult to account for with a generic measure (Raspovic & Wukich, 2014).

The position statement by the American Diabetes Association (ADA) recommends the use of disease specific measures; the Neuro-QoL (Vileikyte et al., 2003) and the Norfolk quality of life-diabetic neuropathy (QoL-DN) instrument (Vinik et al., 2005) for quality of life research in this population (Pop-Busui et al., 2017). It might reasonably be assumed therefore, that these are also suitable for the sequelae of the diabetic neuropathies. Vileikyte et al. (2008) is the only published research found to successfully use the Neuro-QoL tool to assess the QoL impact of Charcot foot. No literature was identified that has used the QoL-DN for Charcot foot and this should be considered as a potential tool for future research.

No research considering the patient experience of living with Charcot foot was found during this literature review despite Department of Health recommendations to focus on patient experience and patient-centred care (Darzi, 2008; Department of Health, 2013). This highlights an important gap in the knowledge base and such research may help to situate the variable findings of the quantitative research base. This knowledge gap supports the need for a qualitative research approach to the experience of living with Charcot foot and presents an opportunity for a different research paradigm to explain conflicting findings. Such research may help to identify areas of concern to this patient group not accessible through the use of pre-defined QoL measures and may assist in improving provision of patient care.

2.12. Psychological impact of diabetes and its sequelae

Whilst the psychological impact of Charcot foot is not well known, the impact of diabetes and many of its other sequelae have been more extensively explored. Evidence indicates a high prevalence of psychological ill-health in people with diabetes (National

Collaborating Centre for Chronic Conditions, 2008). The prevalence of psychosocial issues and clinically significant psychopathology in people with diabetes ranges across diagnostic categories (Young-Hyman et al., 2016) with diabetes related distress and depression being the most commonly reported (Chew, Vos, Mohd-Sidik, & Ruteen, 2016).

The ADA guidelines (Young-Hyman et al., 2016) recommend psychological and social assessment, including screening for depression and diabetes related distress, as part of diabetes management. They recommend that this assessment should occur at the initial visit and then periodically thereafter, even in the absence of any specific indication for review. The guidelines also state that evaluation is indicated during major disease and life transitions, such as the onset of complications, any significant changes in treatment, or alteration to life circumstances (Young-Hyman et al., 2016). Consequently, it may reasonably be assumed that the diagnosis of a pathology such as Charcot foot would warrant evaluation.

Diabetes distress is a disorder which can mimic the symptoms of depression (Beverley, Ivanov, Court, & Fredericks, 2017). However, it is classified as an emotional reaction to the stresses and challenges of living with diabetes rather than a separate psychiatric disorder (Beverley et al., 2017; Dieter & Lauerer, 2018). The reported prevalence of diabetes distress varies. However, one systematic review and meta-analysis in those with type 2 diabetes, estimated it at 36% (Perrin, Davies, Robertson, Snoek, & Khunti, 2017). Slightly higher results were found in the second Diabetes Attitudes, Wishes and Needs (DAWN2) study (Nicolucci et al., 2013), which reported high levels of diabetes-related distress in people with both type 1 and type 2 diabetes, assessed across 17 countries. In

this study, diabetes distress was reported by 44.6% of participants using the Problem Areas in Diabetes Scale 5 (PAID-5) score (Welch, Jacobson, & Polonsky, 1997).

Research exploring the clinically relevant levels of diabetes distress using the diabetes distress scale (DDS), found that almost half of 506 people with type 2 diabetes experienced significant levels of diabetes distress (Fisher, Polonsky, Hessler, & Mullan, 2012). This study attempted to identify the optimal categorisation of diabetes distress in relation to key specific biological and behavioural variables, concluding that even relatively low levels of diabetes distress were associated with these diabetes indicators. Consequently, the recommendation was made to change the grading of diabetes distress from low and high distress levels, to little or no distress, moderate distress or high distress, to more accurately reflect the relationship between diabetes distress and HbA1c, diabetes self-efficacy, diet and physical activity (Fisher et al., 2012). Where even moderate levels of diabetes distress have been shown to affect health behaviours and outcomes (Smith et al., 2013), it becomes increasingly important to ensure that timely assessment is carried out.

Diabetes distress necessarily implies an aetiology and therefore encompasses a wide range of emotional experiences defined by the context of diabetes and its management (Fisher, Gonzalez, & Polonsky, 2014). Consequently, it is important to distinguish the different sources of distress in order to initiate specific, targeted interventions which should be linked to the source of the diabetes distress (Fisher et al., 2014).

One qualitative study was found which explored patients' experiences of living with diabetes distress and type 2 diabetes (Tanenbaum, Kane, Kenowitz, & Gonzalez, 2016). This study conducted six focus groups with 32 adults divided by treatment regimen, separating those managed with and without insulin. The sessions were transcribed verbatim and each focus group was analysed using Braun and Clarke's (2006) thematic analysis. Themes were then compared between groups and against results from the diabetes distress scale (Polonsky et al., 2005). The following major themes were identified and agreed by a coding team with qualitative research training: self-blame: 'I did this to myself' (relating to the participants' diabetes), the burden of making lifestyle changes (in relation to food and weight management), medication related distress (related to the administration of insulin), dissatisfaction with diabetes care and providers (often around a lack of communication), distress related to diabetes control, interrelatedness of mood and blood glucose, interpersonal distress and stigma (social support and stigma when injecting insulin), diabetes-related physical burden (including symptoms, complications, disability and disease progression), worry/fear about consequences of diabetes and distress about comorbid medical conditions. This study concluded that whilst most of the themes identified were captured by existing measures of diabetes distress, some new emerging themes are not currently captured. Those identified as new themes were distress specifically associated with the act of injecting insulin, diabetes related physical burden, health care system related distress and distress caused by comorbid medical conditions (Tanenbaum et al., 2016). Such qualitative data, the authors argue, can provide a valuable perspective on causal relationships between diabetes and emotional distress and can highlight the many unmet needs of this cohort (Tanenbaum et al., 2016). As this study focused only on those with type 2 diabetes, further research may be valuable to assess whether similar issues are also noted in the type 1 population. Additionally, group dynamics in a focus group setting could be argued to influence participant responses. They may also produce less depth in the qualitative findings than methods

such as one-to-one interview. Further qualitative research could help to provide perspective on the mechanisms that link emotional distress to diabetes. Such information may help providers to identify treatment plans aimed at reducing treatment burden (Tanenbaum et al., 2016) and assist in initiating targeted conversations in clinical sessions. If diabetes distress may be precipitated by a complication such as Charcot foot, it is important for practitioners to be aware of these links in order to assist in timely and effective management.

The link between diabetes and depression is also well recognised (Egede, Zheng, & Simpson, 2002) and one systematic review has suggested that the prevalence rate of depression is more than three-times higher in people with type 1 diabetes and nearly twice as high in people with type 2 diabetes as in the non-diabetic population (Roy & Lloyd, 2012). However, it has been suggested that approximately 50% of patients with diabetes and comorbid depression remain undiagnosed and untreated (Hermanns et al., 2013).

Diabetes and depression appear to interact negatively. Depression leads to poor metabolic control and in turn hyperglycaemia may exacerbate depression and diminish response to antidepressant regimens (Lustman & Clouse, 2005). This synergistic relationship between diabetes and depression predicts greater mortality, greater incidence of both macrovascular- and microvascular complications, and a greater incidence of disability ADLs (Black, Markides, & Ray, 2003). Diabetic retinopathy, nephropathy, neuropathy, macrovascular complications, and sexual dysfunction have all demonstrated a significant and consistent association with depressive symptoms (De Groot, Anderson, Freedland, Clouse, & Lustman, 2001). Both minor and major comorbid depression in diabetes are strongly associated with increased mortality over a three year period when compared with

rates for patients with diabetes alone (Katon et al., 2005). Findings from a prospective cohort study (Lin et al., 2009) also suggest that those patients with diabetes and comorbid depression face increased mortality from causes well beyond the cardiovascular risk related mortality usually identified.

There is evidence that psychological ill-health is also associated with the adverse effects of other aspects of the long-term health of people with diabetes (National Collaborating Centre for Chronic Conditions, 2008). The link between DSPN and a reduced QoL is established (Vileikyte et al., 2005; Vileikyte et al., 2009) and, as DSPN is the precursor to Charcot foot, should be explored further.

Vileikyte et al. (2005) reported a positive association between DSPN and depression in a study using the Neuro-QoL alongside the HADS and the revised illness perception questionnaire (IPQ-R) (Moss-Morris et al., 2002). This study found that the symptoms of pain and unsteadiness were independently associated with depressive symptoms both through direct pathways and indirectly through changes in social self-perception. It has also been suggested that perceptions of neuropathy symptom unpredictability, a lack of treatment control and restrictions in ADL could all have indirect links to depression in this cohort. However, pain was significant only when compared with the neuropathy disability score, not the vibration perception test which represents large fibre neuropathy. Perhaps somewhat surprisingly, neither having a current DFU nor past history of ulceration was related to depression scores (Vileikyte et al., 2005).

The findings of Vileikyte et al. (2005) appear to correspond with the findings of Vinik et al. (2005) and Vinik, Paulson, Ford-Molvik, & Vinik (2008). Vinik et al. (2005, 2008) used the Norfolk QOL-DN (Vinik et al., 2005), a 47 item self-reporting QoL questionnaire designed to be sensitive to the various features of diabetic neuropathy, including small fibre, large fibre, and autonomic nerve function. Their study, which consisted of 262 individuals, was split into the following groups: DSPN, diabetic controls and healthy controls. They found that impaired QoL scores were correlated most strongly with the total neuropathy score, which included symptoms of neuropathy, the neurologic examination of motor function, sensory perception, and reflexes. It was also noted that participant perception of weakness appeared to be a prominent factor in impaired QoL, particularly in regard to ADLs and large fibre domains (Vinik et al., 2005). These findings were backed up by their later study validating the tool with a German translation and with a German population (Vinik et al., 2008). Overall, the DSPN group reported greater QoL impairment in all domains, than either the control group or the diabetic control group. However, the diabetic control group also reported high scores in the ADL and autonomic domains, leading the authors to infer that that diabetes itself also interferes with social activities. This, they postulated, may be accounted for by physical and emotional consequences of diabetes, such as discomfort or depression, which interfered with participants' work and ADLs (Vinik et al., 2005) and may have some resonance with the findings of Tanenbaum et al. (2016) exploring diabetes distress. However, whilst this instrument has demonstrated reliability in assessing and differentiating health related QoL impact in the types of diabetic neuropathy, it does not include any reference to the emotional or psychosocial impact of the disease process.

These results may also reflect the findings of an earlier study assessing the relationship between patients' perception of their own inferior limb function and clinical assessment

(Padua et al., 2002). This study, using the North American Spine Society (NASS) lumbar spine questionnaire (American Academy of Orthopaedic Surgeons, 1995; Daltroy, Cats-Baril, Katz, Fossel, & Liang, 1996). suggested that the patients' perception of their physical performance was closely related to their neurological assessment and a reduced QoL (Padua et al., 2002). However, causality could not be confirmed due to the cross-sectional design of the research and the fact that depressive symptoms could also be argued to influence the perception of neuropathic symptoms and impact social relationships (Vileikyte et al., 2005).

Unsteadiness is the symptom shown to have the strongest association with depression (Vileikyte et al., 2005). This finding was backed up by a longitudinal study carried out over 18 months (Vileikyte et al., 2009). The study, which also used the Neuro-QoL and HADS, reported that baseline levels of unsteadiness were indeed predictive of incremental increases in depressive symptoms, independent of changes in unsteadiness over time (Vileikyte et al., 2009). Newer research has since confirmed that people with DSPN report more self-perceived unsteadiness than both people with diabetes and no peripheral neuropathy and healthy matched controls (Reeves, Brown, Petrovic, Boulton, & Vileikyte, 2017). Moreover, these increased reports, identified using the Neuro-QoL and which enquired about balance experienced when walking and standing, showed significant correlation with independent laboratory measures of decreased gait velocity and step length (Reeves et al., 2017). This led Reeves et al. (2017) to postulate that people with DSPN are not only aware of their increasing unsteadiness, but may attempt to self-regulate this feeling by walking more slowly and taking shorter steps. Unfortunately, no information is given regarding the number of recruits to the study as a whole or in each group and only minimal participant demographic information is given. This makes it difficult to assess whether the groups were sufficiently powered or if confounding

variables were controlled for. The study also acknowledges the absence of information on history or fear of falling or depressive symptoms, which makes it difficult to assess what drove the changes in gait characteristics (Reeves et al., 2017). The presence of changes in the characteristics of gait and an increased risk of falls in people with DSPN are well documented (Alam et al., 2017; Brown, Handsaker, Bowling, Boulton, & Reeves, 2015) and may plausibly increase further, following offloading in the Charcot foot population. Consideration of these factors should therefore be given in the clinical setting and further research into these areas should be considered with this subset of patients.

Interestingly, it has also now been shown that greater postural instability is a powerful predictor of non-adherence to offloading devices for the treatment of DFUs, further signifying this as a key area of interest for both patients and HCPs. This may also be of particular interest in the Charcot foot population as similar devices are used in the treatment of both pathologies. Unfortunately, it has been suggested that patients will often not report balance disturbances during medical consultations due to the perception that they are signs of premature ageing rather than illness-related disability (Vileikyte et al., 2003). Patients' perceptions of their unsteadiness appear to be an adequate indicator of actual balance impairment and it has therefore been recommended that clinicians should address unsteadiness and postural instability as a key symptom with their patients during review (Reeves et al., 2017). HCPs should also actively enquire about postural instability in patients presenting with active foot problems requiring offloading and take these into consideration when prescribing offloading devices (Crews et al., 2016). Where such issues are noted, walking devices or exercise programmes designed to focus on strength and balance may be useful.

Providing patients with information on their health status and risk factors in this area may also be beneficial although this has not been proven. Nonetheless, it has been shown that having fewer misconceptions regarding foot health is significantly associated with more positive foot health behaviours using the Patient Interpretation of Neuropathy (PIN) questionnaire (Vileikyte et al., 2006). Conversely, those with a less developed understanding of neuropathy are associated with more potentially damaging foot health behaviours (Vileikyte et al., 2006). These findings were backed up by Perrin, Swerissen, Payne, and Skinner (2014), who identified three clusters of people demonstrating distinct illness schemata related to their peripheral neuropathy in their cluster analysis with 121 participants with DSPN in Australia using the PIN questionnaire. They found that cluster one had more misperceptions regarding the nature of DSPN, cluster two was deemed to be realistic regarding their DSPN and cluster three was uncertain about their condition. Cluster one, who exhibited the highest misperceptions regarding their DSPN, reported undertaking the most potentially damaging foot-care behaviours (Perrin et al., 2014). This further highlights the importance of understanding patient perspectives on illness experience and comprehension.

The variation in patients' ability to accurately interpret neuropathic DFU risks and to generate a coherent link between their cognitive representation of risk factors and foot care advice may play a vital role in motivating foot self-care behaviours (Vileikyte, 2008). This may also be important for the Charcot foot population, as this pathology is often misunderstood and misdiagnosed by professionals and may be difficult for patients to understand. Practitioner awareness of these factors may also help to initiate timely conversations and provide education and resources where required, to help increase understanding and reduce uncertainty in this high risk group of people.

This section has highlighted the pervasive and long-term impact that both diabetes and the complication of DSPN can have on patients' mental and emotional health. Patient and HCP understanding of such factors are important as they form the background in which the diagnosis of active Charcot foot rests. Unsteadiness associated with DSPN may be of particular importance, given that this is the direct precursor to the Charcot foot. The management of Charcot foot by TCC or a removable device may further increase the experience of unsteadiness for this vulnerable population, thereby plausibly increasing the negative QoL and emotional impact. Further research would be required to confirm this assumption. Increased understanding of these complex conditions may also assist patients to improve self-care behaviours and to make sense of their health related lived experiences.

2.13. Related research

A comparable sample to the Charcot foot population may be patients with diabetic neuropathic foot ulceration. One of the key management principles of neuropathic DFUs is the removal of pressure and mechanical stresses (Bakker, Apelqvist, & Schaper, 2012). Techniques used for offloading are often the same as those for Charcot foot such as TCCs or Aircast boots (Carrington, Mawdsley, Morley, Kinsey, & Boulton, 1996) and are recommended by NICE guidelines (2015) as part of the gold standard treatment of neuropathic ulceration in people with diabetes.

Literature exploring the psychosocial effects of DFU have yielded mixed results regarding depression and QoL impact. As has been previously noted (Section 2.11), Willrich et al. (2005) found no significant reduction in cognitive impairment, depression or MCS, in their participants with DFU or Charcot foot. However, they did report a

significant reduction in the PCS using the SF-36. Similarly, using the HADS and Neuro-QoL, Vileikyte et al. (2005) (Section 2.12) reported that there was no relationship between depression scores and having either a current or past history of DFU.

Conversely, Ismail, Winkley, Stahl, Chalder, and Edmonds (2007) found that one third of people presenting with their first DFU did suffer with clinically significant depression. This prospective cohort study of 253 patients used the schedules for clinical assessment in neuropsychiatry 2.1 (SCAN 2.1) (WHO, 1997) to categorise patients into one of three groups: major depressive disorder, minor depressive disorder or no depressive disorder. This tool was applied during a semi-structured diagnostic interview by a trained nurse and, unlike the self-reported research tools, is used for clinical assessment in neuropsychiatry. The reliability and validity of SCAN 2.1 have been demonstrated (Rijinders et al., 2000). Ismail et al. (2007) found that approximately a quarter of those investigated (24.1%, n=61) presented with major clinical depression and a further eight percent (n=21) had minor clinical depression. Together this was associated with an approximately threefold risk of death at 18 months follow up when compared to those patients with no depression (Ismail et al., 2007). A follow up study by Winkley et al. (2012) found that the association between depression at recruitment and the risk of mortality remained highly significant five years later, suggesting that any depressive episode, regardless of severity, could have a long-lasting impact (Winkley et al., 2012).

A more recent study by Hoban et al. (2015), evaluating the effect on mental health of foot problems in a diabetic population, corroborates this finding regarding increased depressive symptoms. They reported greater symptoms of depression but not anxiety using the HADS, greater levels of pain using the McGill Pain questionnaire, and more

suicidal behaviour, using the suicidal behaviours questionnaire in people with diabetic foot complaints than in a comparative sample of people without foot problems. Similar to the research exploring health related QoL in Charcot foot, Hoban et al. (2015) also reported significantly worse health related QoL only in the physical domain, with reduced PCS but not MCS using the SF-36. They therefore concluded that, whilst the SF-36 was not sensitive enough to detect the MCS, the foot pathology group had a markedly reduced health related QoL requiring multidisciplinary treatment and review. The foot problems amongst this sample of 47 consisted of both painful and non-painful neuropathy, ulcers only or ulcers with infection, osteomyelitis and concomitant Charcot foot. Three participants had osteomyelitis only, two Charcot foot only and one cellulitis. Their results were compared with those of 49 people with diabetes but without foot pathology and also with those of 21 caregivers to those with diabetic foot problems.

In contrast to the conclusions drawn by Hoban et al. (2015) regarding the SF-36, Ribu and colleagues published three papers exploring aspects of the health related QoL of 127 adults with DFU using this measure (Ribu, Hanestad, Moum, Birkeland, & Rustoen, 2007a; Ribu, Hanestad, Moum, Birkeland, & Rustoen, 2007b; Ribu, Birkeland, Hanestad, Moum, & Rustoen, 2008). They found that patients with DFU had a worse health related QoL, demonstrated in all scales, when compared to a diabetic control group of 221 people with diabetes but without DFU, and a sample of 5,903 people from the general population (Ribu et al., 2007a). Similar to the results of other studies of diabetic foot pathology, the greatest mean differences were found in the areas of physical functioning, role limitation (both physical and emotional), and general health. Whilst the smallest difference was noted to mental health, this was still significant. These results were maintained even controlling for covariates and cofounders (Ribu et al., 2007a). The research appears robust with extensive detail given regarding sampling. However, all the control groups

appear to have taken part through a mail survey. Therefore, the diabetic control group do not appear to have been physically examined and there is no detail given regarding neuropathy or comorbidity status, making it difficult to assess variability in these areas.

Subsequent papers, using only the data from the DFU group, reported that larger ulcers had a more significant impact on mental health scores and those larger than 5cm² were responsible for a large amount of the variance in PCS (Ribu et al., 2007b). Follow up data were collected at six months and twelve months after baseline (Ribu et al., 2008). Associations between health related QoL and ulcer status showed that participants with non-healing ulcers had significantly lower health related QoL than those with healing ulcers (Ribu et al., 2008). Ribu et al. (2007a) postulated that it was the loss of mobility as a consequence of a non-weight bearing treatment plan that was a major factor in participants' QoL reduction, especially in the areas concerning ADL, leisure and social interaction, strain on relationships and feelings of becoming a burden. However, those with healing ulcers had already reported significantly better general health at baseline, and those with non-healing ulcers had evaluated their general health as poor and believed that it was likely to deteriorate (Ribu et al., 2008). This may again point to the complex symbiotic relationship between diabetes, its complications and mental health noted in Section 2.12 and may be pertinent to the Charcot foot population in this research given the requirement for a similar non weight bearing treatment plan.

In a study by Carrington et al. (1996), comparing QoL in people with DFU and unilateral lower limb amputation against diabetic controls, 52 participants underwent a structured interview using the psychosocial adjustment to illness scale (PAIS) (Derogatis & Derogatis, 1986), the HADS, a QoL ladder (Cantril, 1965) and a specifically designed,

non-validated foot questionnaire. Participants were grouped as diabetic amputees (13, unilateral amputees of 6-18 months), patients with DFUs (12, unilateral ulceration for at least three months, neuropathic or neuro-ischaemic in origin) or diabetic controls (26 age and sex matched diabetic people with no history of DFUs, neuropathy status unknown). This study found that the DFU group reported significantly less satisfaction with their lives than diabetic controls using the QoL ladder and a significantly more negative attitude towards their feet than both the amputees and controls using the foot questionnaire. Results from the PAIS and HADS analyses found that both the DFU and amputation groups had made significantly poorer psychosocial adjustments to illness and had significantly higher depression scores than the diabetic controls, although effects on anxiety levels were not significant. Levels of isolation in both groups were also higher than those seen in controls, which was again ascribed to the participants' loss of mobility (Carrington et al., 1996). Overall, this study concluded that the psychological status of mobile amputees was better than that of patients with DFUs. They postulated that this was because the amputation group members were mobile and had no foot complaints at the time of the research, whereas members of the foot ulcer group were subjected to periods of prolonged immobilisation to treat their foot ulcers, reducing their mobility and QoL. This conclusion led the authors to call for HCPs to consider psychological interventions or rehabilitation in this vulnerable group (Carrington et al., 1996). Further studies may be required to confirm these results given the small sample sizes in each group.

Whilst these studies are variable in their reports of depression and the mental and emotional consequences of DFUs, findings are broadly similar and suggest that limitations to physical functioning and mobility can reduce self-reported health related QoL. This finding is corroborated by a small selection of qualitative research papers

exploring patient perspectives of living with DFU. These papers utilise either interview or focus groups and a variety of methods and methodologies for data generation from constant comparison to phenomenology and were reviewed using the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007).

An early qualitative study (Brod, 1998), which has been extensively referenced in related literature, used focus groups to explore the quality of life issues of both patients with DFUs and their caregivers in order to inform the generation of a disease specific QoL scale. Brod recruited 14 participants with DFUs and 11 of their caregivers, although no information is given regarding from where the participants were recruited or the process involved. Patients and caregivers were each split into two smaller focus groups. The focus group sessions followed a semi-structured interview schedule, which was developed following literature review and discussions with relevant HCPs. This schedule split lines of questioning into four existing QoL domains: social, psychological, physical and economic. Transcripts were thematically analysed by a research team. However, no details were given regarding the background or experience of this team or to what extent they worked together on the analysis. Themes arising from one group were given to the second for confirmation and validation of the findings. Issues were discussed in all four domains for both DFU and caregiver groups. The findings of the DFU group were broadly summarised within their existing QoL domains and then divided into smaller sub-themes. Whilst no direct quotations were used to illustrate the analysis, details were provided to explain each sub-theme. Findings are summarised in Table 5 overleaf.

Table 5. QoL domains and levels and their content extracted from focus group sessions with DFU patients (Brod, 1998)

Domain	Subcategory	Details
Social	Daily life	Major restrictions in performing physical and personal ADL such as bathing and shopping. Dependency on supportive devices. Increasing time taken to plan daily life and undertake ADL as well as dressing and caring for ulcer.
	Leisure	Individuals often curtailed or severely limited with regard to leisure activities requiring mobility. Restrictions were placed on vacations, recreational activities.
	Family life	Feelings of burden resulting from increasing dependence on family members. Recognition of the wish not to impose extra burden on adult children. Emotional tension and strain on relationships with partners due to diabetes and presence of the ulcer.
	Social life	Significant shrinking of social circle due to limited mobility restricting participation in social activities. Feelings of guilt when friends changed activities to accommodate their limitations.
Psychological	Emotions	Feelings of frustration resulting from loss of mobility and independence and uncertainty regarding whether the ulcer would heal. Anger stemmed from frustration and feelings of being a burden on significant others. Worry about the ulcer. Depression and social isolation were discussed.
	Positive consequences	Feeling of being brought closer to spouses/partners. An increased appreciation of the need for foot care. The development of patience in order to deal with the frustrations of daily life.
	Physical health	Feelings of being drained and fatigued due to sleep disturbances exacerbated by pain and discomfort. Antibiotic side effects included nausea, fatigue and general malaise. Fatigue from extra energy required for mobility.

	Treatment impact	<p>Issues of odour and appearance of the ulcers were noted but not highly bothersome.</p> <p>The major impact was mobility restriction which affected all areas of life.</p> <p>Frustration due to immobility resulted in non-compliance with offloading.</p>
Economic	Employment	<p>Approximately half of all patients were required to retire early, lost their jobs or were out of work,</p> <p>Loss of employment opportunity resulted from a loss of self-esteem.</p> <p>Fear of job losses.</p> <p>Decreased productivity for the employed as clinic appointments meant lost time at work.</p> <p>Missed career opportunities.</p>
	Finances	<p>Indirect costs included: increased transportations costs for buses and taxis; expenses such as parking costs for hospital visits;</p> <p>increased telephone bills as the telephone was used as the major link to the outside for both medical and social needs.</p> <p>Extra footwear costs.</p>

Brod (1998) concluded that it was ‘the overwhelming impact of mobility limitations [which] led to a cascading effect in every quality of life domain’ (p. 371). This impact was reported to require the incorporation of a completely different lifestyle for both the patients and their caregivers, which cascaded into increased strain and tensions between family members and alterations to family life. Anger, frustration and worry were all reported by the patient group. However, it was recognised that many of these feelings may have been eliminated if some of the uncertainty regarding the future prognosis were resolved. Unfortunately, none of the patients or caregivers reported having any platform on which to express their fears and concerns. It should be noted that not all sub-themes were negative for these groups. Positive psychological effects were also noted with participants reporting increased patience in dealing with the frustrations of daily life, an increased appreciation of the need for foot care and feelings of becoming closer to their life partners. Ultimately, Brod (1998) concluded that whilst many chronic diseases often affect only one or two domains of QoL (social, psychological, physical and economic), this study reported issues pertaining to all four QoL domains, as patients were unable to compensate for their diminished functional status.

Interestingly, Brod (1998) also reported a remarkable degree of consensus between the reports and themes of patients and their caregivers. These findings correlate with findings by Nabuurs-Franssen, Huijberts, Nieuwenhuijzen-Kuseman, Willems and Schaper (2005), who explored the health related QoL of patients with DFUs and their caregivers at centres across the USA, UK and Europe. Using the SF-36, they found that the presence of DFUs placed a large emotional burden on caregivers and that the health related QoL of this group correlated with that of the patients. They reported that wound care, frequent hospital visits, impaired mobility and fear of amputation were possible causative factors.

Given that feelings of burden may be prevalent in the diabetic population, this area may also require further research in the future.

Two of the later qualitative studies exploring the QoL of people with DFU used phenomenology as their methodology. The earliest of these studies (Kinmond, McGee, Gough, & Ashford, 2003) used IPA. This study explored the lived experiences of 21 individuals with DFU using single, semi-structured interviews. The findings were analysed and framed within the context of loss, using Charmaz' (1983) framework of 'loss of self'. The master themes were presented using this pre-existing framework under the headings: living a restricted life, existing in social isolation, experiencing discredited definitions of self and becoming a burden. Examples of participants' quotations were presented to illustrate all themes with the exception of existing in social isolation. These quotations highlighted the participants' loss of freedom, employment and their meaningful ADL as a consequence of trying to offload their DFU. Of the 14 participants who were of working age, only three remained in paid employment and all reported lengthy periods of sick leave because of their DFU. The loss of employment and inability to maintain good personal hygiene due to the need to keep the dressings dry was also reported to negatively impact the participants' sense of self. Reports of burden prevailed in relation to caregivers and family members who assumed the roles and activities that the participants could no longer undertake. Such restrictions, in so many areas of their lives, were reported by some to lead to depression. One participant discussed his wish for amputation in a bid to regain some sense of control over his life and others spoke of their disregard for professional advice concerning non-weight bearing in order to try to gain back some sense of self efficacy and reduce the burden of restriction placed upon them (Kinmond et al., 2003).

Although the themes presented in this study appear logical and well-reasoned, little information is available to assess how robust these findings are. There also appear to be several inconsistencies with the underlying philosophies of IPA. There is a lack of transparency regarding the steps to analysis, as the authors simply report reading the transcripts line by line and then summarising the results. This may imply a lack of depth and interpretation within the analysis, a feature which is inherent in IPA design. It was also reported that analysis was performed by a multidisciplinary team consisting of a podiatrist, a nurse and a psychologist, with the aim of eradicating any inconsistencies between participants' responses and the researchers' interpretations. It is unclear whether this analysis was performed individually and compared between researchers or performed as a group. The double hermeneutic philosophy of IPA (Section 3.7.2) recognises that the researcher's position, understanding and prejudices will all influence any interpretation of the participants' experiences and therefore, that they may not be eradicated. Rather they should be acknowledged from the outset. There is no information offered regarding the interviewer(s), any prior research experience, their relationship with the participants or reflexive practice. Further, analysing the transcripts within a pre-defined framework does not appear to fit with the inductive approach of the methodology. The inclusion of 21 participants may also have led to a loss of idiographic focus (Section 3.7.3). IPA usually recommends fewer participants in order to gain a more in-depth analysis. Such philosophical inconsistencies, and a lack of detail regarding the steps of the analysis, make it difficult to assess the trustworthiness of the findings. Nonetheless, this is one of the most heavily referenced papers in this area, cited by 28 other published articles at the time of writing.

The second phenomenological study (Watson-Miller, 2005) explored the experiences of people living with DFUs in Bermuda. Six out of a possible 18 patients at a single foot

clinic agreed to participate and underwent a single unstructured interview. The study was carried out from a hermeneutic phenomenological perspective and used data analysis process inspired by Burnard (1991), although the steps are not reported. Researcher position was indicated and a statement regarding reflexive practice was provided. This study details two main master themes: physical and psychological effects. Under physical effects, the burdensome and constant care of the ulcer was discussed alongside the symptoms, pain and concerns regarding odour. The psychological effects noted were anxiety and worry in relation to the length of time which the ulcers might take to heal. Concerns regarding amputation were also noted. Feelings of being dependent on others to assist with ADL, driving, and housework were reported and led to altered family roles and feelings of becoming a burden. Such issues are similar to those discussed in other research (Brod, 1998; Kinmond et al., 2003). Unfortunately, the paper is very brief and no participant quotations were used to illustrate and back up the themes generated, again making it difficult to assess the trustworthiness of the findings.

Due to the scarcity of published qualitative research in this area and the suggestion that both Charcot foot (Willrich et al., 2005) and DFUs (Carrington et al., 1996) may have a more severe negative impact on health related QoL than lower extremity amputation (LEA), qualitative research exploring the experiences of those who had undergone amputation as a result of DFU were included.

In their research, Barg et al. (2017) recruited 39 participants receiving treatment for either DFU (n=19) or LEA (n=20) from three podiatric practices. Of the amputation group, four had undergone a major transtibial amputation and 16 had received minor amputations, which were considered to be limb salvage procedures (14 had transmetatarsal amputation

or higher and two had received a first ray amputation). Single semi-structured interviews were undertaken by one of two researchers. Results were analysed using an integrated approach of grounded theory and deductive coding based on their conceptual model. Two main themes were generated: beliefs about diabetes and their link to DFUs and LEA; and QoL with DFU and LEA. The first theme revealed a limited understanding of the disease process of diabetes and the pathways to DFU and LEA. The second was split into smaller sub-themes, namely, function/independence – disruption/adaptation, attributions to wound/amputation specifics and other impacts on health. A high proportion of the QoL themes centred on function and independence for both DFU and LEA groups. Disruption to the participants' lives and loss of independence was often due to treatment plans and led to feelings of isolation, inability to self-care, and inability to work. Many participants also struggled with their loss of autonomy and found it hard to request help from others, reporting feelings of self-consciousness regarding their presumed dependence and occurrence of unwanted conversations related to their condition. The avoidance of weight bearing and use of an offloading boot to support immobilisation constituted the majority of the disruption for the DFU group. DFU participants reported relying upon assistive devices such as crutches, walkers and wheelchairs. Most were unable to drive and, in some cases, were even unable to leave the house. Conversely, whilst those with LEA reported some issues with balance, learning to use a prosthesis and needing to relearn the mechanics of walking following amputation, some respondents actually described being able to undertake an increased amount of activity without being limited by the constraints of DFU treatment. Barg et al. (2017) concluded that whilst amputation was a feared outcome, some participants, unexpectedly, learned to adapt and, at times reported that the LEA had enhanced their QoL. These findings may help to further illustrate those of quantitative research such as studies by Carrington et al. (1996) and Willrich et al. (2005) in which the QoL of participants with Charcot foot and DFUs were reported to be worse than those of mobile amputees.

Two further papers were found exploring the experiences of those with LEA in diabetes. Livingston, Van de Mortel, and Taylor (2011) explored the experiences of five people with diabetes related LEA using grounded theory. Again, a variety of surgical procedures were undertaken (two below knee amputations, two foot amputations and three multiple toe amputations between the five participants). No information was given regarding time elapsed since last amputation. This study found three main categories that described the participants' experiences: imposed powerlessness, adaptive functionality and endurance. These categories were reportedly related to issues with physical, social and psychological functioning respectively. All participants recalled alterations to the interactions with their spouses and loss of role at home with extra household tasks being assumed by partners, particularly those that required mobility or balance. Poor balance also caused embarrassment in social situations and the inability or reluctance to drive caused further social isolation. Participants' sense of powerlessness was exacerbated by damaged trust in the HCPs treating them, and feeling uninformed and having insufficient information and education regarding both their previous risk factors and current position. Emotions of shock, anger, and disbelief were reported in the initial period post amputation but at the time of interview there was also the sense that participants were developing hope, acceptance and learning to adapt.

The central theory conceptualised from these themes was that of perpetual resilience. This theory identifies that the participants had been forced onto a path that they would have to travel repeatedly given the chronic nature of their condition. It is acknowledged that the five participants recruited into the study were the only people who consented to take part from a potential pool of 30 receiving care in the same health care setting. This may have increased the likelihood of selection bias towards those with fewer psychological difficulties or a more positive attitude post amputation. Therefore, further research was

recommended to confirm the findings. This concept of perpetual resilience may have some theoretical transferability to the Charcot foot population, as the chronic nature of the deformity and instability caused by the active disease process, usually require lifelong monitoring, and a high frequency of complications as described in Section 2.9.

Finally, a particularly rigorous paper was later published by Foster and Lauver (2014), describing the lived experiences of 15 patients with LEA as a consequence of DFU. Amputation level ranged from digital amputation (n=9), to transmetatarsal (n=5), below-knee (n=5), and above knee (n=5), and some participants had undergone staged amputations in an attempt to salvage as much of the foot as possible, resulting in multiple procedures. No information was given regarding time between most recent amputation and interview. Following single, semi-structured interview the results were analysed using Colazzi's step-by-step approach to phenomenology. The methods used together with approaches to ensure rigour and trustworthiness are described in detail. This study generated five major themes: financial burden, social support, powerlessness, placing blame and uncertainty. These themes were explored through a variety of sub-themes. The sub-theme of grief was found to be interwoven with all master themes (Table 6).

Table 6. Master themes and sub-themes from Foster and Lauver (2014)

Master themes	Sub-themes
Financial burden	Loss of income Inability to care for family Costs of medical care Costs of access to care: transportation Costs of medication for diabetes and comorbidities Grief
Social support	Family Community Health care professionals Loss/lack of support Grief
Powerlessness	Loss of body part Inability to self-care Immobility Declining health, increasing comorbidities and complications
Blaming	Self-blame and regret Others: wish care giver did more New onset comorbidity Grief
Uncertainty	Using a prosthesis Returning to work Going out with friends Wound care Grief

These themes show various areas of overlap with previous studies. The authors concluded that HCP understanding of patient experience may help to alleviate participants' fears about seeking medical attention and can direct counselling towards areas of particular concern. They recommend that these directions include signposts towards social support systems and financial options. It was also postulated that timely provision of interdisciplinary care throughout the continuum of care helps to reduce feelings of powerlessness.

The finding that grief is interwoven with each of the master themes is interesting. A paper by Spiess, McLemore, Zinyemba, Ortiz, and Meyr (2014) explores the model of the five stages of grief in relation to diabetic LEA. They examine each of the stages – denial, anger, bargaining, depression and acceptance – in order to raise HCP awareness of 'predictable patterns of patient behaviour' (p. 738). This, they claim, is important given the links between diabetes, depression and the effects on general and foot specific health, as discussed in Section 2.12. Improved recognition of these psychological states may then lead to improved patient care, outcomes and onward referrals for psychiatric support if required. Given the prolonged nature of treatment for active Charcot foot and the uncertain outcomes, this may also be pertinent in the Charcot foot population and further research in the area should be considered.

This section has highlighted important psychosocial issues for the DFU and diabetic LEA population through predominantly qualitative enquiry. Qualitative methods can help to shed light on many important areas of concern from the patient perspective that are often lacking in quantitative research. Whilst none of these studies focused on the patient experience of Charcot foot directly, the experiences of those with DFU and LEA are

arguably very similar and may help to illuminate the experiences of those with this closely related pathology.

All of the studies reviewed highlighted prolonged weight bearing reduction and increasing dependency on significant others as primary factors in their negative experience of living with DFU and LEA. This led to the loss of important ADL and increasing social isolation. Feelings of becoming a burden, loss of control and powerlessness were prevalent throughout. This may add clarity to the findings of some previous research which suggests that the QoL of people with both Charcot foot (Willrich et al., 2005) and DFUs (Carrington et al., 1996) may be more severely negatively affected than that of mobile amputees. In addition, most of the qualitative studies explored have reported expressions of fear, anxiety and uncertainty with regard to healing times and future prognosis. In a pathology as poorly understood and with such uncertain outcomes as Charcot foot, this again is arguably highly relevant to this population. Further, reports of depression and a destabilisation of sense of self were commonplace. In some cases, this was reported to be exacerbated by information from HCPs which was perceived to be misleading or inconsistent. Increased HCP awareness of, and focus on, these important areas is recommended in order to improve patient experience and health related QoL in all diabetic foot complications.

2.14. Biographical disruption

In his seminal work on biographical disruption, Bury (1982) interviewed 30 people with a new diagnosis of rheumatoid arthritis (RA), with the aim of exploring the problems of recognition of emerging illness and the changes in patients' lives and relationships caused by development of illness from the earliest possible point. He asserted that a disruptive

event or critical situation, such as the sudden onset of a chronic illness, could disturb the structures of everyday life and the forms of knowledge that underpin them.

Bury (1982) argued that with the onset of chronic illness and biographical disruption, the taken-for-granted world of everyday life would become a burden of conscious and deliberate action. This, he asserted, could cause even the simplest outing to become a major expedition, leading to social isolation and dependency. In his study, he found that as participants' taken-for-granted behaviours and assumptions were disturbed, their attentions were turned to the bodily states suddenly brought into consciousness, leaving a feeling that they were being taken over by the disease (Bury, 1982). This, he argued, marked a biographical shift in participants' sense of reality and the perceived trajectory of their lives, causing a re-examination of personal biographies and self-concept. Consequently, a mobilisation of resources was required in order to cope and to deal with the long-term aspects of care. However, he also noted that participants were hiding the effects of their illness from their family, either actively or inadvertently, due to disbelief and anxiety (Bury, 1982). He later noted that, for those diagnosed with such chronic illnesses, their meanings and context may not be easily separated (Bury, 1991)

The concept of biographical disruption in the study of illness has become a theoretical paradigm, widely acknowledged as changing the understanding and conceptualisation of lay experiences of illness (Delbene, 2011). Nonetheless, it has not remained uncontested, with even Bury (1991) himself acknowledging that different conditions have a diverse range of symbolic connotations, which vary from culture to culture and can also have a profound influence on patients' experiences and the responses of other people. Further, he later acknowledged that biographical disruption should be considered individually and

within the stage and symptoms of the disease process (Bury, 1991). Sanderson, Calnan, Morris, Richards and Hewlett (2011) argued that continued significant disruption to life should not be assumed at the diagnosis of a chronic illness. They maintained that there are normal typologies, where patients go through stages of disrupted or fluctuating normality or may even suspend their normality to accommodate and cope with chronic illness. This aligns with Williams' (2000) perspective that prejudging illness as biographical disruption cannot be justified. Timing, context, norms and expectations alongside commitment to events are crucial to the experience of our lives, healthy or sick, and the meanings with which we endow it (Williams, 2000).

Nonetheless, the concept of biographical disruption was felt to resonate with the research findings discussed in Section 2.13 and may therefore also usefully inform this study. In addition, the current research explores patients' experiences of active Charcot foot as an emerging illness, which could also be defined as a critical situation for both participants and their lives. Therefore, its inclusion here was felt to be warranted.

2.15. Research questions

The literature explored throughout the introduction and literature review has highlighted how both government and NHS agendas are focused on patient centred, evidence-based care. It is clear that diabetes and other complications such as DSPN, DFU and LEA have serious and long-term negative impacts in terms of psychosocial comorbidities and QoL. However, literature pertaining to patients' experience of living with Charcot foot is scarce. All literature found exploring Charcot foot utilised quantitative tools to examine patients' collective experiences, and the limitations of these tools have been identified. No qualitative explorations of patient experience were found. Therefore, there is a

significant gap in the knowledge concerning patients' reactions to, feelings about, and experiences of, living with active Charcot foot. Subsequently the following research questions were identified:

What are patients' experiences of receiving a diagnosis of Charcot foot and living with the condition?

What are patients' experiences of receiving long term management with a TCC for this diagnosis?

In what ways (if any) does this diagnosis and management of active Charcot foot affect patients' lives?

2.16. Aims and objectives

The following aims and objectives were then generated in response to the research questions:

Aim 1: To explore the lived experience of active Charcot foot on patients' lives.

Objectives:

- To better understand how people experience a diagnosis of active Charcot foot and its subsequent management.
- To explore how patients make sense of their experiences and the meaning it has within their lives.

Aim 2: To interpret, synthesise and align data from emergent themes pertinent to patients' experiences of Charcot foot and to use this information to identify areas in which to enhance patient care and improve quality of life.

2.17. Literature review reflexive statement

My review of the literature throughout the research process has helped to shape all aspects of this study in a variety of ways. When my research journey initially began, I found it natural to focus on the areas of research with which, as an HCP, I was most familiar. Meta-analysis, RCTs and literature based on my biomedical way of thinking were where I felt safe. Whilst I also read qualitative research, I did not find it easy to move away from my fore-structures based on my work as a podiatrist and this biomedical background. I believe I was also strongly guided by the idea that the research which I produced needed to be understandable and useful in a medical setting. Therefore, I was unwittingly situating my research in a language and approach that I felt other members of medical teams would understand, which was less interpretive and less grounded in the underlying philosophies of IPA. This I ultimately feel, hindered earlier drafts of this research.

As I later directed the focus of my reading towards the philosophies behind phenomenology, and the works of the early phenomenologists, such Heidegger, Merleau-Ponty and Sartre (Section 3.3.1), my viewpoint gradually began to shift as I started to make sense of it all. I admit that the sheer density of most of this work meant that this was a very slow process. It was actually the work of later phenomenologists (Ashworth, Carel, Seamon, and Ratcliffe) that helped me not only to make sense of the more classical texts, which they all referenced, but also of how they might be applicable to my research. Each

of these phenomenologists consequently feature in the discussion of my own research (Section 5.1).

The requirement to more fully immerse myself in qualitative literature and to learn to take a more critical stance with regard to rigour, transparency and quality in this field has also been influential. I found the COREQ tool (Tong et al., 2007) very helpful when I began to critically appraise previous publications. My increased knowledge regarding qualitative methods also assisted in this area. I feel that as my confidence in analysing other studies grew I also became more confident appraising and discussing my own research. Retrospectively, I feel that this new insight has changed the way I read and assess publications and has confirmed how important qualitative research is in illuminating and illustrating not only the deeper meanings of situations for participants, but in shedding light on the findings of related quantitative work. Updating my reading and literature review chapter regarding similar research in related areas also helped to increase my confidence in the findings, as I discovered other papers with relatable themes and outcomes whilst moving through the iterative research process.

Chapter 3. Methodology

This chapter will present and justify the study design and theoretical underpinnings of the research together with the associated ontological and epistemological position of the researcher. A critical evaluation of the chosen methodology is provided and ethical issues surrounding the study are discussed. The chapter provides clear details of the practical issues surrounding data collection and participant selection both in the planning of the research and during data acquisition.

3.1. Situating the research

As highlighted in Chapter 2, there is a paucity of research exploring the patient experience of Charcot foot. Most of the research that exists has focused on validated questionnaires in an attempt to quantify patients' collective experiences. This over-reliance on quantitative methods has resulted in a situated knowledge base which broadly considers that those diagnosed with Charcot foot do not suffer from depression, anxiety or reduction in their QoL in terms of mental functioning. However, as highlighted in Section 2.11, it has been suggested that such generic questionnaires do not adequately capture the specific emotional distress of the foot problem (Vileikyte, 2008). Furthermore, the published research findings are at variance with the anecdotal reports given by most HCPs and the patients themselves, which led to the question of whether the quantitative methods previously employed may be too reductionist for the complex nature of the problem. To fulfil the aims and objectives of this research it was necessary to carry out an exploratory study, enabling a richer and deeper understanding of the patient experience and potentially identifying areas in which patient care could be enhanced.

3.2. Qualitative research

Qualitative research methodologies permit the development of concepts that enable researchers to comprehend social phenomena in naturalistic rather than experimental settings and to allow for the importance of meanings, views and the experiences of the respondents to be explored (Powell & Single, 1996). They tend to be concerned with the quality and texture of experiences rather than associations and cause and effect relationships. Thus, the concern is with interpreting what the data means rather than finding its numerical properties (Smith et al., 2009).

Qualitative research methodologies explore meanings derived from the participants themselves and therefore do not use preconceived ‘variables’ which are pre-defined at the start of the research process. This would lead to imposition of the researcher’s meanings and potentially preclude the participants’ own ways of making sense of the phenomena in question (Crotty, 2013). Before commencing any qualitative research, it is vital to take time to consider a number of key philosophical areas that will underpin the research and illuminate the researcher position. Qualitative research involves a set of complex practices that encompass a wide variety of methodologies. These need to be chosen and justified by bringing to light our assumptions surrounding the nature of knowledge and reality and our beliefs about what kind of knowledge can be obtained by our research (Crotty, 2013). The following sections aim to explain how the theoretical position of the researcher has contributed to the formation of the research question and the chosen methodology of this thesis. It begins with an explanation of the selected paradigm within qualitative research, and is followed by descriptions of the epistemological and ontological positions that have helped to shape the project.

3.3. Interpretive paradigm

Broadly speaking, paradigms are belief systems that attach the user to a particular worldview and which contain overarching philosophical systems denoting particular ontologies, epistemologies and methodologies (Denzin & Lincoln, 2011). More basically, they are a set of beliefs that define action, and in using knowledge of these beliefs, a researcher can decide which research designs can be used for a given set of objectives and those which cannot (Gray, 2009).

Of the different paradigms available, positivism and the various strands of interpretivism have been arguably the most influential (Gray, 2009). Positivism offers assurance of unambiguous and accurate knowledge of the world (Crotty, 2013) in which both natural and social worlds operate within a strict set of laws that science can discover through empirical enquiry (Gray, 2009). Whilst the positivist paradigm finds its mainstay in quantitative research, it can actually lend itself to both quantitative and qualitative research (Kumar, 2011). A case study, for example, could be grounded in the positivist paradigm, if written in objective and unbiased detail using quantifiable/measurable variables and used to show outcomes or test a hypothesis in a representative population. A case study by Wu (2011), which details the healing process and procedures for a chronic ulcer in a patient with Charcot foot and peripheral arterial disease, provides a good example of this.

Interpretivism, conversely, looks for culturally derived and historically situated interpretations of the social life-world (Crotty, 2013). It asserts that there is no direct or one-to-one relationship between the world and ourselves, instead suggesting that there is a dynamic interplay between persons and the world around them which is how meanings

are constructed. Interpretivism maintains that natural reality (such as the laws of science) and social reality are different and therefore require different kinds of research methods. Whereas the natural sciences look for consistencies in data in order to deduce laws, the social sciences will often deal with individuals and the way in which they make sense of the world around them (Gray, 2009). HCPs working in all areas are required to provide evidence of clinical effectiveness, to be accountable and to draw on evidence-based practice to improve the quality of services (Finlay, 2011). However, the biomedical model of research favouring RCTs and systematic reviews may leave much to be desired in terms of clinical practice, especially in areas that are at the limit of our knowledge, such as the Charcot foot. Clinical knowledge consists of interpretive action and interaction, which are factors that involve experience, communication and opinion (Malterud, 2001). For HCPs it often becomes evident that one size does not fit all and many treatments shown to be effective in evidence-based practice or recommended in clinical guidelines and protocols may not work for all individuals. A level of interpretation of the evidence and of clinical need becomes standard practice as care plans are negotiated and designed for individual patients with their own histories and individual needs. Therefore, it is as important to understand the patient as it is to understand the disease (Malterud, 2001).

The current study is located in the interpretivist paradigm. This paradigm has appeal on a variety of levels both personally and professionally. Personally, I am relatively well travelled and through this I have witnessed the alternative interpreted truths of other people and in other places. I have always attempted to travel with an open mind and to listen to those with opposing opinions to my own which has often proved very enlightening. This exposure to other truths and realities of life has helped to strengthen disbelief in the unambiguous nature and ‘laws’ of the world that are ‘waiting to be found’,

and acceptance of the interpretive stance where our culture, histories and experiences affect our views of reality and the world.

A paradigm encompasses four areas: Axiology (ethics), Epistemology, Ontology and Methodology.

Axiology - How will I be as a moral person in the world?

Epistemology - How do I know the world?

Ontology - What is the nature of reality?

Methodology - What is the best means of gaining knowledge about the world?

(Denzin & Lincoln, 2011)

Each of these areas is now considered in turn.

3.4. Axiology

Lincoln, Lynham, and Guba (2011) postulate that axiology (or the branch of philosophy dealing with ethics, aesthetics and religion) should be part of the basic, foundational, philosophical dimensions of the paradigm being used. Axiology, or value theory, attempts to address the issue of values in research and covers a wide area of critical analysis and debate including utility, goodness, beauty, right conduct, and obligation (Hiles, 2008). It has relevance to the field of qualitative research as it has a direct bearing on the ethical context of the research and offers an important basis for making our assumptions explicit (Hiles, 2008). In other words, our values will affect not only how we do research but also what we value in research and will help us to find a foundation from which to work.

Whilst it is agreed that deciding which methodology to follow is a primarily epistemological issue, determining which projects to pursue is a fundamentally axiological issue and should always embody the highest principles of human rights and dignity (Lincoln et al., 2011).

The goal of most health care is to improve patient health, but arguably, it is the patients themselves who are best placed to judge how they feel and to identify their key priorities (Devlin & Appleby, 2010). As we have seen, much of the research, evidence and guidelines on which healthcare practice is currently based, are formulated by RCTs, meta-analyses and gold standard clinical trials from the positivist paradigm. However, undertaking careful assessment of the collective experience of patients could help to build a deeper understanding of their personal experiences, identify issues, determine priorities for quality improvement, provide a framework for approaching patients' problems holistically and aid in uncovering new therapeutic options or approaches to care (Coulter & Ellins, 2006; Greenhalgh, 1999). This is particularly pertinent where previous clinical research is scarce or has been inconclusive, such as that seen in relation to the patient experience of Charcot foot and its effect on health related QoL (Section 2.11).

It has been suggested that there is often discordance between the ways in which professionals would like to improve the health of others and the way that those individuals feel is important to them (Lucas & Lloyd, 2005). Nonetheless, HCPs are taught that best practice necessitates the involvement of the patient from the earliest stages of creating their management plans. This process should not only include support by an evidence base and local protocols but also consideration of patient goals, attitudes, their competing responsibilities and economic means (Burrow, 2006). The quality

standard offered by NICE (2012) for improving the quality of patient experience also includes ensuring that patients are given the opportunity to discuss their health beliefs, concerns and preferences in order to individualise their care. This research considers that the individualisation of care, in particular, is of vital importance to successful health care.

An example of this in practice would be a patient who, despite acknowledging that a TCC is the best form of treatment for their active Charcot foot, is unable to tolerate one. This often occurs because the patient is concerned that their DSPN means they will not feel any irritation to the skin or development of DFU under the cast. Without then being able to check the foot every day, as all people with DSPN are advised to do, the patient may report feeling trapped or claustrophobic and experience increased anxiety at the thought of developing further foot complaints as a direct result of their treatment. In these instances, treatment plans would be tailored to these concerns. A removable cast may be manufactured or a removable Aircast boot be issued with strict advice to wear it at all times when weight bearing, whilst allowing the patient access to check the foot. This has the potential to delay healing times but will decrease the reported levels of anxiety, allow the patient to cope with treatment better and improve their quality of life for the duration of the treatment.

Clearly there has been a growing trend towards patient focus and holistic care in the wider arena (Darzi, 2008; Department of Health, 2010; Department of Health, 2013; NICE, 2012; NICE, 2015), which echoes my own personal values. As a practitioner in a busy tertiary referral centre, much of my time is spent listening to patients' stories, their unique situations and histories. Listening and interpreting is a part of everyday life, and practitioners quickly realise that although many people may be diagnosed with the same

condition, all may experience it, cope with it and respond to treatment differently, according to their individual circumstances. Although the dialogue between practitioner and patient has always been at the heart of the clinical encounter (Hogarth & Marks 2004), it should be acknowledged that this takes place in a highly structured transactional space where social expectations can determine the behaviours of both parties (Greenhalgh & Hurwitz, 1999). In the construction of health and illness a tension often remains between what the HCP and what the patient view as important (Hogarth & Marks, 2004). When engaging in the act of representing another person's situation and his/her needs and goals, the very premise of who they are, is based on the interpreted situation from the perspective of the other person (Alcoff, 2009).

3.5. Epistemology

Epistemology asks: How do I know the world? (Denzin & Lincoln, 2011). It tries to understand what it means to know, and provides a legitimate philosophical background for deciding what kinds of knowledge are both legitimate and adequate (Gray, 2009). There are a number of different epistemological positions within which a researcher can work (Madill, Jordan, & Shirley, 2000). The current study is rooted within a constructionist epistemology. Constructionism rejects the positivist view of human knowledge that the objective truth is 'out there' (Gray, 2009. p. 19). Instead, it claims that human beings construct meanings as they engage with the world which they are interpreting. All knowledge, and therefore all meaningful reality, is considered contingent upon human practices and is constructed both in and out of interaction with human beings and their world and developed within an essentially social context (Crotty, 2013). As a culture or society where people construct their own versions of reality between them, it is

necessary to accept the historical and cultural relativity of all forms of knowledge (Burr, 2003).

Contextualist constructionism, a particular position within the broader epistemology of constructionism, accepts the inevitability of bringing one's personal and cultural perspectives to bear on research projects. It asserts that all knowledge is local, provisional and situation dependent, and recognises that both the researcher and subject are conscious beings, acting on and interpreting the world around them within networks of cultural meaning (Madill et al., 2000). This is an important acknowledgement from the perspective of this research. As a practitioner I have both a scientific and experiential understanding of the disease process of Charcot foot and also the experience of caring for those receiving this diagnosis. Each clinical interaction has impacted upon and enhanced my understanding and preconceptions regarding what Charcot foot means to both practitioner and patient. This previous experience could influence interpretation of the data, and since the knowledge presented in this thesis is context dependent and a co-construction between participants and researcher, it is important to recognise any preconceptions and to be as open and reflexive as possible in giving a transparent and honest account of the interpretations.

3.6. Ontology

In many cases epistemological and ontological positions emerge together and it can often be difficult to distinguish between them conceptually (Crotty, 2013). Ontology asks the question: What is the nature of reality? (Denzin & Lincoln, 2011). Considerations about ontological perspectives are fundamental to situating the research. Ontological positions can be described as either realist or relativist (Willig, 2008). Constructionism could be

seen to have a highly relativist ontology, in which the very existence of material objects appears to be dependent on us and in which only arbitrary claims can be made about what is real (Larkin et al., 2006). Relativism questions the ‘out-there-ness’ of the world, emphasising the diversity of interpretations that could be applied to it and rejecting the idea that the world is the orderly and law bound place that many believed it to be (Willig, 2008). Conversely, realists believe that there is an external reality ‘out there’ which can be measured and that knowledge is advanced through the process of theory building in which discoveries add to what is already known (Gray, 2009). Realism can be measured on a scale from naïve to radical (Willig, 2008).

Crotty (2013) maintains that constructionism is at once realist and relativist; asserting that although meaningful reality is socially constructed that is not to say that it is not real. This relates directly to my research. We know that Charcot foot is a ‘real’ condition that exists, can be diagnosed, categorised and treated, but how it is experienced will be different for each individual as there is no one ‘reality’ of what having Charcot foot is like for all individuals even though the condition is shared. Contextual constructionism actually has much in common with critical realism, one of the less naïve forms of realism, which recognizes the subjective elements in knowledge production, and that different perspectives can generate different insights into the same phenomenon (Willig, 2008). This is where I believe that both my research and I are most comfortably situated. The current research is not situated in a completely relativist position, as I do believe in some universal truths regarding medicine and the efficacy of interventions provided through everyday practice. Antibiotics can cure infections; the application of a TCC can allow an active Charcot foot to become inactive. This much has been shown through extensive empirical research and this much I believe ‘I know’. However, I do not believe in one universal reality. I believe that everyone’s experience is their own interpreted version of

the truth. I will never fully be able to recount their version, but only interpret it in my own way as we all interpret the information which we are given.

3.7. Study methodology

My initial aims were to better understand how people experience a diagnosis and subsequent management of active Charcot foot and to explore how patients make sense of this experience and the impact it has on their lives. I also wished to uncover perceptions of treatment programs and to explore individual coping mechanisms employed by people with a diagnosis of active Charcot foot.

IPA using Photo Elicitation was identified as the most appropriate methodology for this stage. IPA was conceptualised in 1996 by Jonathan Smith and has been particularly widely used in health psychology but is now also becoming popular in a variety of other areas such as in the human, social and health sciences. There are a number of studies that use IPA to explore issues in the personal experience of health and illness (Finlay, 2011; Smith et al., 2009). Its focus on subjective lived experience has an intuitive appeal (Hefferon & Gil-Rodriguez, 2011), especially given my position as a practitioner attempting to understand the experiences of my patients. As Pringle, Drummond, McLafferty, & Hendry (2011) argue, it is only by understanding meanings that practitioners can influence health behaviours and lifestyles.

IPA's phenomenological emphasis on the experiences and concerns of participants lies at the heart of all IPA research (Larkin et al., 2006). It is committed to the examination of how people make sense of their major life experiences, maintaining that when a person is

engaged with an experience of something major in their lives, they begin to reflect on its significance. IPA aims to engage with these reflections (Smith et al., 2009) as its accounts privilege the individual's experience (Pringle et al., 2011). IPA is primarily idiographic and therefore concerned with the experience of the particular person rather than making claims at a population level. However, by performing several interviews and analyses the researcher is able to look for convergences and divergences in the data to locate further themes which are shared by participants and may have some theoretical transferability (Smith et al., 2009).

IPA uses an inductive approach to the data collected. Therefore, data analysis is carried out in detail and in context and the analyses are developed cautiously and cumulatively (Smith et al., 2009). Thus, it is an iterative process allowing researchers to reflect on and modify their thinking in light of the next piece of evidence assessed (Smith et al., 2009). IPA aims to capture and explore the meanings that participants assign to their experiences whilst avoiding prior assumptions (Reid, Flowers, & Larkin, 2005). It places the participant's voice as central to the development of the themes, which are data rather than theory driven (Shaw, 2001). For IPA researchers, experience is always already situated in linguistic, cultural, historical and embodied contexts, which is what makes each individual's experience so unique (Larkin, Eatough, & Osborn, 2011). Participants are experts of their own experiences and are recruited because of their expertise in the phenomenon which is being explored (Reid et al., 2005).

It is accepted in IPA that the interview transcript represents the participant making sense of the phenomena in question (Smith et al., 2009). It is also accepted that the interpretation of the themes relies on the researcher's interpretation of the participant's

interpreted experience. This is known as the double hermeneutic method (Pringle et al., 2011). In an opinion piece regarding occupational therapy, Clarke (2009) suggests that through using IPA, it is possible for therapists to develop a deeper understanding of the experiences of their participants, which in turn may facilitate reflection on current practices and lead to changes that enhance service provision. This links directly to the aims and objectives of this research. The three key areas of the philosophy of knowledge that have informed IPA, phenomenology, hermeneutics and idiography (Smith et al., 2009), will now be discussed in turn.

3.7.1. Phenomenology

Phenomenology studies the taken-for-granted, everyday examples of the lived world and attempts to make explicit the meanings that we attach to our human experiences (Finlay, 2011). Edmund Husserl first introduced it in 1900-1901 as a bold and radically new way of undertaking philosophy and an attempt to bring philosophy back into contact with the matters themselves (Moran, 2000). He suggested that we should endeavour to focus on each and every particular thing in its own right, without trying to fit them into our pre-defined systems of categorisation and that experience should be examined in the way in which it occurs and on its own terms (Smith et al., 2009). Since then, it has expanded as both a method and a general movement due to the influences of several key thinkers and philosophers including Martin Heidegger and Hans-Georg Gadamer, among others (Moran, 2000).

Husserl's phenomenology moved away from the Cartesian dualism of reality as being something 'out there' or completely separate from the individual, instead suggesting that minds and objects both occur within experience (Lavery, 2003). This means that the self

and the world are experientially related. The world does not exist 'out there' separate from our perceptions, but rather it is part of us and we are part of it (Finlay, 2011). Husserl maintained that the only objective knowledge which humans could have of anything would have to be attained by a process of consciousness, as this is the medium by which we inevitably encounter the world (Larkin et al., 2006). His famous argument that we should 'go back to the things themselves', refers to the experiential content of consciousness and the various obstacles that can get in the way of its pursuit (Smith et al., 2009). Husserl saw conscious awareness as the starting point in building one's knowledge of reality and felt that 'intentionality' was the process in which the mind is directed towards the objects of study (Lavery, 2003). In phenomenological terms, experience or consciousness is always consciousness of something. The object of which we are conscious may have been stimulated by a perception of the 'real' object in the world or through memory or imagination. Therefore, there is an intentional relationship between the object and a person's awareness of it (Smith et al., 2009). Husserl proposed that by intentionally directing one's focus, one could develop a description of particular realities, thereby coming face-to-face with the ultimate structures of consciousness that he described as essences (Lavery, 2003).

Husserl felt that the human realm essentially entailed an embodied, conscious relatedness to a world of personal experience or that experience was born of a system of interrelated meanings, which he termed the lifeworld (Ashworth, 2008). In order to explore this lifeworld and to get back to the essences of a phenomenon, Husserl proposed that one needed to bracket out the outer world and individual biases (Lavery, 2003). Bracketing involves excluding or setting aside our assumptions, biases and habitual ways of seeing the world with the aim of connecting directly and immediately with the world as we experience it. When our taken-for-granted assumptions are reined in or temporarily

suspended, we are able to see the world anew and immerse ourselves in the immanent experience in order to discover the actual essence of that experience (Finlay, 2011).

Heidegger was trained in the philosophy of phenomenology by Husserl but later chose to disassociate himself from his mentor and his work (Lavery, 2003), asserting that Husserl's construction of phenomenology was a purely descriptive philosophy (Mackey, 2005). He dismisses Husserl's notion of intentionality, replacing it with his own concept of Dasein (Moran, 2000). Dasein, literally meaning there-being, is Heidegger's term for the uniquely situated quality of being human, which also implies and necessitates a degree of reflexive awareness (Smith et al., 2009). In Heidegger's view, consciousness is not separate from the world, but a formation of historically lived experience (Lavery, 2003). Heidegger believed that we are fundamentally part of a meaningful world and that the meaningful world is fundamentally part of us. Therefore, we can only be properly understood as a function of our various involvements with the world and the world can only be properly understood as a function of our involvements within it (Larkin et al., 2006). He maintained that the self and world were not two separate beings but rather belong together in one single entity. Equally he asserted that being was fundamentally linked with time, and that as time is an ever-present horizon, there is no such thing as fixed existence (Finlay, 2011). Therefore, whilst we consistently project ourselves into the future, our concept of whom we are becoming, arises from our past (Finlay, 2011).

Interpretation is seen as critical to the process of pre-understanding and Heidegger did not believe that a person could step outside this understanding as it is inherent to us in the world (Lavery, 2003), arguing that to understand something is first to have interpreted it (Finlay, 2011). All understanding is connected to a given set of fore-structures that cannot

be eliminated. Therefore, he believed that one should be as aware of this as possible and should account for the interpretive influences (Lavery, 2003). Heidegger's phenomenology also dictates that understanding through interpretation cannot be achieved unless the interpretation is grounded in a consideration of time. He considered people to be temporally situated in the world, which would allow our past, present and future to be experienced as a unity. Nursing research has shown experiences such as living with or through illness can be highly disruptive to the concept of time by making the experience stand out and disrupt the normal flow (Mackey, 2005). Heidegger maintains that we are able to cope skilfully with most situations without engaging thought until it becomes necessary when the normal order of things is disrupted or we hit a problem of some kind (Larkin et al., 2006).

Heidegger used hermeneutics in his approach to the study of human existence, meaning that interpretation takes place between implicit pre-understandings and the evolving current understandings of the interpreter and that which is being interpreted (Finlay, 2011). He described the hermeneutic circle of understanding as the process of expressing the fore-structures that situate our understandings and the back and forth movement between partial understandings and the complete whole (Mackey, 2005). The area of hermeneutics is central to IPA methodology and will be given further consideration as we progress through the chapter.

Hans-Georg Gadamer was a student in the 1920s and was influenced by the work of both Husserl and Heidegger. He later chose to extend Heidegger's work into practical application, seeing hermeneutics as the key to clarifying further the conditions in which understanding itself takes place (Lavery, 2003). He maintained that we might only really

know what our pre-conceptions are once the process of interpretation is underway. Thus, the phenomenon in question influences the interpretation, which in turn can influence the fore-structure, which can then itself influence the interpretation (Smith et al., 2009). This interpretive focus is achieved through a hermeneutic circle (Lavery, 2003). He felt that meanings could only ever be understood from the vantage point of the interpreter and that these meanings would vary between different people of different interests in their different situations (Finlay, 2011). To use the words of Gadamer (as cited by Finlay, 2011, p. 60): “The important thing is to be aware of one’s own bias, so that the text can present itself in all its otherness and thus assert its own truth against one’s own fore-meanings” (Gadamer, 1960/1996).

Maurice Merleau-Ponty (1908-1961) also shared Husserl and Heidegger’s commitment to understanding our being in the world but felt the need for a more contextualised phenomenology (Smith et al., 2009). Arguably Husserl was Merleau-Ponty’s biggest influence and it is thought that Merleau-Ponty felt he was continuing Husserl’s project, bringing it to fruition by evoking the unconsidered element of his work (Romdenh-Romluc, 2011). He developed Husserl’s insight into the human organism as primarily an active living body rather than a passive, spatially extended machine (Moran & Mooney, 2002). His existential phenomenological view point regarded the body as the central locus of all life and knowledge (de Jonge, 2002), believing that it is the body that shapes the fundamental character of how we know the world (Moya, 2014).

Merleau-Ponty’s seminal work, ‘Phenomenology of Perception’ was published in 1945. His philosophy asserted the foundational role of perception in engaging with and understanding the world and emphasising the situated and interpretive quality of our

knowledge (Smith et al., 2009). He aimed to show that the world and consciousness are mutually dependent parts of a whole and that the nature of things is determined by our experience of them (Romdenh-Romluc, 2011). His philosophical position saw habit as a presupposed form of understanding that the body has of the world in which it carries out its projects (Moya, 2014). The set of skills or habits learnt in the past become taken-for-granted actions, orientating the body in the world without intrusion into conscious thought (Moran & Mooney, 2002). Thus, our practical understanding of our environment as requiring certain actions and the awareness of our body as having the power to perform them, provides a practical form of self-knowledge in terms of our behaviours (Romdenh-Romluc, 2011).

Merleau-Ponty maintained that it is through the body that we gain access to the world and through consciousness of our embodiment that we are aware of being in the world (Munhill, 1989). He emphasised the distinction between the subjective body as it is lived and experienced pre-reflectively and the objective body as observed and that can no longer be taken-for-granted, such as in the case of illness (Finlay, 2011). For Merleau-Ponty, it is the habitual character of the body which brings out the temporal nature of our being. Just as past experience is at the disposal of the present habitual body, the present is understood in projective, futuristic terms (Moran & Mooney, 2002). This experience of existing within subjective time occurs necessarily through the conscious intentionality of activity. Since Merleau-Ponty's fundamental form of consciousness is to be engaged in activity and the activity of consciousness is undertaken within the world, it follows that time comes into being through the shared interaction of consciousness and the world (Romdenh-Romluc, 2011).

Jean-Paul Sartre (1905-1980) was another leading figure in phenomenology. Widely considered to be the father of existentialism, he arguably became one of the most well-known phenomenological philosophers (Moran & Mooney, 2002). He wrote and published extensively, but his thesis 'Being and Nothingness' was considered his greatest work and became the textbook of existentialism itself (Warnock, 2003). He developed phenomenology in a way that emphasised the lifeworld, similar to Heidegger and Merleau-Ponty (Ashworth, 2008). However, Sartre did not believe in the idea of the self as a pre-existing entity, but rather as an ongoing project to be unfurled, maintaining that we are always becoming ourselves (Smith et al., 2009). Thus, the central concern of his descriptive phenomenology was human freedom and responsibility (Moran & Mooney, 2002).

Sartre described being human as a 'being-for-itself' (Sartre, 2003, p. 97), meaning a being who is conscious of subjective meanings but who has no essence or essential characteristics (Finlay, 2011). The being-for-itself then, has a free existence and must constantly choose to accept or reject its current situation (Moran & Mooney, 2002). Sartre felt that in order to behave authentically, people must realise that they can make and remake themselves by their actions, and thus can become what their actions define them as being (Eyre, 2002). For Sartre, human nature is more about becoming than being. He believed that people not only have the freedom to choose, but are responsible for their own actions (Smith et al., 2009). He also believed that many people operate in a state of self-deception that he termed 'bad faith' (Sartre, 2003, p. 70), refusing to either accept or reject particular situations. He felt that this bad faith was enacted as a lie to oneself, of which one is implicitly and pre-reflexively aware (Moran & Mooney, 2002). This, he felt, was a refusal to take responsibility for one's choices, and to choose instead to accept and conform to the social attributions of others (Finlay, 2011).

Sartre maintained that the world, as we perceive it, is largely shaped by the presence of others (Smith et al., 2009), and introduced the notion of being-for-others as a mode of existence essential to our being in the world (Warnock, 2003). He also described the concept of ‘the look’ (Sartre, 2003, p. 276), reflecting the change in internal feelings that occurs under the gaze of another (Warnock, 2003). Sartre maintained that self-consciousness and emotions, such as shame, can only become apparent on being made aware of being the object of the gaze of another, as these only make sense in an interpersonal context. His philosophy developed the context of interactions and relationships, conceiving experiences as contingent on the presence, or absence of our relationships (Smith et al., 2009).

The phenomenology of Husserl and the hermeneutic phenomenology of Heidegger and Gadamer share many similar components, such as a common interest in lived experience and the rejection of Cartesian dualism. However, they differ in their epistemological, ontological and methodological positions (Lavery, 2003). Those using Husserl’s philosophy seek to understand the world and the objects within it, whereas Heidegger seeks to understand the meaning of Being using hermeneutics (Mackey, 2006). Given my interpretivist position and constructionist epistemology, it is clear that the more descriptive phenomenological methodologies stemming from Husserl’s philosophy would not be suitable for use in this research. Heidegger and Gadamer’s interpretivist framework of inquiry supports the belief that there are multiple realities that are local, constructed and can be altered by the knower (Lavery, 2003), which fits both within IPA methodology and my own belief system. Heidegger, Merleau-Ponty and Sartre each explore and support the view of people as embedded within a culturally situated world of language, relationships, culture and concerns (Smith et al., 2009) and therefore, were viewed as highly relevant to this research.

The work of some more contemporary phenomenologists also influenced this thesis as their publications helped to both situate the work of the seminal phenomenologists noted above, and to situate the findings of this research:

Peter Ashworth uses a lifeworld approach to his phenomenological psychology. Ashworth credits Merleau-Ponty, Amedeo Giorgi and Max van Manen as the influences behind his approach, which focused on the pervasive importance of the 'lifeworld' from an existential perspective. Over 30 years he developed a series of seven 'fractions' or parameters with which to explore and gain a deeper understanding of the experience which a person has of some event or feature of their lived world (Ashworth, 2003; Finlay, 2011). These fractions are discussed more fully in chapter five.

David Seamon also adopted a lifeworld approach (Finlay, 2011) which focused on the spatial aspect of phenomenology. His book 'A geography of the lifeworld: movement, rest and encounter', concentrates on the essential nature of spatial behaviour and the relationships between community and space. He maintained that a satisfying human existence involves links with the locality in which a person lives. From his phenomenological perspective he explores the senses of 'at-homeness' and 'alienation', surmising that these may have roots in the rupture between people and place. He credits the work of Heidegger and Merleau-Ponty as major influences on his thesis (Seamon, 1979).

Matthew Ratcliffe centres his work on the phenomenology of existential feelings and has published many articles and books in this area, including: *Feelings of Being*:

phenomenology, psychiatry and the sense of reality (2008), The phenomenology of depression and the nature of empathy (2014) and Real hallucinations: psychiatric illness, intentionality, and the interpersonal world (2017). He maintains that existential feelings are ‘feelings of the body’ and ‘ways of finding oneself in the world’ (Ratcliffe, 2008, p. 2). His work explores the nature of human experience, combining phenomenology with psychiatry and emotion theory. He draws selectively on Husserl, Heidegger and Merleau-Ponty within his work and specifically builds on Heidegger’s account of mood as an existential orientation (Ratcliffe, 2008). Ratcliffe’s work is referenced and explored further throughout chapter five.

Finally, Havi Carel, is a professor in philosophy whose phenomenological focus explores the experience of illness and of receiving health care. Carel is both a philosopher and a receiver of health care following diagnosis with lymphangioleiomyomatosis (LAM), a terminal condition of the lung. Again, influenced by the classic texts of Husserl, Heidegger and Merleau-Ponty, alongside the more recent works of Ratcliffe and the experiences and various publications of Kay Toombs (1990, 1995, 1997, 2001, 2004a, 2004b), she claims that a philosophical analysis of illness as a human experience is essential to its full understanding. She too has multiple publications and books to her name, the most recent of which, Phenomenology of illness (2016), has influenced this research.

3.7.2. Hermeneutics

The term hermeneutics originates from the science of biblical interpretation in the seventeenth century (Crotty, 2013). Later it developed as a philosophical underpinning for the interpretation of an increasingly wider range of texts such as historical documents

and literary works. Hermeneutics, simply put, is the philosophy of interpretation and is one of the central philosophies of IPA (Smith et al., 2009). The philosophy of hermeneutics recognises that all understanding is historically conditioned and originates from a point of view. As such, in every act of understanding, we presuppose a large amount and take on trust our own prejudices and presumptions (Moran, 2000). As we have seen, both Heidegger and Gadamer were concerned with hermeneutics and embedded it into their philosophies. IPA recognises the central role of the analyst in understanding the experiences of participants. It involves a two-stage interpretation process whereby the researcher attempts to interpret how the participants make sense of their experience (Pringle et al., 2011). This fits with both the contextual constructionist epistemological and critical realist ontological positions of the current research. It also fits well with my axiological position as previously discussed in Section 3.1.

In aligning this research to IPA, I accept that there is no neutral standpoint from which these phenomena can be investigated. Therefore, the researcher's position, understanding and prejudices must all be acknowledged from the outset and remain visible in order to create a transparent account. By adhering to this, it is possible to reflect on the researcher's role in producing any interpretations of the data and in attempting to ground all claims in the participant's claims and concerns (Moran, 2000). This is achieved by keeping a reflexive diary throughout the research process to monitor my own thoughts, feelings and pre-conceptions as these continue to change and develop throughout the process.

3.7.3. Idiography

Idiography is the third major influence on IPA. The idiographic approach focuses on the interplay of factors that may be quite specific to the individual (Ashworth, 2008). Idiographic research is generally used in the human and social sciences and can be seen as an individualising method. This is directly opposed to nomothetic methods, which are generalisable and tend to be used in the natural sciences (Crotty, 2013). It is concerned with the particular (Smith et al., 2009), which in this instance, is the particular experience of being diagnosed with and treated for active Charcot foot.

Concentration on the particular in IPA research occurs in two ways. Firstly, attention is focused on the particular sense of detail given in each participant's account, which should be adequately reflected in the depth of the analysis. Secondly, IPA focuses on understanding how particular experiences have been understood from the perspective of particular people in a particular context (Smith et al., 2009). On a methodological level, this means that IPA studies typically involve a highly intensive and detailed analysis of the accounts produced by a comparatively small number of participants (Larkin et al., 2006) which is preferable to a broader, shallower or simply descriptive analysis that may be seen in other methodologies (Hefferon & Gil-Rodriguez, 2011).

3.8. Limitations of IPA

Whilst IPA was identified as the most appropriate methodology for this research, attention should also be drawn to the limitations of this approach. IPA necessarily requires a small, homogeneous sample in keeping with its idiographic commitments. This could be criticised by those from more scientific or positivist epistemological

backgrounds as rendering the research incapable of generalisation to wider populations. However, Smith et al. (2009) argue that small sample sizes allow for a richer depth of analysis that may be precluded by larger samples. Whilst the findings of IPA studies explain uniquely embodied and situated perspectives, the experience of Dasein is understood as an 'in-relation-to phenomenon' (Smith et al., 2009, p. 29). Provided that the analyst has given a rich, transparent and contextualised account of the data, the reader should be able to consider the findings in terms of their theoretical transferability rather than generalisability.

In IPA research, the findings are, by their very nature, the interpretations of the researcher, which may give rise to doubts about their significance (Pringle et al., 2011). However, whilst Smith et al. (2009) encourage the researcher to go beyond what is immediately apparent during the analysis of the data, they also stress the importance of firmly grounding all claims in the participants' accounts. Pringle et al. (2011) also suggest that the use of quotations and metaphors could be encouraged in order to root the analysis directly in the participants' words.

Willig (2008) argues that, as the most commonly used data collection technique in IPA research is interviews, it must be assumed that language provides participants with the necessary tools to adequately capture their experiences. She questions how successfully participants are able to express the rich texture of their experiences or communicate the subtleties and nuances of their physical and emotional experiences. Interviews also allow the interviewer to engage with participants and to modify questions in the light of participants' responses, extending enquiries into interesting areas (Smith et al., 2009). The extent to which the researcher may be able to draw out more detail from the

participants may therefore depend on the researcher's experience. Often described as 'a conversation with a purpose' (Smith et al., 2009, p. 57), interviewing may appear simple but can be deceptively difficult (Smith et al., 2009). In this study, video recorded practice sessions were held to hone my interview skills, followed by a pilot interview prior to data collection.

Photo elicitation was also used as a method of exploring feelings and experiences that may have been difficult to talk about. It has been postulated that photo elicitation may help a participant to communicate a feeling or experience which they find difficult to articulate verbally by providing a concrete item that can be used to generate discussion (Sandhu, Ives, Birchwood, & Upthegrove, 2013). Transcriptions of the interview data also recorded non-verbal utterances such as laughter, pauses and hesitations so that these too could aid the interpretation (Smith et al., 2009), and could be used to help ask critical questions during analysis regarding both what was said and what was not said (Smith & Osborn, 2008).

Willig (2008) also questions the role of cognition in phenomenology, as phenomenologists are concerned with non-propositional knowledge, the objective of which is to capture the way the world presents itself in an immediate sense including ideas on the margins of consciousness. Willig (2008) feels that Smith's method implies a Cartesian mind/body divide, although Brocki and Wearden (2006) assert that some definitions of phenomenology include more cognitive elements. Willig (2008) also highlighted concern that IPA was unable to provide causal explanations for phenomena. However, this is often not the goal of qualitative research and was not the goal of this

research, which aimed to explore participants' experiences of active Charcot foot and its management.

3.9. Comparison of alternative methodologies

In the course of planning for this research several possible methodologies were considered alongside IPA. Grounded theory was one of these and is often considered to be one of the main alternatives for anyone considering IPA (Smith et al., 2009). Originally developed by sociologists Glaser and Strauss (1967) as a methodology which would allow new theories to emerge (Willig, 2008), grounded theory has its origins in symbolic interactionism (Starks & Brown Trinidad, 2007). Symbolic interactionism understands social reality as a complex network of interactions within a social world. It focuses on the functional relationships between how we see ourselves, how we see others and how we believe others see us. It is generally applied to role behaviour and perception studies (Van Manen, 2007).

Grounded theory is explicitly aimed towards developing theory, through the systematic and theoretical analysis of data, that both fits the data and has relevance to the area of study (Charmaz, 2008). It comprises both a method (constant comparative analysis, theoretical sampling and theoretical coding) and a product (the generation of theory grounded in the data) (Willig, 2008). Grounded theory is a well-established methodology with several available approaches. The most widely used of these approaches is based in constructivism (Smith et al., 2009). Grounded theory relies on theoretical sampling of participants with differing experiences to explore multiple dimensions of social processes until they reach theoretical saturation (Starks & Brown Trinidad, 2007).

The aims of this research were felt to be better suited to an IPA study. Whereas grounded theory studies seek to attain a more conceptual, explanatory level of analysis using a large number of participants, IPA studies focus on micro analysis of individual experience, featuring the nuances and textures of a phenomenon (Smith et al., 2009). The target audience for each may also differ slightly, between practitioners searching to understand the lived experiences of a given phenomenon more suited to a phenomenological approach and those seeking more explanatory models by which to design interventions more suited to grounded theory (Starks & Brown Trinidad, 2007). Ultimately the aims of this study were concerned with lived experience in order to gain a rich and detailed exploratory insight into this under researched group, rather than exploring their social processes and interactions in order to generate theory.

Discourse analysis was also considered. Discourse analysis is concerned with language in use and has a strong commitment to social constructionism (Smith et al., 2009), denying that our knowledge is a direct perception of reality (Burr, 2003). Those utilising this methodology believe that meaning is created through mutually agreed use of language (Starks & Brown Trinidad, 2007). The potential use of discourse analysis was considered from two popular perspectives, that of discursive psychology and that of Foucauldian discourse analysis. Discursive psychology explores how reality is produced, made relevant and dealt with by participants through interaction, rather than how accurately participants' speech reflects inner and outer events (Hepburn & Wiggins, 2005). It does not aim to produce knowledge about the nature of phenomena, but rather the processes by which they are 'talked into being' (Willig, 2008, p. 108). This perspective was felt not to be conducive to the purpose of the research because the aim was to understand patient experiences rather than to explore their use of language. Equally, the methodology was

felt not to be agreeable with my more contextualist, constructionist, epistemological position.

In contrast to discursive psychology, Foucauldian discourse analysis questions the relationships between discourse and how people think or feel, what they do and the conditions within which their experiences occur (Willig, 2008). Foucault's philosophy was also centrally concerned with the relationships between discourse, knowledge and power, seeing power as an effect of discourse and the knowledge generated, as enabling actions to be viewed in an acceptable light (Burr, 2003). Whilst IPA does recognise that reality is both constrained by and also contingent on one's cultural language, it subscribes to a more expressivist ontology which maintains that people are able to disclose their existential world through language (Eatough & Smith, 2017). This perspective may therefore be more suited to research which aims to understand how framing language can help to achieve desired clinical outcomes or health behaviours (Starks & Brown Trinidad, 2007) rather than about patient experience. However, with IPA and its commitment to hermeneutics, idiography and context, participants as individuals and the meanings of their specific experiences are the focus (Smith et al., 2009). This allowed the research to concentrate on the participants themselves and the issues that were important to them rather than on a broader social context, which again was a better fit with the overall aims and objectives.

Narrative inquiry was also considered, as it too is concerned with meaning making and therefore has similar aims to IPA (Smith et al., 2009). The narrative research tradition cannot be attributed to one single figure and therefore, appears to hail from widely differing territories (Hurwitz, Greenhalgh, & Skultans, 2004; Bruner, Sarbin, &

Polkinghorne, 2011). It is said to draw on scholarship and methodology from anthropology, literary theory and history (Bruner et al., 2011). It is also suggested that it draws on aspects of several other methodological approaches, as Josselson (2011) explains: narrative tries to see the world from the view point of the narrator (similar to phenomenology), it creates meaning and considers the social and identity performance of the narration by exploring its structure (like discourse analysis) and it organises data through line by line analysis into primary and secondary themes (as does grounded theory). However, this lack of clarity regarding epistemological influence, single heritage and methodology has led to criticism (Redwood, 1999).

Whilst it shares indistinct borders with other qualitative methodologies, narrative inquiry is distinguished by a focus on narrated texts that represent a life story, or specific aspects of it (Josselson, 2011). According to narrative theory, its primary function is to bring order to what is disorganised and to give it meaning through the telling of the story. It is said that, through these narratives, people can begin to define themselves and bring structure to their very sense of selfhood (Murray, 2008). Narrative inquiry adopts the premise that people understand their lives in storied forms, connecting events with a beginning, a middle and an end. It is recognised that these stories are culturally situated and take place within the context of other intersecting stories (Josselson, 2011).

Although a narrative approach does prioritise the participants' view point and is at least partially grounded in hermeneutics and phenomenology, therefore recognising the co-creation of knowledge between participant and researcher, it was not felt to be right for this study. The participants were only at the very beginning of their story with Charcot foot, having acute, active disease and a recent diagnosis, and therefore may not have been

able to make sense of their situation at that point in time. Also, as a novice researcher, it was felt that a firm grounding in philosophy and epistemology, and a rigorous method, would be more advantageous at the current stage of my research career. Therefore, IPA was felt to be better suited to this piece of research.

3.10. Ethics and governance

This next section explores the ethical issues considered prior to the commencement of the current research.

3.10.1. Ethical approval

The research was reviewed and approved by two separate ethics committees using the IRAS system. Initially, University of Brighton Faculty Research and Ethics Committee approval was gained (Appendix 1) and subsequently approval from the Research London - Camden and Islington Research Ethics Committee (13/LO/1314) (Appendix 2). Site-specific permission was also sought and obtained from the hospital where the research took place (Appendix 3).

3.10.2. Patient public involvement

Patient public involvement (PPI) was undertaken prior to ethical approval for guidance with the project planning. PPI is defined as the active involvement of patients or members of the public acting as specialist advisers, based on their experience of a health condition (INVOLVE, 2009). The public have been involved in research and development for a number of years and in a variety of different ways, such as identifying and prioritising research topics, being part of research advisory and steering groups, undertaking research projects and reporting and communicating research findings (INVOLVE, 2009). Their

perspectives and expertise can help to add important value and quality to the research (Simson, 2010). Whilst they can be recruited for this role via the NHS they are not acting in the same way as research participants and therefore do not require ethical clearance to take part (INVOLVE, 2009). It is recommended by the Department of Health (2005) that ‘relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research’ (p. 8). If this process in research is carried out to a high standard, it is more likely to result in ethical research (Hanley et al., 2004).

The people who choose to get involved in research and development and do not have other, professional roles (such as doctors, nurses, researchers and social workers) have a distinct, complementary role to play in the research process (Hanley et al., 2004). The term, involvement in research, implies an active partnership of public and researchers in the research process rather than the use of people as the subjects of research (Simson, 2010). PPI in research can then be described as research that is done with or by the public, and not to, about, or for them (Hanley et al., 2004). Williamson (1995) suggests that those involved in PPI can be split into two groups, overt consumers who become involved because they are motivated by personal experience or health issues, and covert consumers who have particular skills that they can bring to the role. The PPI group involved in this research was named the ‘discovery group’ and consisted of four overt consumers/participants who had experienced and received treatment for active Charcot foot in the past. Each member had a diagnosis of chronic or inactive Charcot foot and still received management of the complications of subsequent deformity and regular monitoring through the foot clinic from which participants were to be recruited. People who have chronic (inactive) Charcot foot were deliberately chosen to form the discovery

group. It was felt that, having experienced Charcot foot at all stages, they would have an in-depth understanding of how the diagnosis and treatment had impacted their lives.

Robinson et al. (2012) suggest that there are four levels of PPI, which each offer a varying degree of involvement in the research process: public ignored, public acknowledged, public advised and public engaged. This study fits into the public acknowledged category. This represents a collaborative approach to the research but may not give PPI participants a great deal of power over the project by virtue of its top-down approach. This is because the research concept and design were professionally led and the perspectives of the discovery group were sought at a later stage. That said, the positive impact of PPI involvement within the research process has been shown in many areas, and can help to improve matters relating to the design and execution of the study, the relevance of the participation forms, the suitability of language used and the quality of informed consent (Wyatt et al., 2008).

For this study, each member of the discovery group was given a formal invitation (Appendix 4) and time to consider whether to take part. They were then issued with an algorithm depicting the planned course of the study (Appendix 5) and a selection of paperwork to review before the meeting. A patient participant information sheet (Appendix 8), the proposed photography guidance sheet (Appendix 9), two consent forms; the initial consent form and photography consent form (Appendix 10 and 11), the proposed interview schedule (Appendix 12) and the demographic data collection sheet (Appendix 13) were issued for review. The group were invited to comment on the protocol and all of the paperwork via a group discussion in order to ensure that the project focused on issues that were of genuine importance to the patients and that all literature

was easily understandable. The discussion was also used to give the semi-structured interview schedule a stronger patient centred focus. The group session was recorded and transcribed verbatim with the permission of all parties involved.

All parties agreed that they thought the research was of value and saw no problems with the research design. The participant information sheet was felt to be very long but able to be understood and was all deemed to be necessary. It was agreed that this would always be talked through with the potential participant in order that they should fully understand the research and what is being asked of them. Regarding the location of the research at King's College Hospital, all parties agreed that this was the ideal place for convenience of transport and privacy although it should be kept completely separate from the diabetic foot clinic to improve confidentiality and to allow participants to feel more comfortable. The use of photographs prompted lots of discussion. It was agreed that this was a good idea and that this method would put the focus back on to the participant but initially the concept and the guidance sheet were felt to be confusing.

As a result of the PPI session the following changes were made to this study:

- The photo prompt sheet was altered to include examples and to make the instructions clearer.
- One question regarding the experience of being treated at the Diabetic Foot Clinic at King's College Hospital was removed from the interview schedule as it may make patients feel uncomfortable.
- The order of questions was also changed in order to improve the flow and allow the participants to talk with confidence, firstly to questions about their

understanding of Charcot foot and their own journey to diagnosis and finishing with the section about their photographs where it is hoped that they will undertake the vast majority of the talking.

- The second (photography) consent form was simplified and changed to make it clearer as it was felt to be a little confusing.

3.10.3. Role of the researcher

One of the main ethical issues when designing this research project was how to ethically and rigorously balance my dual roles as practitioner and researcher. My concern here was to try to readjust the possible patient/participant and practitioner/researcher power imbalance. Additionally, I needed to consider how to cope with any confusion that may have been brought about by patients talking to me in a researcher role and subsequently seeing me as a clinician again. In order to approach the issue as ethically as possible I collaborated both with my supervisors and PPI group as detailed in Section 3.10.2.

All parties in the PPI were strongly in favour of having a practitioner as interviewer. They felt that a prior understanding of Charcot foot and its treatment were important to building trust and would allow open conversation about its impact, circumventing the need for the participants to describe and explain the illness.

During the planning stages, I recognised that patients might feel pressured to take part in the study, possibly fearing refusal would impact on their clinical treatment. Therefore, I aimed to combat the risk of coercion and power imbalance when recruiting through the use of posters in the waiting room for participants to self-select into the study. The

clinical team were also asked to provide the initial approach to any patients suitable for inclusion and to provide them with an information sheet. The information clearly stated that any decision not to take part would not affect their future treatment and that they were free to withdraw at any time without consequence. I only contacted potential participants who had shown interest at a later date, using their preferred method of communication (telephone, email, face-to-face). If patients did not want to take part, a note was made in their clinical file in order to avoid multiple approaches being made and this was not followed up again.

As the potential participants were those in the active stage of Charcot foot disease they were newer to the clinic and therefore firm practitioner/patient relationships were not anticipated. The practitioner role was also part time (two days per week) within a team of six podiatrists. It was agreed that I would not treat the participant in clinic for the two visits after the interview and that this could be extended should patients not wish to be treated by me thereafter. This would cause no inconvenience to either participants or practitioners in the current clinical set-up and it was hoped that it would help to reduce the risk of discomfort to the participants given my changing role.

3.10.4. Informed consent

Informed consent for this study was given in two parts. The initial consent form (Appendix 10) ensured that participants had received the information sheet and had time to consider whether to take part. It assured participants that confidentiality practices would be observed, their anonymity would be protected at all times and they were free to withdraw at any time. The second consent form (Appendix 11) concerned how the images presented as part of the photo elicitation aspect of the interview (explained in Section

3.13.3) may be stored or used after the interview. This gave participants continued control over their images.

Two patients brought in hard copies of photographs that they gave me immediately following the interview. Four participants provided electronic copies of images after or during the interview. One participant provided electronic images to discuss but declined to send them to me. One participant looked at his photographs alone at home and discussed what he had looked at but did not bring them with him to interview. All participants who allowed me to have copies of their images consented to them being used for this thesis, future publications and presentations.

3.10.5. Confidentiality

The need to preserve the dignity and confidentiality of all the participants was paramount and remains an essential criterion when considering their human rights. Confidentiality and anonymity were assured on the participant information sheet (Appendix 8). Potential risk of confidentiality breach was kept to a minimum through the use of patient coding and pseudonyms. These were allocated prior to sharing transcripts with supervisors. The only exception was the consent forms, which were kept locked in a cabinet separately from the transcripts. All data will be kept for five years after study completion for audit trail purposes as suggested by Yardley (2008).

Interviews were held in a private room away from the clinic where the conversation could not be overheard. Other clinical staff were not informed of the names of participants who

consented to take part in this research. I adhered to the confidentiality codes of practice of both King's College Hospital and the University of Brighton.

3.11. Risk assessment

There were felt to be few risks associated with the completion of this research. Those that were identified are explored below.

3.11.1. Distress

The biggest risk to the participants in this research was felt to be that of distress caused by the interview. The topic was potentially very sensitive and the participants may never have had an opportunity to speak about this previously. In all interviews it was made clear that the participant could stop the conversation at any time should they start to feel uncomfortable. All participants were informed of how to access follow on support after the interview. None of the participants became distressed within the interview and none of the interviews were terminated early. One participant was offered referral for additional psychological support at the end of the interview. However, this was declined.

Another potential risk identified was researcher distress caused by interviews and immersion in potentially sensitive and emotive data. To combat this, a reflexive journal was kept and regular supervisory meetings scheduled. Emotional support was available from both the NHS and the University of Brighton. This was never needed, although the support of the researcher's supervisors via telephone was required after one of the interviews due to concerns for patient safety with regard to his diabetes and increased frequency of hypoglycaemic episodes. As support had been offered to the participant and

was declined, and because the participant reported that he had already booked a GP appointment to address this issue, no further action was taken.

3.11.2. Hypoglycaemia

There was a risk of hypoglycaemic episode during the interviews given the background of diabetes in the patient sample. To avoid this scenario, interviews were not booked at lunchtime to allow participants to eat prior to the meeting. A blood glucose monitor, Lucozade and biscuits were also available in line with the protocol used in the clinical setting. Refreshments were also offered to participants on completion of interviews. None of the patients experienced hypoglycaemia during the course of an interview.

3.12. Operational considerations

Attention is now given to the logistical areas that required consideration prior to data collection.

3.12.1. Research population

The research population for this study was obtained from a cohort of patients being treated for active Charcot foot at a diabetic foot clinic at a London hospital, which is part of the National Health Service (NHS). The decision was made to recruit from only one centre, in keeping with IPA's idiographic commitment (Smith et al., 2009). IPA uses a thorough, purposive sample to obtain a homogeneous group of participants (Smith & Osborne, 2008). It is not claimed that the findings of this research will be generalizable due to this specificity in the sampling and the specialist nature of the clinic but it is felt that there will be theoretical transferability of the findings (Smith et al., 2009). It is anticipated that sufficient detail is given throughout the thesis that the reader will be able

to make links with their own personal and professional experience to assess the transferability into other settings.

3.12.2. Setting

The hospital based diabetic foot clinic was primarily identified as the most appropriate setting for this research due to its specialist nature. Charcot foot is rare, affecting less than 1% of the overall diabetes population (Frykberg & Belczyk, 2008). NICE (2015) guidelines state that those suspected to be suffering from active Charcot foot should be referred straight to a multidisciplinary foot care service. The hospital is a tertiary referral centre for complex foot pathology in people with diabetes, with a large multidisciplinary team. This results in a higher than average number of patients with Charcot foot being treated at the clinic and therefore available in the potential participant pool. My position as a practitioner at the clinic also meant that I had ready access to this pool. Ethical consideration was given to my dual role as practitioner and researcher prior to commencing this research as discussed in Section 3.10.3.

3.12.3. Sample and participants

In qualitative research, the type of sampling employed is determined by the chosen methodology and area under investigation rather than the need to create generalisable findings (Higginbottom, 2004). IPA's emphasis on idiography necessarily privileges the accounts of the individual, offering a different perspective from other approaches (Pringle et al., 2011). Given the complexity of most human phenomena, IPA recommends the use of a small sample size to allow a more concentrated focus on detailed accounts of individual experience (Smith et al., 2009). Ideal sample size should be considered on a study-by-study basis, although the general adage 'less is more' is often promoted

(Hefferon & Gil-Rodriguez, 2011, p. 758). Whilst there is no right answer to the question of sample size in IPA, Smith et al. (2009) suggest between four and ten interviews for professional doctoral studies but make no recommendations for PhD as this depends on the research question and quality of the data gathered. As a starting point for this research, the aim was to recruit approximately eight to ten participants for interview. Given the extent and richness of the data, recruitment stopped at eight following advice from the examiners at the transfer viva and discussions with supervisors.

Inclusion criteria primarily comprised any patient between eighteen and ninety years of age with a diagnosis of either type 1 or type 2 diabetes mellitus and active Charcot foot. It is currently unclear whether the precipitating factors of Charcot foot impact patient experience. Therefore, only people with diabetes were included as this is the most common aetiology (Wukich & Sung, 2009). For the purpose of this research, suitable patients with active Charcot foot were defined as those receiving treatment via offloading for Eichenholtz stages 0-2 (Sanders, 2010) (Section 2.8). Participants had to be receiving management through offloading, as this is currently the only management proven to be effective (NICE, 2015), as discussed in Section 2.10. Offloading was not restricted to TCC. However, since this is the gold standard treatment (NICE, 2015), all participants were receiving this form of management. Participants were required to have had their diagnosis for at least 2 months prior to interview, giving them time to digest their diagnosis and commence management. It was felt to be unethical to approach people immediately after they had received their diagnosis. The research question also explored what it was like to live with active Charcot foot. Therefore, it was felt that they needed to have had sufficient time prior to interview to experience life with the condition. To qualify for inclusion, management needed to be at the foot clinic where the research was being undertaken, in keeping with the requirement for a thorough, purposive sample of a

homogeneous group of participants (Smith & Osborne, 2008) and for easier access to the potential participant pool. Due to the qualitative nature of the study and need to understand the participant information sheet, participants were required to have good use of the English language and be able to give informed consent for themselves. Potential participants were excluded if they had a history of, or current DFU that required treatment with a TCC as it was believed that this might influence patients' perceptions of their present lived experience.

Eleven people in total were approached and issued with participant information sheets. Two patients initially accepted but declined prior to giving formal consent without giving a reason. One participant was interested but received a cancer diagnosis soon after approach and the added burden of interview was then considered too great. Eight interviews were carried out. The sample consisted of six males and two females; two with type 1 and six with type 2 diabetes. The mean age was 59 years (range 46 to 73) and the mean duration of diabetes was 16 years (range 5 to 34). Time from symptom onset to diagnosis ranged from three days to six months. Duration of casting therapy prior to the interviews ranged from three to seven months.

3.12.4. Recruitment

The participants were recruited in two ways. Firstly, posters were placed in the clinical waiting room to allow potential participants to self-select (Appendix 6). Secondly, clinicians working in the diabetic foot clinic at the hospital helped to identify potential participants from amongst those they treated during the day in clinic. Those identified as suitable were given or posted an invitation letter (Appendix 7) and an information sheet (Appendix 8) and their preferred contact details collected for the chief investigator (the

researcher) to contact them. If willing to proceed, the photography guidance sheet (Appendix 9) was issued and the offer made for provision of a disposable camera (all patients declined this offer preferring to use digital photography or pre-existing images). Any outstanding questions were answered and a date was arranged for the interview.

3.13. Justification of method

There is a wide range of available data collection techniques that generate different types of data. Whilst strictly speaking there are no right or wrong methods of data collection, there are more or less appropriate ways of collecting data to answer a research question (Willig, 2008). The method of data collection for this research was semi-structured interviews using photo elicitation. The following sections provide justification for these methods.

3.13.1. Use of semi-structured interviews

This study was undertaken from a phenomenological standpoint with the aim of elucidating our current understanding of what it means to live with a Charcot foot. It has been suggested that, in order to reflect phenomenological philosophy, instead of gathering data, its collection should be considered in terms of data generation, where meanings emerge through co-creation (Finlay, 2011). IPA data generation is then best suited to a method that invites participants to offer a rich, detailed, first person account of their experiences (Smith et al., 2009), as the aim is to know how an individual experienced something emotionally, cognitively, bodily and within the experience of their life (Finlay, 2011). Due to IPA's idiographic commitment (Smith et al., 2009), interviews were identified as the most suitable method.

Interviews may be classed as structured, semi-structured or unstructured (Smith & Osborn, 2008). Structured interviews are generally designed to be answered in terms of predetermined categories, suitable for numerical analysis, and are therefore non-compatible with the philosophy of IPA research (Smith & Osborn, 2008). Unstructured interviews can sometimes be used to capitalise on IPA's ability to explore unanticipated and unexpected findings with the use of one single core question. However, this approach is not recommended for novice researchers (Smith et al., 2009).

Most IPA interviews are semi-structured, in which questions asked by the interviewer function as triggers that encourage the interviewee to talk (Willig, 2008). Interview questions are generally described as open-ended and non-directive (Brocki & Wearden, 2006). However, it should be remembered that the researcher's interview questions can drive the interview (Willig, 2008). It is generally assumed that a good interview will predominantly be led by participant concerns and that these issues will be followed up by the researcher (Smith et al., 2009). An interview schedule should be designed and used to guide rather than dictate the course of the interview (Smith & Osborn, 2008). This may be especially helpful to the novice researcher (Smith et al., 2009).

The combination of photo elicitation and semi-structured interviews was decided upon to ensure that all claims made by the research were grounded firmly in the patient experience rather than formulated from the practitioner perspective. This was achieved by asking the participants to bring in three to five photographs that represented their experience of being diagnosed and living with Charcot foot. They were given time to reflect on which images to bring, with the aim of enhancing the interview content by encouraging participant reflection prior to the interview on the experience of being

diagnosed with active Charcot foot. The interview schedule consisted of open questions, placing the participants in control of the issues that would be prioritised and discussed during the session (Appendix 12).

3.13.2. The interview schedule

Guidance provided by Smith et al. (2009) and the PPI group was used to help inform the semi-structured interview schedule (Appendix 12). It was designed to facilitate a comfortable interaction with the participant to allow them to talk at length and provide a detailed account of their experiences of living with active Charcot foot. As recommended by Smith et al. (2009), the interviews began with what were felt to be relatively simple questions such as: What do you understand about Charcot foot? Such questions allowed the participant to recount descriptive details such as their journey to diagnosis. The later questions that introduced the meanings of the photographs were very open, and follow up questions were iterative, purely leading on from the topics that the participant wished to discuss.

3.13.3. Photo elicitation

Photographic and visual research methods have been used for a long time in the social sciences and are increasingly used in health research (Affleck, Glass, & McDonald, 2012). Visual research focuses on what can be seen. How humans 'see', like other sensory modes, is mediated by physiology, culture and history (Prosser, 2011), a position that fits well both with the researcher's theoretical and philosophical positions regarding the nature of knowledge and with the philosophies of IPA itself. It is an inductive research approach that provides a unique way for the participants to communicate dimensions of their lives (Clark-Ibáñez, 2004). Visual research is not about an image or

object in itself but is concerned with the perception and the meanings attributed to them (Prosser, 2011). Likewise, the use of photographs is not designed to represent empirical truths or 'reality'. They are there simply for researchers to use as a tool to expand on questions and simultaneously to provide a unique way for the participants to communicate dimensions of their lives (Clark-Ibáñez, 2004).

Photo elicitation is one such visual method and is based on the simple principle of inserting a photograph into a research interview (Harper, 2002), during which the participant interprets and explains the meaning behind the image (Close, 2007). Photo elicitation is still a relatively novel approach to qualitative data collection and involves asking participants to take photographs to record their real life experiences (Sandhu et al., 2013). Photographs can capture complex information about different emotions, events, and relationships that can be teased out during the interview. The photographs are used as a reference point during interview and can be employed to acquire rich verbal data (Frith & Harcourt, 2007). Photo-elicitation can be particularly effective in exploring feelings and experiences that are difficult to talk about, both because the photograph provides a concrete item that can be used to generate discussion and because it may help participants to communicate a feeling or experience which find difficult to articulate verbally (Sandhu et al., 2013). The use of photographs demands description, detail and explanation, which also help to reduce assumptions about shared researcher-participant understandings of specific phenomena (Olliffe & Borttorff, 2007). This is something which it is important to recognise in the analysis.

Previous studies have maintained that findings generated with photo elicitation went beyond the normal scope of those generated by regular words-alone interviews, allowing

the interviewees to reflect on related but indirect associations with the photographs themselves (Clark-Ibáñez, 2004). Close (2007) concluded that photo elicitation was a powerful tool with which to alter the dynamics between the researcher and participant in order to ensure that the research experience was both enjoyable and meaningful. Photo-based methods give the participants more control over the direction of the interview, allowing them to regulate what is seen and what is discussed, rendering them the experts and teachers (Affleck et al., 2012). Photographs can ease rapport between researcher and interviewee, as the subjective meanings of the images are the primary concern of the interview, and thus can be a powerful tool with which to simultaneously gather data and empower the participant (Clark-Ibáñez, 2004). It was hoped that, by employing this method during my interviews, the potential power differential – with myself in position as both researcher and practitioner – might be redressed by placing control in the hands of the participants. By so doing, it was hoped that a more open and insightful understanding of the experience of life with a Charcot foot would be gained.

It has also been argued that photo elicitation adds to the credibility of the data, as it ensures that participants' own views about the meaning and importance of various aspects of the data are taken seriously. It involves participants in the data collection process, as they either take or find their photographs, and also in the initial analysis when they explain during interview what the photographs mean to them (Sandhu et al., 2013). Photo elicitation is a method that inspires collaboration as two people sit down together to explore the meanings within the photographs (Harper, 2002) and to co-create knowledge. The use of a variety of methods, especially involving other qualitative data sources, is also important because it increases the robustness and rigour of the research (Affleck et al., 2012).

3.17. Data collection

3.17.1. Pilot interview

A pilot interview or study can be used to pre-test a particular research instrument such as an interview schedule and may give advance warning about areas which may cause a problem in the main research or protocol and indicate whether proposed methods or instruments are inappropriate or too complicated (Van Teijlingen & Hundley, 2001). In IPA research it is also important to learn the interview schedule by heart as it may be distracting for participants if the researcher has to frequently refer to their notes. Constantly trying to find their place in the schedule can also be a distraction for the researcher. Therefore, Smith et al. (2009) recommend conducting sufficient pilot interviews with friends or colleagues to learn the schedule.

A pilot interview with a chronic Charcot foot patient was carried out at King's College Hospital soon after ethical approval for the research had been obtained. This took place under similar conditions to the actual interviews, although it was held early one morning before the start of a clinical session that the patient was set to attend. It was a useful experience, allowing the researcher to practise using the interview schedule, which worked well. It also confirmed that the clinical area was not appropriate for interviews as there were too many distractions and it made it difficult to separate the role of researcher from that of clinician. It was also decided that interviews should not occur immediately prior to a participant's clinical appointment, as this was distracting to both participant and researcher during the pilot. The pilot interview and subsequent analysis were completed in order to enhance the researcher's interview technique and to rehearse and refine data analysis skills, in conjunction with supervisory support, thereby adding rigour to the data and method used later on.

3.17.2. Planning and carrying out the interviews

Following the pilot, it was time to commence actual data collection and consideration was given to where to hold the interviews. A suitable meeting room had been identified, but this was rarely available at the times required and room bookings had to be arranged through the hospital clinic organiser. The room changed between interviews; sometimes the larger meeting room was available and sometimes a consultation room was used. By always arriving early it was possible to adjust the room so that the experience would be the same for all participants, with interviewer and interviewee sitting at right angles to each other over the corner of a desk or table. In an attempt to induce comfortable conversation, the desk was never placed between interviewer and interviewee, but at the same time, it was necessary to have somewhere to place the two recording devices and a note pad.

It was imperative that the participants recognised the interviewer as a researcher during the interviews and not as a podiatrist in the clinic. Therefore, the interviews were strictly conducted on designated research days and smart clothes were worn rather than a clinical uniform. Occasionally participants were collected from the foot clinic, if this was their preference, but where possible they were met at the coffee shop at the entrance to the hospital. Beverages were always offered prior to the interview and food afterwards. The researcher adopted a relaxed and friendly manner during the interview, always explaining that the session would be more like a one-sided conversation, with the researcher saying very little apart from asking questions. Participants were also warned to expect what may appear to be silly or obvious questions and were told that these would be simply to clarify areas for the benefit of the tape recording. All participants signed consent forms prior to commencement of the interviews, all of which began with the completion of a

demographic data collection form (Appendix 13). The average duration of the interviews was one hour.

3.18. Transcription

On completion of the pilot interview, the audio recordings were transcribed verbatim into a Word document in the table format suggested by Smith et al. (2009). Transcriptions included all words used, including incomplete sentences, false starts, laughter and repetition of words as suggested by Willig (2008).

I did not find that the transcription process helped to immerse me in the data as I had anticipated. Instead I found that I spent a vast amount of time worrying about whether the appropriate grammar was a full stop, a comma and how to identify the pauses for example. Not being able to touch type also meant that I was not listening to whole sentences or sections of the recording at a time. I found myself listening to a few seconds at a time and frequently stopping the recording as this was the only way to ensure accuracy in the transcript. I reflected on the experience and discussed it with my supervisors, ultimately agreeing to hire a transcriber from the University of Brighton to complete the remainder of the transcriptions. On receipt of all of the transcriptions, I spent time listening to the recordings of each interview to check for accuracy and to immerse myself back into the interviews. This was repeated several times to begin with and notes were made on initial reactions to the data, prior to beginning formal data analysis.

3.19. Data analysis

The interviews were transcribed verbatim and re-read several times whilst listening to the recorded version. Listening to the recordings and simultaneously reading the written transcripts helps the researcher to become as immersed as possible in the data. Given the idiographic focus of IPA research, each transcript was initially analysed individually. Inductive, thematic analysis of each transcript was undertaken in line with the recommendations of Smith et al. (2009). The stages of this particular data analysis are briefly described below:

- Initial exploratory coding was written in the left-hand margin of the transcript with respect to three aspects of the text, Descriptive, Linguistic and Conceptual. This line-by-line review stayed very close to the written text and was colour coded in order to help make the differentiation more easily visible.
- Secondly, emergent coding was undertaken alongside the text to identify clusters of related words and extrapolate emergent themes, such as ‘sense of self’. This area is interpretive. Therefore, researcher position was considered throughout this process. Annotations regarding thoughts and feelings about the text were kept in my reflexive diary in an attempt to retain a reflexive frame of mind and to aid transparency when writing up. An example of an annotated transcript is presented in Appendix 14.
- The next stage involved re-examining the possible themes and grouping them further according to any similarities, thereby allowing identification of potential themes and sub-themes.
- These were then placed into a table linking the themes to participant quotations and page numbers and re-examined for relevance. An example is shown in Appendix 15.

- Once I had completed my initial analysis I was able to compare my findings with an analysis of the same transcript by my supervisor during a supervision session. I found that we had identified many similar areas of interest and had highlighted similar potential themes, and this served to increase my confidence and reassured me that I was approaching the data in a suitable manner.
- Each stage was then repeated for all participants and transcripts.
- In the final stage, the thematic analyses of various participants were compared to identify connections across emergent themes, to look for convergences and divergences between them and to tabulate possible themes and subthemes across the group. These themes were discussed with my supervisors through each stage of the process and refined slowly. An example of this is shown in Appendix 16.
- Master themes were then developed in relation to the thematic clusters.
- On completion of my first draft of the findings chapter, all transcripts were re-read and any areas felt to be important which had been missed were added to the relevant subthemes to ensure a full and comprehensive account was presented.
- Several versions of the findings chapter were written prior to the final version presented in this thesis.

3.20. Evaluating quality in qualitative research

The validity of research corresponds to the degree to which it is accepted as sound, legitimate and authoritative (Yardley, 2008). Whilst the traditional criteria for assessing quantitative research (reliability, objectivity and statistical generalisability) are often inappropriate in qualitative research, and the general ethos of the different methodologies

incompatible with fixed, universal procedures, some way of evaluating quality is absolutely essential (Yardley, 2000). Yardley (2008) neatly outlines four main principles for assessing the quality of qualitative studies: sensitivity to context, commitment and rigour, coherence and transparency, impact and importance. These have been considered in turn and are now discussed in relation to the current study.

3.20.1. Sensitivity to context

Yardley (2008) states that sensitivity should be shown to the context of existing theory and research. Sensitivity to the context of this research was shown in the introduction (Chapter 1) and literature review (Chapter 2), where a thorough justification for the research was provided and existing literature regarding Charcot foot explored. Consideration of the evidence gap, regarding patient experience and the requirement for further insight to assist with truly patient centred care, led to the formulation of the research questions (Section 2.15). The findings were also reviewed within the context of currently available literature and with respect to how they might contribute to improved patient care (Chapter 5).

Good qualitative research should also show sensitivity to the perspective and social-cultural position of participants as this may influence whether they feel able to take part and express themselves freely (Yardley, 2008). Sensitivity was shown in this area by initially deferring to a PPI group as detailed in Section 3.10.2. Ethical consideration was also given to my dual position of researcher and clinician and the effect that this may have on participant response (Section 3.10.3). I attempted to control for this by introducing the photo elicitation part of the method (Section 3.13.3) and asking open-ended questions in the semi-structured interviews (Section 3.13.1). Within the data analysis and presentation of the findings, the participants' own words were used as much

as possible to ensure that the findings were firmly grounded in the participants' experiences (Chapter 4).

3.20.2. Commitment and rigour

It is hoped that a demonstration of the commitment and rigour within the current study has been demonstrated by the detailed accounts given throughout the thesis. This research required the approval of two ethical committees and site-specific assessment prior to commencement. A purposive and homogeneous sample was sought in keeping with the research question. I have spent a great deal of time with patients diagnosed with Charcot foot at all stages and completed considerable examination and analysis of the literature and how it applies to clinical practice, demonstrating my level of commitment to the study on a personal level.

I have also invested a great deal of time reading about and investigating IPA throughout the research process, from the conception of the idea to finalising the thesis, and I attended multiple training courses and specialist interest group meetings to improve my methodological competence. My supervisors were consulted during the analysis to discuss the interpretations and in an attempt to improve the rigour of the study. The thesis also attempts to justify all decisions made with regard to the methods used, findings and conclusions.

3.20.3. Coherence and transparency

According to Yardley (2008), the coherence of a study is the extent to which it makes sense as a 'coherent whole'. This should be determined by the clarity and power of the argument made for the study and the way in which it was carried out. It is hoped that the

first two chapters of this thesis explain the importance of the study and that this chapter provides a suitable rationale for the use of IPA, its theoretical background and why it was considered the most suitable approach for this research.

Smith et al. (2009) suggest that a coherent IPA study should make the reader aware that the findings are the researcher's attempt to make sense of the participants' understanding of their experience, and to this end, a reflexive statement has been included at the end of each chapter. The importance of reflexivity is discussed in Section 1.7. In an attempt to make the findings of this study transparent and explicit, several participant extracts have been included so that the reader will be able to judge how well the interpreted themes have been led by and grounded in the participants' voices (Chapter 4).

3.20.4. Impact and importance

Yardley (2008) argues that there is no point in carrying out research unless it has the 'potential to make a difference' and provides a firm answer to the question 'So what?'. Charcot foot is a potentially devastating condition which this research has shown to have a profound effect on QoL and the ability to perform ADLs. The interviews provided a vast quantity of powerful data that is presented in the following chapter. Chapter 5 discusses these findings alongside published literature and hopefully highlights how the findings of this IPA study have expanded upon what has previously been shown in qualitative literature. It also offers firm ideas about the impact which research could have on future practice. It is hoped that the thesis has been written in such a way that any reader will be able to recognise areas that will have some theoretical transferability into their own field of practice.

3.21. Methodological reflexive statement

In this section I will examine how I have influenced the research design and process. I found the area of prospective reflexivity (Atta & Edge, 2017) in the methodology section of my research far easier and more natural in many ways than the retrospective reflexivity (Atta & Edge, 2017) required later on. Prospectively applying reflexivity to areas such as my dual researcher/practitioner role, for example, felt more like solving a problem that I could try to unpick in a systematic way with the final goal of generating a good quality piece of research.

During the planning stage, I agonised over my position and dual role. I tried to critically analyse how the questions I asked and the settings that I was required to use would be conducive to promoting a good quality, collaborative approach to the research and provide the participants with the best opportunity to describe their experiences in their own terms. Some areas of this process appeared fairly simple, such as altering my appearance by wearing smart professional clothes rather than my uniform to reduce my visual image as a practitioner. Also, trying to meet the participants away from the foot clinic was helpful, and I tried to arrange the rooms so that there was never a desk in between the participant and myself, to make it feel more like a conversation than an interview, to encourage the participants to relax and therefore, hopefully, talk more openly. Other areas involved greater consideration. Here I found the PPI group to be very useful in terms of both making practical adjustments to the wording of documentation and clarification of ideas, and to allay my own concerns and worries regarding my dual role in particular. The process and outcomes of the PPI group are noted further in Section 3.10.2.

In addition to justifying my dual role as researcher, Dwyer and Buckle (2009) suggest that examination of group membership be considered by the researcher, given the

intimate relationship they have to both the data and analysis. I would argue that I am neither insider nor outsider in respect of this research, arguably occupying what Dwyer and Buckle term, the space between. I do not share the experience of my patients in terms of either the presence of diabetes or of active Charcot foot. Therefore, I will not be able to see things from the same patient point of view. Thus, they may not feel able to speak to me in quite the same way as they would an 'insider'. However, I am not a complete outsider either, so may share some of the same language and cultural references with the participants when discussing Charcot foot. Indeed, this was seen as a positive in the PPI group (Section 3.10.2) who felt that the researcher role would be best suited to a practitioner whom they knew understood Charcot foot and its complexities as these areas would be too difficult for them to try to explain. Whilst my dual role was something that I initially worried about extensively, I would now argue that this 'in between' status is in fact a privileged position, one requiring a lot of trust from the participants, but one which, if handled correctly, may produce some very rich discussions.

Trying to assess my own expectations of what the findings might be and how they might affect the interviews was more difficult than anticipated. I was aware that I expected the experiences of living with active Charcot foot to be profoundly negative, but given my practitioner, role my pre-understandings were mainly focused on many of the practical issues such as the loss of ability to drive, work and difficulties bathing, that would routinely be discussed in clinical session. I was keen to avoid limiting our discussions to such areas and their practicalities as much as possible and therefore found the use of photo elicitation (Section 3.13.3) to be very helpful. I had no idea what photographs the participants might present me with, whereas the participants had time to choose them and consider what they might like to say. Therefore, I feel that I went into the interviews with

more of an open mind – particularly in the early stages – and confident that the participants had more control over what was discussed.

Although I was happy with my method and had discussed both the interview schedule and use of photo elicitation with my supervisors and my discovery (PPI) group, I was aware that I may still limit participant responses in interview via my interview technique if I fell back into the habits of clinical lines of questioning or came across as focusing on clinical concerns. Whilst I did feel that my role as a practitioner helped to prepare me for asking open-ended questions and encouraging patients to talk freely, I recognised that the style of inductive, patient led, probing questioning, required for a successful IPA interview, would be very different. Therefore, in preparation for data collection, pilot interviews were undertaken with a friend and relative in order for me to practise listening to their responses and bringing them back to points of interest with follow-up questions such as: ‘Would you mind if we returned to something you mentioned earlier?’ and ‘Would you mind if we explore that idea a little further?’.

I later undertook a video-recorded interview in the lab at the University of Brighton asking a volunteer about her experience of living with type 1 diabetes. The practice interviews had a very positive influence on my approach to beginning data collection and really helped instil confidence for ‘the real thing’. I found I was able to return to areas of interest and gently guide the process whilst allowing the participants to discuss areas of importance to them. Nonetheless, I was surprised by how intrusive I felt I was being when probing people about their private thoughts and feelings. At times it made me quite uncomfortable and reluctant to probe too far which did concern me because it cast doubt on my ability to handle the actual interviews and probe sufficiently to gain the depth

required for a good IPA interview. I felt, with my practice participants in particular, that I had no real right to probe as this was not a 'real' interview. I received good feedback from my volunteer at the end about my style of interviewing and she felt that I was paying attention due to my follow up questions. I was also able to watch the video back and critique myself as an interviewer, which I found very interesting. I feel that these practice sessions boosted my confidence and allowed me to hold a more confident and positive pilot interview with a chronic Charcot patient at the hospital as my final preparation. This interview and the impact that it had on my real interviews was discussed in Section 3.9.1.

Reflecting on the data collection following the first few interviews prompted me to make one change to the protocol; I decided to start recording the interviews as soon as both the participant and I were seated and once the participant's verbal and written consent had been obtained. This occurred primarily because I felt that on one occasion I had missed an opportunity. In the early interviews, the demographic data sheet was completed prior to recording. During the start of Brian's interview, whilst completing the demographic information, Brian began talking about his experiences and stated that receiving his Charcot foot diagnosis had left him feeling as if he had been "hit by a bus". He having said this without the recording device being on, and I knowing that I had potentially missed an opportunity to delve into a deeper discussion about it right away, caught me by surprise and left me feeling unsettled as we started the interview. When I asked later if we could return to what we had previously been discussing during the data collection, he was less forthcoming, having already partially explored it prior to the actual interview. I left the interview that day feeling flat and quite negative about the experience, not wanting to start analysing it right away and feeling that the experience and interaction had been less than fruitful. It was only later that I realised that Brian's interview was in fact one of the

richest that I had. I had felt negative about the whole thing due to that one missed statement, which had then affected the entire interview for me. This I felt reflected my novice status, but fortunately was not detrimental overall as Brian actually spoke extremely eloquently about his experiences and still left me with some very rich data.

In actual fact, many of the early participants were keen to start the discussion of their experiences right away, and it was just one critical incident that caused me to reflect on this more fully. The decision to start the recording device earlier meant that I could relax and let the participants take the lead from the outset if they wanted to start talking straight away. It also cut down on repetition as I was no longer required to keep returning to areas that may have warranted further exploration in the early stages. As a consequence, the whole experience felt less scripted and therefore more like a natural conversation which would allow for a better collaborative approach.

Chapter 4. Findings

This research explored, for the first time, the lived experience of people diagnosed with active Charcot foot as a complication of diabetes mellitus. This chapter presents the findings of eight semi-structured interviews undertaken at a specialist diabetic foot clinic in South London. At the time of interview all participants were receiving treatment with TCC for their active Charcot foot.

Eight participants diagnosed with active Charcot foot were interviewed (six males and two females; two with type 1 diabetes and six with type 2 diabetes). The mean age was 59 years \pm 9.8 years (mean \pm SD) and the mean duration of diabetes was 16 years (\pm 12.5 years). All patients were treated with TCC therapy. One patient had bilateral involvement and was treated with TCCs to both feet simultaneously. Time from symptom onset to diagnosis ranged from three days to six months (10 ± 9.5 weeks). Three patients had already developed Charcot foot deformity at the time of presentation at the foot clinic. Duration of casting therapy prior to interview ranged from three to seven months (3 ± 1.8 months). Table 7 summarises participant details and is designed to facilitate the reader's understanding of each participant.

Table 7. Participant demographic details

Pseudonym	Gender	Age	Diabetes Type1/Type 2	Duration of Diabetes	Area of Occupation	Symptoms to diagnosis
Graham	Male	67	T2	5 years	Retired - Business	2 weeks
Steve	Male	59	T2	15 years	Health / Medical	3 days
Stacey	Female	46	T1	34 years	Self-employed - Beauty	4 months
Brian	Male	63	T2	12 years	Driver	1 month
Linda	Female	73	T1	33 years	Retired - Office based	6 weeks
Roy	Male	69	T2	6 years	Retired - Carer	5 months
Bill	Male	51	T2	14 years	Self-employed - Technical	6 months
Colin	Male	53	T2 (Insulin-treated)	10 years	Security	2 weeks

Following data analysis, three master themes emerged that reflected participants' shared experiences and enabled a deeper understanding of this experience to be presented. These master themes were:

1. Life journey interrupted
2. The hindered body in places and spaces
3. The diminishing self in a restricted lifeworld

The themes have been prioritised according to their relevance to the research question. They are presented in a way that aims to avoid repetition and promote ease of reading whilst staying true to the participants' experiences. It should also be noted that, due to the

double hermeneutic nature of IPA research (Pringle et al., 2011), these themes represent the researcher's understanding and interpretation of participants' lived experiences.

Each master theme was divided into smaller sub-themes which detail varying aspects of the participants' experiences (Table 8).

Table 8. Study master themes and sub-themes

Master theme	Sub-theme
4.1. Life journey interrupted	4.1.1. Life before Charcot – A world without limits 4.1.2. Death of old life - into decline 4.1.3. Towards an uncertain future
4.2. The hindered body in places and spaces	4.2.1. Negotiating a hazardous world 4.2.2. Life contained
4.3. The diminishing self in a restricted lifeworld	4.3.1. The search for the lost self 4.3.2. The stigmatised self 4.3.3. The relational self

Each theme and sub-theme are presented and illustrated by verbatim extracts taken from the participants' transcripts. Some of the photographs presented by participants as part of the interviews, alongside explanations of what these images meant to them, have been interspersed throughout the chapter to provide deeper insights into their lived experiences. Minor changes to the extracts have been made where necessary to protect the anonymity of participants, such as place names or other identifying features. Where pauses in the text are present, these are shown by the use of three full stops (...). Where a word is implied but not stated it may be added in square brackets [like so] for clarity. If a section of the text has been omitted this is demonstrated by the presence of square brackets []. All

participants, and any family mentioned in the excerpts have been given pseudonyms to protect their anonymity.

4.1. Master theme 1. Life journey interrupted

This theme explores the sudden interruption to the temporal flow of participants' lives as a direct result of the diagnosis and management of active Charcot foot. The embodied experience of Charcot foot appeared to highlight the time-bound nature of their 'being'. The impact of diagnosis and management was so significant that it appeared to change participants' perceptions of their own lives, as their preconceived life journeys were derailed and sent along a different path. Participants separated their lives into alternative timelines; what came before Charcot foot, and life after diagnosis. The past became revered as the best of days, instilling a deep sense of longing for previous worldly interactions. Conversely, with their present day lives drastically altered for an unknown period, and in the face of uncertain outcomes, feelings of loss arose and participants' sense of mortality was brought directly into consciousness. The future then became a thing to be feared.

4.1.1. Life before Charcot – A world without limits

This sub-theme reflects participants' feelings and projections regarding their lives and interaction with the world prior to diagnosis. The retrospectively perceived positivity and joy of life before the hindrance of active Charcot foot management featured highly throughout the transcripts and overtly positive discourse was used. Situations, activities and worldly engagements experienced and undertaken prior to management of Charcot foot were given primacy in their individual accounts.

Life prior to diagnosis and management of active Charcot foot with a TCC was often recalled as though being without limits, open, free and full of possibilities. The separation of past and current life was summarised succinctly by Bill who referred to it as life “before Charcot”, or “BC”. He used the abbreviation with the image that follows:

We’d won the Scottish championships which was a year...of 1 BC, one... a year before Charcot. Um... that was the team, that’s the guy I run the club with that did the cartoon so... obviously I was in charge of the team, um... but our age won in the Scottish championships which was probably unbelievable, in fact it was unbelievable (Bill, 36, 5-9).



Figure 12. A picture presented by Bill depicting his award-winning martial arts team as Ninjas. This could be seen to represent how "unbelievably" strong and powerful they felt at the time of becoming champions.

Bill’s use of the term “BC” feels almost biblical, based on its more commonly accepted use in the modern calendar (‘Before Christ’). From his post-diagnosis position, his life “BC” was retrospectively perceived as exceptional, even against a background of 14 years with diabetes. Bill’s repeated use of the word “unbelievable” could be viewed as accentuating how far removed his current life now felt from the past. With the diagnosis of active Charcot foot, and the onset of casting, such worldly interactions and activities

were no longer a possibility. Bill's entire world could be seen to extend along a different path, or a whole new timeline, dictated by his new embodied experience within the world.

Steve had a similar focus on his pre-diagnosis life and former fit and healthy self and attended the interview with his official work photograph.

So that is me, better and fitter than I had ever been in the previous 20 years, and that's where I'm going to get to once I get liberated again (Steve, 19, 11-13).



Figure 13. An official work photograph brought in by Steve, a copy of which was displayed prominently at his place of work. This could be seen to represent the confident, capable, powerful man with whom he had previously identified.

Steve presented this photograph with pride as an image of what he felt himself to be at the pinnacle of his fitness; a “*better*” version of his current self to which he wanted to return.

Steve's use of the term “*liberation*” suggests incarceration, entrapment and punishment bringing to mind images of freedom from torturous suffering against the odds. This

powerful statement retained a sense of hope that he would return to his former self and life after this period of suffering from active Charcot foot was over, a return to when he was healthy and strong.

This fragmentation of life before and after Charcot foot was demonstrated by all participants, as their ways of being in the world altered post-diagnosis, giving rise to a consistently idealised dialogue of life “BC”. It could be suggested that all participants lived their pre-Charcot foot lives in a state of taken-for-granted everydayness. However, their bodies were each brought into sharp focus with the diagnosis and management of active Charcot foot. There was a sense of independence, directionality and movement in the individual accounts of life “BC” which did not appear later on:

I bought it [her car] for me...laughs...so that I could go out shopping and I could potter where I wanted to without having to ask anybody (Linda, 13, 9-11).



Figure 14. The car that Linda could no longer drive following application of the TCC. She missed the sense of freedom and autonomy associated with moving herself around freely and independently.

We [Brian and his wife] used to have quite a lot of trips um.... down the coast and we've had 3 or 4 day breaks or day trips.... I suppose you could say that was a hobby we had (Brian, 9, 10-12).

We [Graham and his dog] used to like to... you know, you'd meet up with your friends and their dogs and you could walk round and round, there's different routes you could take (Graham, 8, 14-16).

I wasn't professional or nothing like that, I just enjoyed being on the bike (Roy, 8, 15-16).



Figure 15. Photographs presented by Roy depicting the bike he missed riding. These images reminded him of the associated health benefits of cycling that he was now missing and the ease with which he was previously able to move around.

The participants had open access to the world in their lives before Charcot foot. Their worlds were felt to extend out in front of them, large, fulfilled and full of family, friends and fun. They discussed trips to the coast, holidays, visits to pubs, walks with pets and fun with their children. Descriptively, it may appear that participants were talking about these activities and interactions. However, what they were interpreted to be discussing

was their autonomy, choice and freedom in a life now perceived as without limits in comparison to their restrictive post-diagnosis life. Participants previously felt in control of their lives and life choices, and these choices represented who they were as sentient beings. These interactions within the world were so ingrained in the participants' lives that they afforded a sense of meaning and represented who they each felt they were as people. This was highlighted by Stacey and Steve:

I'm an outside person. I like being out and about. My work is free, I'm mobile, I can go if I want, if I don't want to go I don't have to, so I've always buzzed around, you know, quite freely.... (Stacey, 41, 11-14).

Late in life, five years ago we both became cyclists (Steve, 16, 1-2).



Figure 16. A photograph depicting Steve and his wife completing a cycle race. This was a significant activity that he wife shared as a pastime.

Stacey's extract demonstrates the sense of both independence and freedom that she experienced in her life pre-Charcot foot. She "buzzed" around, giving the impression of flight and autonomy. She felt free and unrestricted, exhibiting agency and control over her life choices. Her interaction with the world was part of her and she took a meaningful, active part in that world. With her use of the phrase, "*I'm an outside person*", she recognises that part of her very selfhood was wrapped up in being outdoors, within the world and her freedom to interact with it as she wished.

Steve's use of the phrase "*we became*" also highlights the importance to him of the activity and how he felt it was part of a joint identity, shared with his wife. Their interaction with the world formed part of their joint 'being' as a couple. This movement within the world expanded into hobbies, passions and meaningful activities for all participants, which were often shared with family and friends. It appeared to make the world feel more open by virtue of space, life goals and social interactions. Similarly, Colin commented:

I like walking, like in the green... anywhere green, I love walking around, you know what I mean and... I just love the green life you know (Colin, 12, 14-15).

Colin did not just love going to green open spaces, he "*loved the green life*". This "*green life*" could be seen to represent a larger more existential form. It could be argued that it represented the life force of nature or the rejuvenating power of being out and at one with the natural world. Here, Colin appeared to acknowledge how he and this "*green life*" coexist and give meaning to one another through a shared interaction. The essence of the

“*green life*”, nature and the wider world were represented in many of the images shared by the participants for discussion:



Figure 17. Linda and Bill shared images of the gardens that they had previously enjoyed tending and nurturing.



Figure 18. Steve and Linda presented images from the holidays that they had previously taken and the outdoor pursuits that these had entailed.



Figure 19. Linda and Graham presented photographs of their dogs and discussed the walks that they were no longer able to take.

For each of the participants, years of actively engaging with the world and others in their own particular ways provided life experiences which helped to define them as individuals. Participants' lives before diagnosis were seen as limitless and full of every sort of possibility. Participants appeared to look back and see themselves as fit and healthy people with agency and choice. This idealised vision of life 'BC' seemed to take on a new significance post-diagnosis.

4.1.2. Death of old life - into decline

This sub-theme explores participants' shock at their initial diagnosis and how they viewed their present situation in direct contrast to their lives before Charcot foot. Post-diagnosis, participants' conscious intentionality turned to their interrupted life journeys, giving rise to an existential crisis. As participants' embodied experiences within the world altered, previous struggles appeared to recede, highlighting the severity of their current situation. It reflected the way in which having active Charcot foot initiated a sense of overall

decline in the participants' lives and a sense of bereavement for the old lives they felt they had lost.

Several participants described their initial shock and dismay at receiving their diagnosis:

It came as a... well a hell of a shock really, you know what I mean er... you know... I was sort of knocked sideways really and I haven't... I've never been to hospital before, um... never really had to have any treatment for anything. As I say, I get the odd aches and pains but I don't really bother to go to the doctor's that often and it came as a total shock really, I was a bit devastated with it all really (Brian, 5, 5-11).

Shock, absolute shock. My daughter said, when that professor came down, she said your face was a picture, she said it was absolute horror (Linda, 19, 9-11).

There is a sense within these abstracts of the general disbelief experienced by participants upon receiving their Charcot foot diagnosis. The repetition of the word “*shock*” by Brian and Linda emphasised this overriding initial reaction. They both also used the words “*hell*” and “*horror*”, invoking images of terror and nightmares. When conveying the completely overwhelming force with which this realization made its impact, Linda described her level of shock as absolute, suggesting that for her this event was without parallel, infinite and complete. Similarly, Brian's use of the phrase “*knocked sideways*” gave the impression of an unexpected and uncontrollable force making him unsteady. He indicated that he had always considered himself relatively healthy and strong, shrugging

off previous “*aches and pains*”. This accentuated the impact of receiving such an unexpected diagnosis, leaving him with the feeling that his life had been knocked off course.

In the excerpt below, Steve highlights the severity of his Charcot foot diagnosis, in comparison to previous illnesses, and the impact that this had on his life:

Never noticed it with the others [illnesses], they were bumps in the road. Currently well this is a decline, not least because it may have been an acute onset, but boy is it a chronic problem and it was clear two days later I was going to survive the kidney hit, but it ain't clear two days after this (Steve, 25, 1-5).

Whilst Charcot foot was not a threat to Steve's mortality, it presented a threat to the survival of his past fulfilling life. His diagnosis had such a forceful impact that Steve now perceived all other health concerns, even a potentially life threatening renal complaint, as small and insignificant “*bumps in the road*”. These now seemed to be minor stumbling blocks that could be overcome, in contrast to the downward spiral caused by his Charcot foot. This might reflect the road map of his life, across which he had been steadily journeying. The diagnosis was to him a significant landmark on the way towards his eventual demise, a prognostic factor regarding what lay ahead.

Equally, Brian reported struggling immensely with the unwelcome interruption to his pre-planned life journey:

I want to go back to work, I... basically had plans to work until I drop (Brian, 7, 2-3).

I've never been unemployed, so it would come as a bit of a shock just to pack in altogether. Well I'm retired now aren't I really, through no fault of my own (Brian, 7, 13-16).

Working was a high personal priority for Brian, a part of his life story. He had no thoughts of retirement, despite being 63 at the time of diagnosis, and claimed never to have contemplated a life without work. His aim to “*work until I drop*” gives some indication of the life-affirming effect on him of having a vocation and a reason to get up in the morning. His personal sense of meaning regarding his work appeared inextricably linked to life itself. There is a sense of denial here as the sudden and involuntary change to his life was something that he struggled to accept. This was highlighted when he used the future tense, acknowledging that it “*would come as a bit of a shock*” before correcting himself. The phrase “*through no fault of my own*” further highlighted the way in which the condition had imposed itself upon him and his life.

As participants found themselves thrown from their old lives and life journeys into a new and unknown situation within the world, many appeared to become mentally as well as physically overwhelmed. Several participants noted that their Charcot foot diagnosis presented them with more than just a physical problem:

The only things I seem to remember now are my hospital dates and how long this has been on my foot. I don't remember a lot else. If you said to me what did I do last Saturday, I couldn't tell you, that's completely gone. And then I thought should I go to the doctors, you know, am I going a bit senile (Stacey, 20, 3-10).

There have been occasions up there [in clinic] where you felt she [the Podiatrist] knew that this wasn't just a physical question. And I think some of that needs to be addressed up front. It's a chronic illness... it ain't cancer, but by God it's a shock to the system (Steve, 32, 13-17).

Yeah, I kind of lost interest but... I think I kind of lost interest in a lot of things actually, um... you know, when the Charcot... I mean that's a... I know that it wasn't just physical, you know (Bill, 34, 18-20).

For both Bill and Stacey, many areas of their lives were felt to be pushed into the background following diagnosis. The extracts above give the impression that living with Charcot foot was swallowing up their lives and consuming their thoughts. They were so subsumed by Charcot foot management that it intruded on the whole of their lives and caused them to lose focus on, and appetite for, many other formerly important areas. Stacey indicated that she was so overwhelmed by her diagnosis and its management that she had begun to question her own mental and cognitive health. The idea that she may be going “*senile*” appeared to indicate that she felt she was losing her grip on the realities offered by her former life.

Similarly, the all-encompassing effect of the condition was compared to the impact of a terminal illness by Steve, alluding to the impact on his global health status. Steve's extract in particular, gave the impression that this had not been adequately recognised by the practitioners dealing with him as he went on to discuss the "*sort of mind-body interaction, not alluded to strongly*" (Steve, 31, 23) by those around him. Here Steve clearly indicated that, whilst the mind and body are inseparable, the practitioners dealing with him clinically may have only considered his physical health without looking at the psychological impact. There was recognition here that the psychological impact needed to be acknowledged and "*addressed up front*", as additional emotional support was required to help participants to cope with the initial effects of diagnosis. This was felt to be very important and an area that needed to be acknowledged and spoken about explicitly during clinical encounters.

When discussing the initial post-diagnosis period, Bill likened his experience to being in a black hole:

I mean there was a big black hole, no basically I mean this leg was like a millstone (Bill, 30, 25-26).

The words "*black hole*" are dark, depressive and overwhelming and could be representative of the inescapable effect of active Charcot foot on the rest of the participant's life. Black holes are a dangerous phenomenon with a gravitational pull so strong that they consume everything around them, where even time and space are unable to exist in the same way. This could be seen as representing the profound and all-consuming effect of active Charcot foot on participants' lives and personal journeys.

Millstones equally denote heaviness, biblical punishment and drowning under the weight of something inescapable, adding further strength to the previous metaphor and the idea of the immense weight that Charcot foot had on Bill's life and mental health.

As participants' participation and place within the world were consistently brought into question and they were devoid of the ability to play an active role in their own lives, many began to question what was really left. There was a profound sense of emptiness resulting in a period of mourning for the death of their old lives, a sentiment echoed by many of the participants:

They said, well in a sort of code version of what they told me is just sit in a chair and wait until you die (Bill, 8, 16-17).

There's a sort of bereavement about it all you know. I'd lost my life. The life I had (Steve, 31, 16-18).

It's all come to a stop hasn't it, now this [his Charcot foot diagnosis] has happened (Roy, 23, 8-9).

Bill perceived the advice given to him, regarding reduction in weight bearing activity, as a "code" or hidden message that life as he knew it was over. Bill's interpretation of Charcot foot was that he was required to sit in a chair and watch life pass him by, passively awaiting death. Roy's statement "*It's all come to a stop*" also highlighted how

Charcot foot represented the cessation of the autonomy, freedom and happiness that the world had to offer. Participants' discourse turned to one of grief and bereavement as they began to mourn these losses.

Conversely, Stacey appeared to have moved past the stage of grieving as she had found a way to continue some of life's meaningful activities with the aid of an electric mobility scooter:



Figure 20. Stacey walking her dogs with the aid of a mobility scooter. With the scooter, she was able to regain some independence and increase her levels of meaningful activity.

I couldn't get any help for a scooter and like I said I'm lucky my mum got me one, or I might have cut my wrists by now...laughs... (Stacey, 25, 13-14).

Whilst Stacey jokingly said she may have cut her wrists if it had not been for the scooter, it could be argued that her use of humour around the subject of attempted suicide masked

earlier feelings of pain and possibly depressive symptoms. The scooter provided a lifeline back into the world. Whilst she still used the discourse of death, her example was perceived as a near miss since, with the help of the scooter, she had been able to regain her place in society.

One notable divergence from this theme was provided by Graham. Whilst he did report significant losses in meaningful activity, such as walking his dog (Figure 19), he also stated:

Being retired it means I don't do a lot anyway... (Graham, 7, 12-13).

This may have been due to the significant change in life that had already taken place upon his retirement less than two years before diagnosis. His interaction with the world prior to diagnosis had arguably already gone through a major shift, altering his being within the world from working man to one who didn't "*do a lot anyway*". This recent life alteration, from working man to retired man, may have rendered his more recent restrictions slightly less meaningful than for some of the other participants who were potentially considering such a change for the first time.

This sub-theme examines how participants experienced an immediate cessation of the lives they had known with the onset of active Charcot foot management. As the enforced lack of mobility overwhelmed their bodies by altering their sense of situatedness within the world, many also reported a sense of overwhelming psychological burden. There was a sense from some, that the psychological impact was so severe that it engulfed many

other areas of their lives. This left many with a deep sense of grief and bereavement for what they had lost. The participants appeared hopeless and diminished by these losses as their entire lifeworlds were put on hold and became unrecognisable. Participants highlighted how their entire life journeys had been derailed with the onset of Charcot foot management.

4.1.3. Towards an uncertain future

In the light of their present struggles, and with their previously perceived life plans disrupted, participants' conscious intentionality turned towards their futures. Many felt that their anticipated futures were erased with the advent of a Charcot foot diagnosis. Many things that they had envisioned and anticipated for their future lives were suddenly out of reach. This left them with a sense of loss, anxiety and fear about what may lie ahead. Their sense of biographical temporality shifted as they each struggled to readjust and reimagine what life would be like in the future, seeing only further negativity ahead. Someone for whom this featured particularly heavily was Steve:

I'm 60 in the summer, I felt good about that. It felt a... it felt like older age was going to be better than younger.... than middle age was. And of course, if you look around you see all these older people doing all this shit now that my parents and others didn't, and it's a different life now for older people who are close to retirement now, and that appealed and I miss it badly (Steve, 17, 3-8).

Steve appeared acutely aware of the loss of future opportunities. His future was meant to be fun, a new chapter in his life with potential for new adventures. Instead, the prospect

of fun-filled older years had been removed with the onset of Charcot foot. He yearned for future experiential possibilities which were no longer in his grasp, craving a future life and opportunities now denied to him. All hope for the future seemed lost. Similar feelings of hopelessness were voiced by other participants, leading to questions regarding their own mortality:

I suppose I had actually thought when I... yeah, how long have I got, you know. Um... no because... yeah.. it's partly you're saying well... my mother's 84 and she's still fairly active, and I think well that rules that out (Bill, 40, 18-22).

I mean my father worked all his life but... and I don't think he ever had a day off, he was... really didn't want to retire, he retired and got Alzheimers Disease, you know... if you... and I've always worked, since I was 15 (Brian, 7, 10-13).

Struggling to see into their own future, Brian and Bill looked back to the past for frames of reference. The underlying assumptions that Bill may grow old like his mother, and the hope that Brian would not share the same fate as his father appeared to have been destroyed. Bill had assumed that his later years might be like those of his mother, who remained “*fairly active*”. However, as he now no longer perceived himself as a fit and active individual, that vision of his old age was extinguished, giving rise to thoughts of his own mortality. Conversely, for Brian, the knowledge of his father’s fate following retirement filled him with fear of a similar experience following his own recent and unwilling retirement. With such frames of reference regarding their perceived and

planned futures now seemingly invalidated, the participants' sense of loss was accentuated.

For Bill and Stacey, it was a future of restriction and uncertainty that they struggled to envision. Their thoughts turned to practical options to deal with these concerns:

Like if you say to me now look, this is going to actually be two years and you probably will end with it [the foot] sort of a bit like that [deformed], I'd probably say now well what are my options of having the foot off, you know, you'd have a prosthetic, you're over it in a couple of months and life's back to normal (Stacey, 12, 1-8).

I was going to ask for my foot to be removed because I thought I'm probably going to be more mobile and more active without it than I am with it, um... and I thought that's maybe the only route that I'm going to have to go (Bill, 28, 20-24).

Both Stacey and Bill considered amputation as a viable option and a potentially preferable alternative to living with Charcot foot in the future. The idea of living with a prosthetic limb seemed to offer better, or possibly more certain, outcomes than life with Charcot foot. The expectation appeared to be that life as they knew it, with autonomy, freedom and mobility, would be “*back to normal*” (Stacey) much faster with an amputation. Perceiving a drastically decreased future quality of life due to Charcot foot, Bill felt potentially without other options if he ever wished to be fulfilled or rebuild his activity levels. He went on to say:

I mean if it happened to the other one down the route. I would... I would find a way to convince myself to lose both the legs, I think I'd probably be... if I could have a much better quality of life. I think that's what it's coming down to. It's not the end of life, it's basically quality of life... (Bill, 41, 21-25).

Bill's quality of life was so markedly reduced following diagnosis that having to live with another Charcot foot was simply not an option. Thus, even a future as a double amputee was preferable at this stage and indeed appeared to be the only option if he wanted to regain some of this pre-Charcot foot quality of life. With his taken for granted future life and health brought to consciousness, Bill's future seemed bleak. Facing the end of life as he knew it, he felt he may have to begin to try to prepare himself to reach out for ways to regain his old quality of life at any cost.

Not all participants reacted in the same way. Colin's was the polar opposite reaction to the idea of amputation:

You can have your foot amputated and things like that, you know. I thought oh my God, I'm only 54... 54 at the time, I don't want to... I don't want to be going without a foot yet, you know what I mean, and I thought oh Jesus (Colin, 26, 22-26).

The absolute horror at the idea that amputation might be a possibility was in itself almost too much for Colin to contemplate. His focus on age indicates that he saw himself as a relatively young man, potentially fast forwarding to the life of an older, even less able-

bodied version of himself. Even considering the risk of losing a limb sent him into blind panic. His proclamations of “*oh my God*” and “*oh Jesus*” further highlight his desperation, as though calling for divine intervention to help him to make sense of the situation and possibly a way to avoid this fate as his entire future was brought into question:

I just thought oh is life worth going on for, you know what I mean. I do... I do feel depressed, I must admit, I really do. I sometimes wonder if it's all worth it, you know, just going on, to be honest with you, I don't know... (Colin, 19, 20-23).

Facing the cataclysmic possibility of amputation, the loss of his old life and his anticipated future – in which, “*all the things I've mentioned to you I love doing, and I can't do...*” (Colin, 20, 16) – Colin openly questioned what would be left to make life worth living. Confronting the end of life as he knew it and the sudden ending of some of his anticipated life stories, feelings of depression prevailed. Similar accounts of the period soon after initiation of their Charcot foot management were given by half of participants:

I was depressed for all January and February and I couldn't do my work properly, more for that reason than any other. I was fed up, depressed, unhappy... unhappy.... er... that's much less now, I don't know quite what it is... (Steve, 30, 25-26, 31, 1-3).

Oh terrible, in fact I felt suicidal at times, and I'm being serious. I thought I don't want to wake up, I mean how long is this going to go on for (Brian, 29, 13-15).

I mean I didn't get suicidal or anything like that, but I don't know if I was far from it, or how far away (Bill, 34, 14-16).

Moving towards an uncertain future following diagnosis seemed an almost impossible task to some of the participants as they gave a sense of becoming completely engulfed by their negative emotional states. Participants seemed unable to make sense of their feelings but were aware of their depression. Whilst Bill maintained he had not been “suicidal”, he was still uncertain how to judge just how far away from this state he was. Brian preferred the comfort of sleep to the reality of having to face the world. Nothing in the participants' lives, futures or even their state of mind seemed certain following diagnosis, though it should be noted that this had improved to some extent for both Bill and Steve by the time of their interviews.

For Colin, the psychological impact of trying to deal with his diagnosis had a dangerous ongoing effect on his insulin regime and diabetes control:

I think it's more to do with the way I'm feeling at the moment um... because er... sometimes when I'm putting the insulin in I put it in and I don't care... you know? I just don't care how much I'm putting in sometimes, I just turn it, not even counting how many units I'm putting in, I'm just injecting you know... um... which is not good (Colin, 22, 7-12).

I know I am getting depressed, you know what I mean, and er... I just don't want to do something silly (Colin, 20, 1-2).

Colin appeared to be struggling with his diagnosis to the extent that, from his current standpoint, nothing else mattered. There was a sense that he was at breaking point and was giving up on life, playing roulette with his health by sabotaging his insulin control which had led to some severe hypoglycaemic episodes. Whilst he was able to recognise that this was “*not good*” he appeared utterly out of control and unable to help himself. In his altered, post-diagnosis mind state, the idea of overdosing on insulin was perceived as “*silly*”, but not inconceivable. Recognising this, he had already made an appointment to see his diabetes specialist nurse and GP prior to the research interview. These actions could be perceived as a cry for help and as an outward sign of the inner turmoil that he was experiencing as he grappled to gain some semblance of control over the situation.

This sub-theme has highlighted the fear which participants felt regarding their perceived, dramatically altered, futures. The futures which they had envisioned for many years no longer seemed plausible, and their lives felt increasingly uncertain, causing them to question what lay ahead and leading to depressive symptoms for some. For others, the sub-theme also raised the question of amputation and whether or not they could cope with a future as an amputee, which may have been interpreted as offering more certainties than life with a Charcot foot from their current situation.

Master theme 1. Summary

Participants’ conscious awareness of life and all that the world had to offer was seen within the context of time and interaction within the world. With the onset of Charcot foot and management with a TCC, participant interactions were disrupted, causing them to look back with renewed appreciation to their lives before Charcot foot. Their present experience was engulfed by a sense of mourning for their past lives as the flow of time

and passage of expectation for their future lives became dislocated. This present alteration to their lives appeared overwhelming and participants reported feelings of depression. The disrupted sense of continuity to participants' envisaged life journeys then led to thoughts of the future. The future with Charcot foot appeared bleak and filled with personal decline and demise, filling participants with a sense of fear. This could be seen to represent an ontological disturbance in their very 'being in the world' as they struggled to adjust to how the world now existed for them and what lay ahead.

Master theme 2. The hindered body in places and spaces

This theme explores the participants' altered relationship with their lived worlds following diagnosis and management of Charcot foot. Participants universally recalled how TCC application impeded their ability to interact with both the world at large and in their familiar environments. The extent of the sudden restriction in participants' ability to move and interact within familiar places and spaces with the onset of active Charcot foot management had increasingly impactful consequences on their life projects. This immediate altered human relationship with the world seemed to place endless obstacles within their everyday lives. This made their lived worlds much smaller and promoted feelings of isolation.

4.2.1. Negotiating a hazardous world

This sub-theme reflects the participants' altered relationship with familiar environments which suddenly appeared full of danger and difficulty following application of the TCC and subsequent reduction in mobility. Participants suddenly became consciously aware of the role that their environment played in their lives. Environments which were previously unconsidered and seen as facilitating their day-to-day existence, such as stairs, kitchens

and buses, now seemed dangerous. Their intentionality towards these surroundings altered and conscious attention was required to negotiate their lived worlds afresh.

Many participants recognised that they were no longer able to perform familiar tasks in the same way. Several reported falls upon undertaking regular daily activities after commencing management in a TCC:

I've got dogs downstairs who have a drink and spill a bit of water on the floor and that one little bit of water and you go flying um... and I'm clumsy (Stacey, 27, 4-6).

That's my garden and I can't... I can't weed...[laughing] I tried the other day, I nearly fell into the border, because the wretched weed wouldn't come up (Linda, 12, 7-9).

Because I can't feel my foot, [in the TCC] um... I tread on my slipper or something, you know, so I go crashing down the stairs, you know... I managed to throw my dinner over the bannisters the other day...[laughs] (Graham, 6, 12-15).

Both Linda and Graham attempted to play these events down, making a joke and using laughter as a coping mechanism, or possibly to mask an element of fear, whilst reflecting on events that are arguably very worrying and frustrating. Graham's use of the term "crashing" denotes a sudden and unplanned impact, as though his ability to negotiate simple tasks safely in his own environment had come to an abrupt halt. Perhaps this also

indicated how he felt about his life whilst managing his active Charcot foot and about his ability to manage independently.

Whilst this body-world disruption appeared to present a real problem for many of the participants, it was an area mentioned by Roy in particular, many times throughout his interview. He presented the photograph in Figure 21 to illustrate such difficulties and the dangers involved in everyday tasks such as managing personal hygiene at home. He also frequently discussed falling. It could be argued that this highlights his preoccupation with the effect of the TCC on negotiating his lived world post-diagnosis:



Figure 21. A photograph presented by Roy depicting a pine shelf that he used over the bath to keep his leg raised and dry whilst attempting to negotiate daily bathing. He discussed the dangers of this action but appeared to have no other option.

It's normal... sappy, silly little things where you'd have to... where you do them without thinking that you can come unstuck with that. Because it takes your balance away (Roy, 25, 11-14).

Yeah, I went down... I went straight down... that foot literally shot forward like that. Like I was on a roller skate... and I went down on my back (Roy, 39, 14-16).

Roy's use of "*literally shot forward*" and "*on a roller skate*" has similarities with Graham's use of "*crash*" and Stacey's use of "*flying*". This imagery gives the impression of speed and a loss of control, a sudden sharp jolt, alongside Roy's repetition of the word "*down*", emphasising the only direction in which he could possibly see his life and independence moving. The loss of these unconsciously performed, instinctive actions that enabled them to live and move safely and independently led participants to feel that they were becoming unstuck and foolish. This may also indicate how they felt psychologically, as well as physically unbalanced and increasingly disconnected or detached from their previous lives when everything was easier. Most participants mentioned simple tasks which they could no longer easily manage throughout their interviews. They generally focused on their struggle to perform smaller, everyday actions, such as bathing and shopping – recalled by Roy as "*soppy*", "*silly*", and possibly previously insignificant – as those which caused the most problems. Seemingly menial tasks previously perceived to be simple and automatic, were now fraught with hazards and danger. An inability to dominate their own home and familiar environments could subsequently be argued to diminish their sense of 'at homeness' in the world.

Such inability to continue with their 'normal' daily lives in their own homes had a negative impact on participants' feelings of control and agency:

So I have also lost control, in a small way, of my environment... my domestic environment... (Steve, 27, 12-13).

I'm not in control. And when I really, really feel that is when I've had a couple of weekends where I've got one of my kids saying can I go here, can I go here, and the other one's saying can I go there, can I go there? And Nigel my partner's doing one thing with one of them and I just feel like screaming and saying I can't say you can or you can't because I'm not in control (Stacey, 17, 16-21).

With their agency and control so diminished, an overriding sense of anguish emerged. This was particularly prominent in Stacey's transcript where she appeared torn between the demands of her old life and her current sense of helplessness. The severance of the confidence and control that she had prior to her diagnosis left her feeling lost and seemed almost to paralyse her ability to make enough sense of her thoughts and feelings to make simple decisions. Her need to scream and to release some of her internal anguish could be seen as an external means of losing control and composure, giving the outside world an indication of the internal loss of control she was experiencing.

In order to negotiate their surroundings and to improve the offloading of their active Charcot foot, most participants reported using crutches. Interestingly, both female participants also reported how the use of these ambulatory aids caused other ailments, further highlighting the reciprocal relationship between body and world. This brought their entire ailing bodies into consciousness, transforming their bodily intentionality, as they struggled to negotiate the world in the presence of such disabling management:

My hands are cracked and... really basically because I don't want to use my foot. I want my foot to have the best chance of me not walking on it any of the time so I

don't... I'm either kneeling on a chair, walking around on my knees which does ruin... I've got big bruises on my knees from doing so... um... yeah that's been a sort of disappointment... my shoulders kill me (Stacey, 4, 7-13).

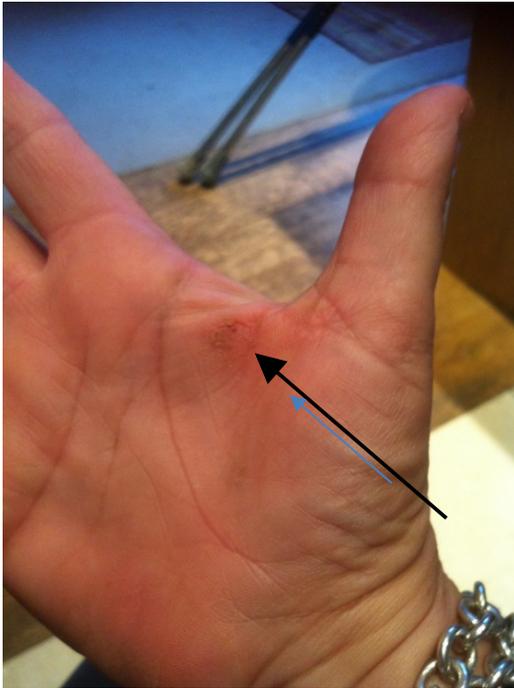


Figure 22. A photograph of the callouses on the palm of Stacey's hand presented when discussing the difficulties experienced when trying to negotiate her surroundings whilst offloading her foot, and the consequences for the rest of her body.

Stacey's foot remained her primary focus of attention, making her very compliant with the use of her crutches. However, her role as a working mother and housewife required that she had to push her body beyond its perceived physical limits to remain mobile. These new ways of negotiating her surroundings only exacerbated problems in other areas. In particular, she reported that her shoulders “kill” her; giving the impression of taking her over. The more she attempted to help herself continue with the daily routine, the more the rest of her body struggled to cope. For Linda, on the other hand, the pain and struggle with her crutches made her feel weak:

Well I've got a bad elbow anyway and I've got one of those plaster casts that you can put under your elbow to help and um... yeah, I've been putting that on because it's just... it's just so... it is, it's taking the strain of your body isn't it, onto the crutches and it's just weak in itself and it really hurts, even now it hurts, so yeah. So, we tried (Linda, 18, 24 - 19, 1-5).

Unlike Stacey, there was a sense that Linda felt the need to heed these symptoms and take a step back. This could possibly be accounted for by their respective life stages. Stacey was a working mother of two young boys, unable to stop working and moving around whilst caring for her family, whereas Linda was already retired and possibly had fewer immediate demands and less need to maintain the same level of pre-diagnosis mobility. The fact that Linda finished this statement with “*we tried*” gave the impression that, despite her own and her family’s best efforts to keep her going, she was tired and overwhelmed by both her Charcot foot and its side effects. Her use of the past tense “*tried*” suggests she had already decided she wanted to give up and to stop interacting with the world in the way she had pre-Charcot foot. She possibly felt she did not have the energy to try in the face of so much pain and difficulty.

This sub-theme highlighted how the impact of active Charcot foot management for all participants far outweighed the perceived degree of physical limitation. In their hindered bodies, participants experienced their familiar environments and lived worlds differently from the way they did in life before Charcot foot. Everyday previously safe environments became littered with both physical and emotional hazards breaking down participants’ sense of agency and control. Consequently, their conscious intentionality with regard to

the world was altered to reveal a persistent level of danger everywhere. Many struggled to find ways to cope in a new, more hazardous world.

4.2.2. Life contained

This sub-theme reflects participants' perceptions of how their entire lives became smaller and more restricted with the onset of Charcot foot management. In stark contrast to life before Charcot, which was full of activity, movement and possibility, as described in Section 4.1.1, life with Charcot foot receded as the wider world became less and less accessible. Whilst all participants experienced this containment and restriction in their lives, it appeared to manifest in a variety of ways. As opportunities to engage in everyday life projects were lost and participants' sense of agency withered, a profound sense of isolation was instilled.

I've managed to contain my life anyway and I don't go far (Steve, 10, 23-24).

It's changed my life in a way because er... as I say, I can't drive, not that I'm too bothered about driving, but er... I can't walk, if you like, down to the village um... to the shops and things, you know, so I have to adjust myself (Graham, 9, 9-12).

It was like my life was... well to be shut indoors really (Stacey, 6, 2).

Well we don't really go anywhere now (Brian, 14, 20).

Participants spoke consistently of activities they could no longer take part in and the sense of containment and frustration which this caused. Their language became very flat and passive, giving the impression of stasis and of being forced to sit and stay closed off from the world. This further highlighted the new sense of passivity and inactivity in their lives which was sharply juxtaposed with the active language about and movement seen earlier in life before Charcot (Section 4.1.1). As participants' corporeal beings experienced such restriction in the world, their everyday social connections were disrupted, altering their engagement with the world from dynamic to static. Participants were no longer able to drive or walk and negotiate the world in the way they used to. They had been cut off not only from their former lives but also from the people, interactions and experiences that went with them:

I'm interested in all sorts of things, but I'm not used to just being interested on the internet. I'm used to being there, doing it (Steve, 26, 21-23).

Whilst Steve remained interested and keen to experience so many of the things that life had to offer, he had been relegated to bystander status, an observer of his own life, sitting on the inside looking outward to the world with a longing that would not be fulfilled by mere observation. The world had shrunk from a big exciting place, full of opportunity and potential, to the confines of the flat screen of a computer or laptop. Experiences were suddenly virtual, to be read about and explored on websites or via snippets watched online. Most of the participants reported similar experiences:

I keep watching Coast on the television, although I've seen them all numerous times, but er... yeah, I miss that [minibreaks with his wife] (Brian, 20, 10 -12).

I don't know what options there are... um... apart from sitting down indoors and reading, which I do... which I have been doing now, reading, um.... or watch television. Um... no, there's nothing else... nothing else that.... As for the driving, the only thing I've substituted it with is PlayStation... (Colin, 16, 8 -13).

For Brian, for whom minibreaks with his wife were their main shared hobby (as described in sub-theme 4.1.1), these former holidays had shrunk to re-runs of Coast on TV, tantalizing glimpses of the world that remained out there, although he was now kept away from them. For Colin, his love of driving was partially substituted by PlayStation games. For many of the participants, even basic tasks such as shopping were now undertaken courtesy of the Internet. The wealth of opportunity which life had previously afforded them no longer felt within the participants' grasp.

Only two participants, who had existing hobbies which were conducted indoors, were able to easily maintain a meaningful form of activity. Graham reported that, whilst he wasn't a "couch potato" (12, 9-10), he continued to enjoy listening to music, and Roy's friend would come over so that they could paint together:

I collect vinyl records. So... what I do is er... I've been putting them onto CDs so I can store the records and er... yeah... so that's a hobby of mine, you know and I enjoy it (Graham, 12, 5-8).

I do oil paintings, you know... and my neighbour who's come up with me today, he started it when he retired but... he'd never done it before, so I ended up showing him a few things like (Roy, 23, 19-22).

Whilst participants felt as though their lifeworlds were smaller and more restricted, the world outside remained essentially the same. Their personal sense of containment promoted feelings of isolation which appeared to manifest in different ways as they each struggled to make sense of how their interactions with the outside world were altered. In many cases this sense of isolation was reinforced by the participants themselves as they struggled to adjust:

For a long time I avoided things that required me to explain myself, so my hair was the longest it had ever been because I wouldn't go to the barber. Now my wife dropped me off at the barber, I pootled in, she'd pick me up again, but I wouldn't go, didn't want to have to tell the barber (Steve, 27, 17-21).

I'm not going to go into details with you [friend on the telephone], but I've got something... I've got a cast on my foot. And he goes, what, have you broken something? I said no, no, no, no. I wish I had, but it's nothing like that. [Laughs]...I didn't even bother explaining to him, I just said look, just take it from me I can't come [away on holiday], I've got a cast on my foot, and that was that (Colin, 38, 5-10).

This avoidance of situations requiring explanation could be viewed as a self-protective mechanism. Both Steve and Colin's lifeworld's had become so markedly disrupted that nothing seemed to make sense. The strange and unfathomable nature of Charcot foot was also so difficult to explain that it was easier not to bother. Being unable to make sense of the situation themselves appeared to leave Steve and Colin with a sense of dislocation from their lives. Thus, it was easier to simply withdraw from situations requiring interaction, such as the barber for Steve, or to cut people off with statements like "*just take it from me*" (Colin). This confusion left them unable not only to articulate their feelings to others but also possibly to accept their altered lives themselves. It appeared far easier to shut everything out, further exacerbating their sense of isolation.

Whilst some participants deliberately isolated themselves to avoid having to explain their situation, others curtailed their involvement with the world by avoiding familiar, previously meaningful activities that they now found too painful to watch. Bill reported that he had deliberately started to avoid some of the larger martial arts training sessions:

I started being away, um... you know, basically while the training's on (Bill, 38, 14-15).

I might go up again in October, I might not, because one thing is you feel so jealous (Bill, 27, 7).

Bill recognised and openly acknowledged that it was too uncomfortable to be a bystander in what had previously been such an important life project. He needed to protect himself

from feelings of jealousy and of missing out. Linda however, possibly still struggling to make sense of these feelings herself, appeared to find this harder to articulate:

But you can't do it... what you can't do...and on holiday I couldn't play tennis with my grandchildren [] That was... I didn't go up there and watch (Linda, 9, 3-8).



Figure 23. A photograph presented by Linda of her family playing tennis. She indicated her discomfort at the thought of having to watch them play on holiday when she was unable to join in. Instead, she elected to stay away.

Linda cut herself off in this statement rather than try to articulate how difficult it would have been to witness a family activity in which she should have taken part. As spectators in life's activities, which they had previously enjoyed, the participants' sense of belonging seemed to have altered. This left them feeling like outsiders or strangers in previously familiar situations. As they could no longer interact within their old familiar lifeworld in ways that made sense, some participants preferred to isolate themselves further, to guard against what was simply intolerable to watch if they could not take part.

This sub-theme explored the sense of isolation experienced by participants as a by-product of their impaired mobility and reduced interaction with the outside world. It also highlighted how participants further isolated themselves with a protective shield from feelings of pain at the loss of familiar ways of interacting with the world. Participants' inability to explain this strange pathology and their ongoing struggle to manage life inside a TCC also appeared to lead to loss of confidence in social interactions. As the participants' embodied experience of the world became smaller and more insular, feelings of isolation prevailed.

Master theme 2. Summary

The aim of this master theme was to highlight participants' ongoing struggle to negotiate changing environments in the context of their unexpectedly hindered bodies. Participants' embodied consciousness of their lived places and spaces altered with the application of a TCC. As such, they encountered hazards at every turn and the world suddenly became a smaller place. For most, the management of active Charcot foot meant shutting themselves away, becoming boxed in, trapped and confined, away from the outside world. This felt lonely, bleak and isolated. This isolation appeared simultaneously as a consequence of immobility and as a self-perpetuated response to the participants' struggle to cope with what was happening to them.

4.3. Master theme 3. The diminishing self in a restricted lifeworld

This theme examines the diminishing sense of self that occurred following the destabilisation of participants' individual lifeworlds. Charcot foot management made the

participants' taken-for-granted worlds feel unfamiliar, and notions of selfhood and sociality were subsequently negatively impacted. Participants' lives lost much of the personal meaning and value previously fed by occupations, interactions and the social roles they had filled. Such important roles had helped to provide them with a sense of self-worth which subsequently diminished. Participants' identities, images and relationships became increasingly uncertain as they each struggled to make sense of the loss of their previously taken-for-granted ways of feeling, thinking and acting which had become the defining characteristics of their former selves.

4.3.1. The search for the lost self

This sub-theme reflects the direct impact of the diagnosis and management of active Charcot foot on the participants' sense of self. In their hindered bodies, participants felt reduced to lesser people, diminished in the face of their decreased abilities. This appeared to leave them grappling to make sense of their new post Charcot foot selves and in search of new definitions of themselves in their less able bodies. The lack of information available to the participants was felt to exacerbate feelings of confusion and loss. This section aims to highlight how the participants referred to their new diminished selves and their confusion about where they now saw themselves and their place in the world.

With the initiation of Charcot foot management and a reduction in their ability to negotiate their lived worlds, participants experienced a threat to their autonomous being. This left them feeling disempowered and like lesser versions of their former selves:

...but now clearly I'm an at risk person (Steve, 1, 12-13).

Steve did not refer to himself as having “*at risk*” feet, he referred to himself as an “*at risk person*”. This highlighted his feelings of vulnerability and that he felt potentially “*at risk*” of losing his former self, behind a barrage of health complications and decreased abilities. He had openly gone from being a high-powered, visible, active man with endless possibilities ahead (Section 4.1.1) to struggling with work and other basic functions. This version of himself felt less recognizable and less fulfilled. Others recalled a similar loss of sense of self:

Well you're different, yeah you're different and you... like I said. With things that normally you would take for granted, you're limited now (Roy, 37, 21-23).

It makes me feel inadequate, you know what I mean um... yeah it's just... it's just not normal to have that on your foot, you know, 24/7 you know, um yeah it...I feel... I feel um... I feel less of a man if you like... if you... yeah, I suppose I do, I feel.. yeah, I feel less of a man (Colin, 35, 17-21).

Participants' discourse consequently turned to the language of vulnerability and loss as Colin reported feeling “*inadequate*” and “*less of a man*” and Roy “*different*” and “*limited*”. Both had been stripped of the ability to perform effectively in many areas of life and felt they were being reduced to lesser people, possibly lacking in the manly qualities of strength and endurance. With the commencement of casting therapy, their taken-for-granted ways of being in the world were brought into question, taking with them their strength, pride and masculinity. Roy's focus in particular involved how his

actions now differed from what he used to be able to do, linking ‘doing’ with sense of self and who he used to ‘be’.

Aware that they could no longer fully identify with the former fully able-bodied versions of themselves, participants began to question where they now fitted within the world. Many appeared to undergo a temporal loss of identity following diagnosis, exacerbated by not only their loss of function but their uncertainty regarding how long this would continue:

I think the thing that concerns me most is the length of time I am going to be stuck in this cast (Graham, 9, 16-17).

One of the worst features of this thing... [tapping the desk] none of you know when this will end (Steve, 30, 24-26).

Well the original Podiatrist I saw at the doctor's said you'd have to have a cast on for a couple of months, and then from coming up here, it seemed to go up and up in time, er... and the last one I saw here said you could have it on between a year and two years (Brian, 3, 17-20).

Graham's use of the word “*stuck*” emphasised how he viewed his current position. Participants appeared both physically and metaphorically caught in a suspended state, between their previously able and now less able-bodied selves. With their bodies so

disabled in relation to their old daily lives, it could be argued that the unity between body and self was undermined. As Steve noted, whilst tapping on the desk to accentuate his point, nobody was able to say “*when this will end*”. Steve’s use of “*this thing*” highlighted how Charcot foot and its management felt like something almost separate from the rest of his body and how the entire episode felt alien to his previous state of being. The confusion caused by this limited or conflicting advice left participants feeling that practitioners were being evasive. For Brian, the length of time just “*seemed to go up and up*”; it was vague, misleading and intangible, leading to the feeling that a life free from Charcot foot was far from attainable. There was a sense that participants remained confused about their probable prognosis and what to expect.

As participants tried to make sense of their transitioning sense of self, they leant towards definitions which were familiar to them, questioning whether if they were no longer able-bodied – were they disabled?

Are you disabled with a Charcot foot? (Roy, 36, 26).

I don't see myself as disabled, um... but I see myself as, you know... what do I see myself as? I really don't know (Bill, 47, 25-26).

The overwhelming sense from these extracts was total uncertainty, loss and confusion. Neither Roy nor Bill appeared able to say where or how they currently viewed themselves. There was a sense of helplessness as participants struggled to reconcile themselves within the parameters of either the definition of disabled or able-bodied

people. This ambivalence led Bill to directly question where he now placed his sense of self, appearing to try to work through the thought process during the discussion, but to come up with nothing. It could be suggested that participants were left in a virtual no man's land, belonging nowhere. Many participants held on to the hope that their health and mobility would improve. However, in the absence of any concrete knowledge regarding how long this period of perceived disablement would last, their confusion was magnified. This left some participants adding a temporal qualification to their definitions to help them to make sense of their situation.

I've never used the word disabled, because I'm not paralysed and I... well let's assume I'll get better. But I am disabled at the moment, but I've never thought it, and others have used the term and it isn't that it was inappropriate. I am currently disabled, I am now... (Steve, 22, 11-15).

As a disabled person, which I've started calling myself now, I tell people I'm not an invalid, but I appreciate I'm disabled at the moment (Stacey, 10, 26-28).

I don't know how long you're on the sick before you become disabled, or temporary disabled, or am I classed as disabled? I don't know, you know, [] I would class myself as being temporarily disabled (Brian, 24, 26-28 - 25, 2).

The disconnect between how society appeared to perceive the participants and how they perceived themselves only confused them further in the absence of a firm sense of identity. There was a clear sense that participants were searching for answers about their

new place and self in the world but coming up with none. Steve appeared to be working through the thought process during the discussion stating in one breath that he had “never” thought of or used the word disabled with regard to himself and then in the next “*I am currently disabled, I am now...*”, highlighting that he may not have been ready to accept this definition of disability as a part of himself at that stage. He seemed to find the word “*disabled*” more comfortable after being referred to as disabled by other people, again possibly feeling that if this were the view of others in society, it would help to legitimise his claim.

Similarly, Stacey contradicts herself slightly in her extract. At no point in the transcript did she state she believed herself to be disabled, saying only “*I tell people*” and am “*calling myself*” a disabled person. This almost feels as if she is hiding behind a definition that others may recognise as she tries to explain her current embodied state to people around her. However, in a similar way to Steve, she does not appear to be either able or ready to fully integrate this definition into her personal sense of self. She clearly also felt the need to qualify this, stating that she was not “*an invalid*”, a potentially more derogatory term inferring weakness or a feeble nature stemming from her Charcot foot, something with which she did not appear to identify.

Brian gave an equally confused account, reflecting his inner struggle to make sense of his situation. Slightly different to the others, he seemed comfortable defining himself as temporarily disabled in his new less able-bodied state. His confusion was exacerbated by society, and more specifically the welfare state, which did not classify him as disabled and therefore did not offer him the help or support that he felt he so desperately needed. This could be said to have left him more confused and isolated than ever.

The lack of clear guidance around, and understanding of, the pathology of Charcot foot were contributing factors in the emotional turmoil experienced by participants. This lack of clinical advice and clear guidance on their new limitations and futures left participants grasping for other sources as they tried to seek out further information about where they now fitted within the world:

I've looked it up on the internet, but I've really concentrated on the diagnosis and the topology and I don't know if... I don't know where I'd look or if it exists about outcome, future, duration, rehabilitation (Steve, 15, 6-9).

Originally with the Charcot, he [his friend] looked it up on his computer and he said oh you could have your foot off. And I said oh thanks a lot... and he worked backwards from there (Brian, 30, 19-21).

I looked it up on the internet and saw what could happen and thought well I hope it's not going to happen to me (Linda, 19, 21-22).

The Internet appeared to provide the most accessible means of finding information for the participants. For Steve, it was important to break down his literature searches, focusing only on the process of the disease initially, as he did not feel ready to face information regarding the future and what the prognosis might mean for him. This drip-feeding of information was perceived to be his way of coping with the extent of both the literature and diagnosis and an attempt not to become overwhelmed.

For some, the information and images caused further fear, as demonstrated by Linda who did not progress past the images that filled her with dread at what could potentially be her fate; she possibly felt too overwhelmed to continue. Brian had to ask a friend to help him look for information, stating, *“I’m not into computers. Someone looked it up on the computer for me”* (Brian, 1, 12-13), highlighting further difficulties for those who are not computer literate. Unfortunately, he too came across the worst-case scenario of amputation in his initial search which could potentially have been a very shocking and alienating revelation. This was further exacerbated by the apparently dismissive way in which he was informed that he would be required to spend a period of time in a TCC:

I mean er... the Podiatrists, they’re dealing with people like me all the time but they just sort of flippantly say oh you have to have a cast on, like that, but it sort of shuts your life off, there and then for however long you’ve got the thing on for, you know (Brian, 11, 2-5).

The shock of diagnosis for Brian and the way in which he was informed of his recommended management plan left him at a loss and *“disillusioned”* (Brian, 11, 17). This could be perceived as a very dehumanising and disempowering experience which may have inflamed the confusion at his changing sense of self. He describes feeling like just one of any number of patients that the HCPs had to deal with, potentially leaving him further isolated and less likely to turn to them for help and advice. This highlights that whilst his physical condition may have been treated adequately, Brian’s personal experience of living and coping with Charcot foot was not accounted for or addressed. Bill highlighted a similar discrepancy between the advice needed and that given:

I think you'd really need time, because it's such a brand new subject effectively. You really need time to sort of soak it in and then ask more questions and... but when you're only seeing somebody maybe once a month, it's difficult because you go in there loaded with questions and they've only maybe got five minutes to see you and you never can ask. I always know when I've overstayed my welcome because they're backing off out the door (Bill, 15, 24 - 30, 16, 1).

The opportunity to ask questions was perceived as vital and was mentioned by several of the participants as they struggled through the sense-making process, although from Bill's statement above, this was not always achieved. Most appeared to feel that having access to more information would be beneficial and would have helped them to understand and cope with their diagnosis better. It was clear to Steve that any form of further advice would have been preferable to that he actually received:

I think I would have benefited from more specific advice about weight bearing. And even if it was bullshit and you don't really know the answer, but made it up, a few rules would be better (Steve, 10, 14-17).

This statement could be said to imply a degree of desperation. There is a grasping tone, hinting at the absolute need for something more tangible to grip onto, even if it was not true, as Steve underwent this traumatic transitory period in his life.

With the intrusion of Charcot foot management in the participants' embodied sense of self, their pre-existing beliefs about themselves and their place in the world were brought

into question. Participants appeared to feel as though they were at risk of losing themselves behind their new reduced place in the world and as though they were somehow becoming lesser versions of their former selves. They seemed unsure of who exactly they were at the point of interview as they struggled to integrate their altered body with their existing self-concepts. The lack of available information was felt to exacerbate their struggle to understand and come to terms with such dramatic and sudden changes.

4.3.2. The stigmatised self

This sub-theme explores the sense of stigma and shame experienced by the participants and the consequences of this with regard to their fragile sense of self and perception of their own visibility within the world. The reactions of others in response to the alteration in participants' physical appearance following TCC application were a perceived cause of stigma. Similarly, the fear over longer-term changes in image due to surgical footwear were reported to be a concern for some. Stigma, self-blame and shame were also discussed in relation to the background presence of diabetes.

For many of the participants, their sudden inability to control how they projected themselves to the world brought an unwelcome change to their self-image. For Stacey in particular, “*as a woman*”, her footwear represented part of her feminine persona. The way she was able to present herself to the world not only enabled her to think she looked good, it also changed the way she felt about herself:

I felt I was dressed really... when you feel really nice, going out, blah blah blah, and then it got to the shoe situation. I said that I was going to put on a bit of a heel, to match up with... I can't remember what I had on, whether it was the

Aircast or this cast, and I was going to match them up and Nigel told me not to be so stupid and put a pair of flat boots on. But as a woman, it's nice to go out in... I don't wear big high heels anyway, but I think you always feel a bit more dressed in a nice pair of shoes and that was a real downside. That was a big thing that hit me, being in a flat boot, that I would normally wear daytime. Didn't have any dressy nice shoes to go out in, so I did feel a bit... well underdressed. It sort of wiped the rest of my clothing out I found (Stacey, 8, 3-15).

Having control over her footwear previously enabled Stacey to project her social identity to the world. Her conscious intentionality with regard to her feet now appeared to elevate their status in her life, as Stacey referred to her footwear as a “*situation*”. Having to wear a cast to a public event appeared to eclipse the rest of her outfit and assumed full focus both of her altered image and her consciousness of the cast and its social impact. It could be argued that this felt quite dehumanising as she no longer felt “*dressed*” and felt that the cast wiped out the rest of her outfit, leaving her exposed. The cast was then interpreted as a public representation of her illness, the very embodiment of her disease, rendering her former self less visible. For Stacey, her sense of self and image, both as a woman and as a facet of her work in the beauty industry, could be argued to be a priority, further increasing its perceived impact.

Similarly, for Steve, a prominent and arguably very visible man at the top of his profession, the changes in his appearance and mobility were keenly felt. He was acutely aware, when he took to a wheelchair, of the perceptions of others concerning his perceived level of mental capability as a consequence of his very obvious physical impairment:

If you go, in a wheelchair in particular, but look disabled in any event, people subconsciously start to treat you as if you were mentally disabled as well. Not fully, but impaired in some way, and they don't have the same.... respect is the wrong word, but they just don't treat you with the same seriousness (Steve, 19, 23-28).

In a profession where an image of strength and health may have been valued highly, Steve seemed to feel that he was becoming increasingly invisible following the change in his appearance. He appeared to view himself as though reflected through the eyes of others as the level of “*seriousness*” afforded to him in his publicly less able-bodied state deteriorated. Steve experienced the sensation that his power and importance were being eroded at work and with them a part of himself:

While he [his manager] talks a really good and supportive game, he will frankly erase me and he tried to already (Steve, 20, 12-13).

For Steve, the stigma of physical ill health was manifested in feelings that others were trying to erase him, with the implication that he was no longer fit for his public role. He appeared to feel that he had been labelled by those around him, seemingly becoming his disease. This was perceived to affect not only his physical but also his mental capabilities. This left him focusing on his corporeal body as it was perceived by others. Feelings of embarrassment and shame then took over as he stated many times throughout the interview; “*I'm embarrassed and humiliated by the feet, I really am*” (Steve, 13, 19-20).

His use of “*the feet*” in this statement as opposed to ‘my’ feet further highlighted how alien this new sense of being felt compared to his former sense of self.

Colin was potentially the participant most disturbed by the reactions of others as his perception of his increased level of visibility became a preoccupation and great source of distress:

I use the underground, yeah? Close quarters you see, you're sitting down against... opposite each other and things like that and you're looking down, and you can see them [other people] looking down at your foot, you know what I mean, and you think if I could just hide it somewhere, you try... I try to hide it behind my other foot, you know what I mean, but there's no way I can really, you know what I mean, it's too big (Colin, 23, 25-30 - 24, 1-2).

I can't... I can't stand on the door [at work], I can't stand on the door... I'm not prepared to stand on the door with that thing on my foot for one, and um... because I feel embarrassed, everybody coming in and seeing me with it on (Colin, 17, 12-16).

Colin felt increasingly visible and as though the TCC actively drew the focus of others who were “*seeing*” him as strange and different. This may be viewed as a projection of how Colin felt; less comfortable, shamed and embarrassed by his altered appearance. He seemed to feel instantly alienated from both the people and the world around him, leaving a sense of claustrophobia and panic. He felt unable to escape the stares and judgements of

those around him in the same way he could not escape the cast. He wanted to hide and find protection by disappearing and becoming invisible.

Footwear was also mentioned as an issue for Stacey and Roy as a further, longer-term visible reminder of their foot complaint:

They [orthopaedic footwear] remind me of the shoes you'd put on a teddy bear to fit their big whacking feet into. In fact that's exactly what I think of them, and I want to still wear my boots and stuff like that. I'm happy to wear orthotics inside, but, you know, I draw the line at that vision I've got of the teddy bear boots really. Big wide... bouffy things... (Stacey, 10, 1-6).

I mean I know that they do shoes for this type of thing, I mean God knows what... would that be that big would it that shoe (Roy, 32, 15-17).

The image Stacey presented of orthopaedic footwear was clown-like and exaggerated. They were designed to fit “*big whacking feet*”. This was possibly how she feared her feet may look once the active Charcot foot process had settled. Whilst invisible interventions such as orthotics may have been perceived as tolerable, surgical footwear would not allow her to disguise any remaining deformity. This possibly highlights her fears regarding a permanent alteration to her image, an important facet by which she was able to demonstrate her sense of innate identity. Thus, it could be argued that the participants feared the potentially more permanent transformative power of their footwear, marking them out as different and attracting unwanted attention. They were eager to hide ongoing

deformities from others in order to regain their former image and identity, perhaps feeling, like Steve, that they may not be taken as seriously in their large and clown-like attire. Their view of surgical footwear would not project the present selves that participants wanted the outside world to see. Footwear could be seen as a critical part of self-image and self-representation to the outside world, potentially preventing participants from being able to actualise their unique selves apart from their disabilities.

Feeling shamed, stigmatised and embarrassed after viewing themselves through the eyes of others, some of the participants then looked back again to examine the trajectory that had brought them to this point:

It [Charcot foot] would be avoidable if I had had far better diabetic control, if I had obeyed all of the rules instead of cheating, which I did. We probably all do. And it would have been better if I hadn't got to this point. And so those feelings are... it's your own fault... Come on... a lot... a lot... within me and mine... which is public humiliation and shame (Steve, 22, 2-7).

I did used to consume, before I was diagnosed, an awful lot of sugar (Brian, 25, 29 – 26, 1).

When you introduce food to diabetes anyway that's a downfall, that's when it goes here, there and everywhere, so whereas I was really controlled before, you know, my diabetes can start bouncing a bit from eating the wrong stuff, and then I'm

thinking am I making the foot worse by it not being controlled and... then I get up the next day and do the same thing again (Stacey, 13, 11-18).

If I'm doing something wrong I need to know, you know what I mean, it ... whatever... if it's food I'm eating or not, I don't know what it is (Colin, 21, 5-9).

As participants questioned how they had arrived at their current situation, feelings of self-blame and guilt rose to the surface. In each of the abstracts above a particularly moral tone is adopted, with words such as “*cheating*”, “*fault*” (Steve), “*awful*” (Brian), “*wrong*” (Colin) and fears of “*making the foot worse*” (Stacey). There appeared to be an ethos of participants apportioning blame upon themselves for the existence of their Charcot foot because of their actions and relationships with food. The introduction of food was even referred to by Stacey as a “*downfall*”, a failure on her behalf that had become her undoing. However, she also noted that, whilst she had long since recognised that her behaviours were at times self-damaging, she had not always been able to stop herself, thereby creating an ongoing spiral and further guilt. Steve in particular believed that the entire experience could have been avoided had he “*obeyed all of the rules*”. There is a submissive, robotic air to this statement, as Steve demonises himself as untrustworthy and harbours sentiments of guilt and self-contempt. This explicit judgement of himself, possibly for his perceived unhealthy lifestyle choices, gave rise to feelings of stigma, “*public humiliation and shame*”, as he assumed that others would likely judge him the same way.

The idea of blame could also be seen in discussions about self-abuse with both Steve and Stacey:

Because with diabetes it is either chronic disease of self-management, self-abuse, self-mismanagement... for me at least guilt is never far below the surface, never, never, never. And I'm not happy with this disease (Steve, 13, 16-19).

The [first] six weeks of having Charcot, you know, I was so careful, really didn't want to put on weight. My diabetes was probably one of the best periods of time it was controlled, apart from having my kids and that. But it's almost like I can self-harm, self-destruct with my diabetes (Stacey, 12, 15-23).

Each of these statements was strongly worded. “*Self-management, self-abuse, self-mismanagement*” (Steve) and “*self-harm, self-destruct*” (Stacey) are terms loaded with blame. Whilst Steve’s diabetes itself gave rise to these feelings, the presence of Charcot foot appeared to add an extra dimension. Unlike many of the more hidden complications of diabetes, management of active Charcot foot with a TCC offered a visual reminder to the world of these complications, adding to his humiliation. Stacey also discussed the complex relationship that she had with her diabetes and its control, as she had veered from excellent self-control to periods of self-destruction, highlighting the symbiotic relationship between feelings, emotion and diabetes management. The importance that she placed on her Charcot foot was evident from her comparison of when she was pregnant with her two children and such optimal control was a priority for their health. However, in her periods of poorer control, self-harm and self-destruction, the battle for

self-control seemed lost, possibly reflecting her internal feelings regarding Charcot foot and the effect it was having on her life.

Participants felt very visible, and for some, increasingly invisible, inside the cast as it removed their power, eroded their individuality and was a beacon of unwanted attention highlighting their deteriorating health and lives. This led to feelings of shame, blame and stigmatisation as they were forced into self-evaluation, viewing themselves through the eyes of others. Some participants appeared to fear that this would continue if orthopaedic footwear were required in future, potentially permanently altering their self-image.

4.3.3. The relational self

This sub-theme examines the direct effect that the diagnosis of Charcot foot had on the personal relationships of the participants. Participants already struggling to cope with their diagnosis and the associated life changes also had to consider loved ones' reactions to life alongside a Charcot foot. Feelings of increasing burden to loved ones through the loss of previous life roles were pervasive throughout many of the participants' accounts. The complexities of these interactions often ultimately resulted in a form of withdrawal from family members.

The relational self was one identified as less autonomous, increasingly dependent, and a source of burden. Where many participants were the primary income earner or housekeeper prior to their diagnosis, they suddenly had to be provided for or ask others for help around the home. With the cessation of these important self-affirming roles, participants were left at a loss and uncomfortable with their new reliant selves:

I picked my daughter up from school and I'd take her and we'd go shopping, and I'd take her down the supermarket, and now her partner, he er.... She goes down there and does the shopping and waits for him to come and pick her up and er... they bring it round to me and then go home (Graham, 20, 7-11).

If I want a few pound for something, I've always got to ask her [his wife] for money (Brian, 9, 28 – 10, 1).

He [her husband] works long hours and to then come home and do housework in the house, blah, blah, blah, it's too much, you know. He'll end up having a heart attack (Stacey, 23, 5-8).

I've got this feeling that I'm making him [her husband] work... I don't want to make him work too hard... [] Yes, so... I do... I suppose, a bit more than I should (Linda, 16, 5-9).

With the onset of active Charcot foot management, Graham suddenly found himself reliant on his daughter for help with tasks that pre-diagnosis he had helped her to do. The reversal of this part of their father-daughter relationship also potentially reduced some of their quality time together. The last four words of his statement “*and then go home*” make the task feel burdensome and rather perfunctory. This highlighted Graham’s awareness that his daughter was having to go out of her way to help him, which was likely not convenient, and made him feel uncomfortable. For Brian, the loss of his job as a consequence of Charcot foot management took him from breadwinner and provider to a

kept man, as he found himself financially reliant on his wife. The constant need to ask permission for even the smallest of things whenever he wanted “*a few pound for something*”, could have been quite humiliating for him and a constant reminder of the autonomy he had lost. For both of the female participants, their previous role as housekeeper was impossible to uphold without assistance from their spouses. This inability to continue to manage the home effectively made them feel even more burdensome, anxious and fearful for their partner’s well-being.

Stacey was the only mother of young children in this sample. Being a mother was a huge part of her identity and this had been severely compromised by the onset of Charcot foot. There was a sense that with her loss of function she was metamorphosing into a different kind of mother entirely:

I think, you know, all these mums that er... they talk about in the newspaper for their kids shouldn't have been doing this, shouldn't have been doing that, and I think well I'm one of them now (Stacey, 18, 10-18).

Stacey no longer appeared to feel that she could be the mother that she had been prior to the onset of her Charcot foot. There was a sense of otherness, a difference between herself and “*these mums*” that she had negatively read about previously, and with whom she would never have identified before. She appeared to be waiting for the exposure, judgement and public retribution for the new neglectful parent which she felt she had become. This could be argued to highlight feelings of judgement about herself at her

failure to maintain her role as the mother with whom she previously identified. She went on to state:

I can't always face going back upstairs again to go and give them a kiss goodnight sort of thing. So, I do tell them I'll be up later and they're normally asleep by the time I go up, because it's then bedtime for me to go up (Stacey, 27, 23 - 28, 1-3).

The loss of her ability to kiss her little boys goodnight could be seen as causing not only a physical but an emotional distance between them as the most instinctive, nurturing aspects of mothering, to comfort and cuddle ones children, were lost. This induced further feelings of guilt and failure similar to those experienced by many participants. This emotional and physical distance developed in many relationships, as participants struggled to make sense of the sudden changes in their lives brought about by the management of Charcot foot:

I mean since I've had this because and the leg and that, I've been sleeping downstairs. She sleeps upstairs and I can just go off to bed, I won't even say goodnight you know. I know I'm in the wrong to a certain extent, but... you know, what do you do? (Brian, 10, 5-9).

She doesn't like the feel of the cast on her at all, so of course she... she'd rather I slept in the front room, so of course that's interfered with my love life as well, you

know what I mean, and um... non-existent love life at the moment, er... um... which again I do....I miss that... I miss that as well (Colin, 29, 5-10).

As participants struggled to come to terms with life with a Charcot foot, many appeared to regress and shut themselves off from other members of the family. The extracts from both participants carry a heavy sense of loss, as they seem aware of the distance being created between themselves and their spouses, but unsure how to alter the situation. In the case of Colin, this distance appeared to be instigated by his wife and he openly mourned the loss of their more intimate moments together:

It's the intimacy, there's just no intimacy between us anymore (Colin, 29, 18-19).

The loss of intimate moments and sexual relations to which Colin was referring could also be argued to exacerbate a loss of emotional connection between them as they each struggled to come to terms with the effect of the management of Colin's Charcot foot on their lives. He feared the effect which the situation was having on their relationship but felt unable to discuss this with his wife:

I must admit that's how I feel. Hmm. And I don't... I don't think she's aware... well I don't... well I haven't told her that she makes me feel like that, because, you know what I mean, that's only just going to add more pressure onto her (Colin, 35, 26 - 36, 1-3).

In his struggle to make sense of his situation, Colin appeared to fear increasing the sense of pressure and burden he was causing his wife. He appeared to close off emotionally in the face of this fear, because whilst he recognised the need for extra support he was unable to reach out for it. Thus, he chose to keep his feelings hidden. A similar sense of secrecy was noted in the following extract from Steve:

I manufactured a mini-row and took myself off into one of the kids' bedrooms and the real reason was I wanted to cry. But I didn't want to do it in the bedroom because I didn't want her to, you know, comfort me and say it'll be alright or whatever. I didn't want to do it. I just wanted to crawl under a rock. So I crawled into one of the kids' beds and crawled under that duvet (Steve, 31, 15-21).

Unable to reconcile himself with this new burdensome, less autonomous self, Steve appeared to be trying to close out the world and the person closest to him by retreating and shutting himself away. It felt important for him to hide his grief, pain and suffering from his wife, to push her away with a manufactured argument, legitimizing his disappearance and giving him the time and space he needed. He may have wished to protect both his wife and their relationship by hiding his true feelings in a similar way to Colin. He was also potentially protecting himself from further shame, from the visible self-pity and loss of control that came from his need to cry and express his grief.

This sub-theme has explored how, with the onset of active Charcot foot management, both physical and emotional distances were created between family members. Feelings of guilt, burden and failure then prevailed. Participants' sense of self, as part of a larger

entity in the family, altered. For some, familial roles were completely reversed, leading previously empowered individuals powerless and vulnerable. With the loss of these roles an element of the self with which they had previously identified was removed.

Master theme 3. Summary

This master theme has explored the multifaceted effect that Charcot foot diagnosis and the initiation of casting therapy had on the participants' sense of self. As active Charcot foot management commenced, participants' reduction in mobility gave rise to a reduction in the sense of self. This led many to question where they now fitted within the world, leaving them with a temporal loss of sense of self and struggling to find answers. Self-image suffered as participants were no longer able to present themselves in ways which felt natural, altering their very visibility within the world. This led to feelings of stigmatisation and shame and linked their Charcot foot with their diabetes control. Finally, the effect on relationships and participants' relational sense of self was also impaired as they began to feel burdensome to the family as many of their life roles were lost. This led to feelings of both internal and external separation, further pain and suffering.

4.4. Chapter summary

The analysis throughout this chapter has explored the lived experience of eight people diagnosed and living with active Charcot foot against a background of diabetes mellitus. This was presented in terms of three main master themes: life journey interrupted, the hindered body in places and spaces and the diminishing self in a restricted lifeworld. Each master theme was split into smaller sub-themes in order to fully examine the complexity and diversity of areas discussed by the participants.

Within master theme one, participants' sense of temporal disturbance and loss of previously planned life journeys were explored. Feelings of reverence to participants' past lives were examined as they focused on how limitless and full of possibility their pre-Charcot foot lives now appeared to their post-diagnosis selves. The participants experienced a deep sense of mourning and loss for their old lives as they struggled to come to terms with the loss of their meaningful activities and interactions within the world. The final sub-theme explored participants' fear for the future and the disturbance to the entire perceived time line of their lives. In stark contrast to currently available literature, this section also revealed feelings of depression.

The second master theme, the hindered body in places and spaces, explored how with the initiation of the management of active Charcot foot, participants' experience of their lived space was altered. Following initiation of casting therapy even safe environments such as home presented hazards and instilled a sense of fear and danger at every turn. This led to a containment of the participants' lives, effectively causing their entire lifeworld to shrink and reduce to virtual experiences. A deep sense of isolation prevailed and was further exacerbated by the participants as they tried to protect themselves from confronting the pain of their losses and struggled to adjust to life with an active Charcot foot.

Master theme three, the diminishing self in a restricted lifeworld, primarily explored the participants' altered embodied relation to, and interaction with, the world. These alterations caused them to feel lost and reduced, and separated them from the selves with whom they had previously identified. Many participants underwent a temporal loss of identity. This was exacerbated as they struggled to search for information regarding where they now fitted within the world in their disabled bodies. Image as part of identity

was also examined in the stigmatised self, as participants were forced to review themselves through the gaze of others. This was examined alongside diabetes as the aetiology of their Charcot foot which led to feelings of guilt and blame. Finally, the effect on participants' loved ones and their relational selves was examined as participants found themselves to be an increased burden to others. Some also stepped back from relationships creating both physical and emotional space from relatives.

4.5. Findings reflexive statement

In this section of my reflexivity I consider how I may have affected the research findings. It is essential to reflect openly on my own cultural situatedness because I am co-creating research with other people (Shaw, 2010). I am a white, unmarried, British female and I undertook this research in my early to mid-thirties. My age in particular may have marked me out as different to my study population whose ages ranged between 46 and 73 at the time of interview (see Table 7). Also, of my eight participants, only two were women, further differentiating me from two-thirds of the study population. I felt that the person with whom I had the greatest rapport was Stacey, the female participant closest to my own age who spoke very freely and openly with me throughout. The participant who remained the most stoic, and with whom I found it most difficult to build rapport where I could explore his innermost feelings, was Graham, one of the older male participants. This may reflect some of the findings reported by Underwood et al. (2010) in their paper regarding reflexivity and impact of age-cohort differences between researcher and research participants. They noted that cohorts of older people were uncomfortable speaking about their bodies, often giving shorter answers and comments than younger participants due to the socially constructed and culturally constituted nature of their generation.

Whilst I did try to consider my dual role as practitioner and researcher carefully and to negate as many conflicts with regard to this duality as possible, it is likely that this still affected interactions with my participants. Graham was one of two participants who redirected clinical questions back towards me during the interview (the other was Roy, notably the two oldest male participants). For example, when I directed the conversation towards any concerns he had, he would sometimes try to turn the conversation back to a clinical question, possibly to mask any discomfort:

Well, it's er... it's a bit awkward getting around, isn't it? This is it, you know, but um... occasionally I get a twinge in it, but I always put that down to old age to be honest. But no, I don't er... I'm just wondering, you know, as I say, have you seen the x-rays (Graham, 14, 19-20 - 15, 1-2).

Although I was able to deflect questions back to the interview, without cutting off or alienating participants (in this case, I said that I did not recall having seen the x-ray, but that one of the clinical staff may be able to check after the session), this reference to my clinical role made me realise that, despite every effort to distance myself from the clinic and present myself as a researcher (as discussed Sections 3.10.3 and 3.21), this was how participants saw me, at least in part. Graham was possibly one participant who was more comfortable with me in that role.

There was further evidence that I was still viewed as a practitioner in the potentially muted responses which participants gave regarding their experiences within the foot clinic itself. Potentially fearing the consequences of their interview may affect their

medical care, participants may have tried not to make negative reports or may have distorted their accounts in order to make themselves or their compliance look good. Examples include Brian's retraction after calling the response from a podiatrist in the clinic flippant, and Roy's preamble prior to making a criticism of his TCC:

Er... well maybe, I didn't say flippant but they... they just sort of say... (Brian, 11, 10-11).

No disrespect meant to anybody... (Roy, 18, 7).

Whilst I was not trying to ascertain the participants' experiences of the clinical sessions, this is in fact an important part of their lived experience, and had they wished to discuss it further, my dual role may have prohibited this. On the contrary, Bill, who also acknowledged my role within the clinic, acted almost conspiratorially when disclosing in a small way that he hadn't always been completely complicit with advice given by his surgical consultant:

I don't know it's maybe not such a good thing... if you maybe don't tell Ray [consultant] ...both laugh... (Bill, 46, 29-30).

In addition, whilst I was recognised as a specialist podiatrist, I was also seen as a student studying for a postgraduate qualification. There was a risk that the participants may not have taken me seriously since they were aware I was studying for a qualification and may

possibly have questioned my motives for speaking with them. Despite this, my status within the clinic, and the fact that participants were on occasion initially approached by another HCP, may have helped to give me the credibility I needed. All participants appeared to feel that this work was of genuine importance. Of course, their responses to me with regard to the research may also have been affected by a need to appear supportive for fear of later retribution. Ultimately, it was the nature and level of detail in the responses, which led me to believe that the participants were accepting of both the study and myself and not inclined to hold back. As Colin reported at the end of his interview:

I feel like I'm speaking to a counsellor...laughs a lot... rather than someone doing research. Sorry about that... (Colin, 36, 15-17).

Whilst I did not openly disclose that I am unmarried I do not wear a wedding band and used to be told frequently in clinic that I appeared younger than my 30 years. This may have left participants feeling that I would not understand the complexities of their relationships/marriages and may have influenced what areas of their lives participants were happy to discuss with me. It is perhaps of note that only one participant discussed sex. Colin discussed this quite openly with me which did initially surprise me at interview, although looking back my surprise was not reflected in the transcript. Colin was the last of my participants to be interviewed and sex was an area that, naively, I had not considered previously. Reflecting on my surprise, this was possibly because it is not an area that I have ever really discussed in my previous clinical interactions, although with further reflection, this is something that as practitioners we should potentially be more open to, especially as sexual dysfunction is also a known side-effect of diabetic

neuropathy. Difficulties in this important area of relationships are acknowledged much more openly in other pathologies, such as rheumatoid arthritis where, for example, literature is available to offer practical advice regarding sexual positioning. Remaining closed to the possibility that sex was an issue for the participants could have potentially barred me from smaller less obvious inferences to the topic in other conversations and therefore influenced my lines of questioning.

I struggled for a long time to write the findings chapter – possibly due to my medical background and in part because of the way that I learn and understand things. I like to lay things out and clearly explain them, resulting in repetitive and descriptive writing as I attempt to situate every point and make my thoughts clear both to myself and the reader. A lack of confidence meant that I would often reiterate the same point in another way to make sure I was being understood. I feel that my background in a medical field, and maybe my own rather literal personality, also often made it difficult for me to initially delve into the deeper levels of interpretation. The findings chapter was the most difficult to write and conceptualise and the findings themselves went through many iterations before they became what is presented here today. Initial versions used the idea of breaking down sub-themes into concepts. As I concentrated on compartmentalising sections, the chapter lost flow and synthesis making the work feel fragmented and repetitive. Removing the breakdown of sub-themes into concepts when writing-up has helped me to produce a smoother, more integrated chapter. I also initially placed all of the quotes backing up my themes in a table at the start of each sub-theme to help me focus on them collectively whilst writing, in an attempt not to micro analyse and discuss each participant individually. The tables were subsequently removed, but this practice helped me to achieve more synthesis as I wrote.

Finally, I feel that as a consequence of my long research journey and several iterations of this chapter, that I have come to a point where I am more confident in my interpretations of this work. My new-found confidence was bolstered by being offered an oral presentation of my findings at the 2nd international IPA conference in Glasgow this year, where I received excellent feedback regarding my themes, use of photo elicitation and the PPI group. A copy of the abstract is shown in Appendix 16.

Chapter 5 Discussion

The primary aim of this study was to explore and gain an increased understanding of the lived experience of active Charcot foot as a consequence of diabetes mellitus. An interpretive phenomenological approach was used in order to generate a rich, thick textual account, highlighting the hitherto unrecognised issues associated with the diagnosis and management of active Charcot foot. Findings consistently demonstrated that both the severity of the diagnosis and effects of the on-going management with a TCC had a profoundly negative impact on all aspects of daily life, participants' sense of self, psychological state, relationships and lived time and space. Notably these findings are at odds with the currently available, mainly quantitative literature, which predominantly suggests that active Charcot foot only has a significant impact on the functional component of health related QoL (Chapman et al., 2011; Dhawan et al., 2005; Pakarinen et al., 2009; Pinzur & Evans, 2003; Raspovic & Wukich, 2014; Raspovic et al., 2015; Sochocki et al., 2008; Vileikyte et al., 2008; Willrich et al., 2005).

This chapter begins with an exploration of the findings highlighted in the previous chapter in relation to the research question and within the framework of existing literature and phenomenological philosophy. A discussion of implications for clinical practice will then be undertaken, followed by examination of the strengths and limitations of the study and suggestions for further research and practice. The chapter will conclude with a reflexive statement.

5.1 Discussion of the findings within the framework of the existing literature

Participants' accounts of their lives following diagnosis and initiation of management for active Charcot foot highlighted the embodied nature of their experiences. The lived body represents our source of meaningful understanding in the world (Todres, 2007). Merleau-Ponty (1962) described a person's body as their 'vehicle of being in the world', stating that 'having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and to be continually committed to them' (Merleau-Ponty, 1962, p. 82). In the cases of the participants in this study, the diagnosis of active Charcot foot rendered their foot and therefore their 'vehicle' for negotiating the world, damaged. The initiation of management with a TCC further impeded their mobility. With their ability to negotiate their lived worlds hindered, participants found their entire lifeworld altered. Ashworth (2003) recounts a list of seven 'fractions', which combine to make up a person's lifeworld:

- Embodiment – How the situation relates to feelings about their bodies, including emotions and disabilities;
- Temporality – How the sense of time duration and biography is affected;
- Spatiality – How their pictures of the geography of the places they need to go and act within are affected by their situation;
- Project – How the situation they are in relates to their ability to carry out activities to which they are committed to and which they regard as central to their life;
- Selfhood – What the situation means for their social identity and feelings of agency, presence and voice;
- Sociality – How the situation affects relations with others;

- Discourse – The sort of terms employed to describe and live the situation, e.g. social, commercial, ethical or educational etc.

Each fraction exists in relation to the others and whilst each may be differentiated, they may not be separated (Van Manen, 1998). For the participants in the current study, it was clear that no area of their lifeworld was left untouched by their active Charcot foot, with findings appearing to mirror these fractions. Therefore, as this chapter progresses, each fraction will be explored sequentially in relation to the lifeworld alterations of the participants.

5.1.1. Embodiment

The belief that in health the body goes unnoticed (Ratcliffe, 2008) or is ‘passed by in silence’ (Sartre, 1958, p. 354) is well accepted in phenomenological philosophy. In daily life our embodied consciousness generally engages with the surrounding world pre-reflectively (Finlay, 2011), as ‘it is the essence of consciousness to forget its own phenomena’ (Merleau-Ponty, 1962, p. 58). Thus, our corporeal reality as a whole tends to disappear within the flow of daily life (Aho, 2013). As Hammell (2004a, p. 298) neatly paraphrases Sartre (1958), ‘one does not examine values or meanings when engaged in the predictable routine of daily activities, but when crisis compels reflection’. Therefore, in the normality and routine of life pre-Charcot foot, it could be suggested that much was taken-for-granted. This taken-for-granted aspect of life took a sudden turn when faced with the diagnosis and management of active Charcot foot and the opportunity to reflect on this during the interviews was highlighted.

With the onset of active Charcot foot management, participants' sense of 'embodied consciousness' (Finlay, 2011, p. 30) appeared to have been altered. This may be explored further, at least in part, using Merleau-Ponty's (1962) exploration of phantom limb pain in which he states: 'To have a phantom arm is to remain open to all the actions of which the arm alone is capable' (Merleau-Ponty, 1962, p. 81). Whilst participants of this study did not have a phantom limb, they did have a limb which, whilst it remained physically present, was no longer fully functional. Experience and proprioceptive awareness of the lived body is not that of individual limbs, it is an awareness of movement which involves the whole body (Romdenh-Romluc, 2011). As such, the inability to perform actions reported by Roy as "*soppy*" or "*silly*" (25, 12), such as negotiating stairs (Graham), pulling up weeds (Linda) and negotiating the wet floor of the kitchen (Stacey) without falling, (Section 4.2.1), increased participants' embodied sense of confusion. Whilst participants retained an understanding of how to complete these tasks, the ability to carry out such actions safely and intuitively was lost. Toombs (2001) suggests that this may remain the case for as long as the body remains open to the types of actions to which the affected limb would be central, if it were still functional.

Such losses serve to accentuate the difference between the objective body and the habitual or subjective body (Carel, 2012). The 'objective body' (Finlay, 2003a, p. 167) is one generally known as the 'other'. We are able to observe and objectify another's body, subject it to investigation, dissection, admiration and criticism. In doing this, we become aware of it as a biological thing, material and contained. In times of illness when we are unable to take our bodies for-granted we can do this to ourselves. There is a fundamental ontological distinction between this perspective and the 'subjective body' as lived and experienced pre-reflexively, in the taken-for-granted world, prior to the onset of illness (Finlay, 2006, p. 20). Although the participants' objective bodies still had four limbs,

their lived bodies were required to negotiate the world without functioning as they did previously. Hence, the presence of active Charcot foot is not merely a suboptimal dysfunction of a bodily system. Rather, it represents a systematic transformation in the way that the body experiences and can perform tasks as a whole (Carel, 2012). This removed the participants' sense of bodily certainty that is attached to the passive expectations of our actions (Ratcliffe, 2014). To use Ratcliffe's (2014) example here, 'when I put one foot in front of the other, I do not merely anticipate that it might touch the ground; I take it as a given that it will' (p. 272). Once more, this loss of bodily synthesis with the world is demonstrated by the confusion which Roy experiences when stepping off the bus and falling over, as noted in Section 4.2.1.

In health, people come to know their body and to trust in the information it provides for them through their senses. When these senses are blocked or distorted, such as in the case of DSPN and its complications, the information provided may become difficult to interpret or understand (Corbin, 2003). This can give rise to bodily doubt (Carel, 2016) and a loss of trust within the world (Ratcliffe, Ruddell, & Smith, 2014). This resonates with the findings of Vileikyte et al. (2005, 2009) that feelings of unsteadiness were predictive of depressive symptoms and also with Vinik et al. (2005, 2008) that perceptions of weakness as a consequence of DSPN were a prominent factor in impaired QoL (Section 2.12). Such feelings of bodily doubt, Svenaeus (2014) argues, can have 'the power of overwhelming, plaguing, and deadening the self in a way that can feel like parasitic overtaking' (p. 202). Stacey, for example, began to question her own cognitive function, as hospital dates and the Charcot foot were all she felt able to think about (Section 4.1.2). Likewise, Bill felt that at times his life had been consumed by a "black hole" created by the embodiment of Charcot foot.

It could be argued that this represented a feeling of ‘unreality’ (Ratcliffe, 2016, p. 64) or an altered feeling of being in the world. Meaningfulness in life is about finding meaning in reality. It implies a feeling of engagement with living and having things that matter within our lives. Lack of meaning may manifest in general apathy and lack of involvement (Stevens, 1997). This apathy and lack of involvement were evident in several of the participants’ accounts post-diagnosis, as their altered embodiment removed their ability to engage in their old, normal lives, relegating them to passive beings. Such reports also bear similarity to research exploring the experience of living with DFU (Section 2.13), where the imposed mobility limitations of treatment, affected participants’ ability to conduct meaningful ADLs and engage with their lives as they had pre-ulceration (Brod, 1998; Kinmond et al., 2003; Watson-Miller, 2005; Foster & Lauver, 2014; Barg et al., 2017).

An altered sense of embodiment and estranged engagement with the world can result in the painful feelings central to depression (Svenaeus, 2014). As the participants in this study struggled to come to terms with their new embodied state within the world, many experienced low mood and symptoms of depression (Section 4.1.3). Such feelings of intense sadness can be a paralysing experience, further suspending active pursuit and leading to an all-enveloping passivity (Slaby, Paskaleva, & Stephan, 2014). Again, this can be seen in Steve’s account where he describes how his feelings of depression, more than anything else, negatively affected his ability to cope with work (Section 4.1.3). In depression, drive and impulse can become exhausted, and, in milder forms, this may manifest in a loss of desire, pleasure and interest in the world (Fuchs, 2014). This can result in active resistance to the flow of life which allows us to engage in matters of the world together with others (Svenaeus, 2014). Examples of such loss of drive, desire and

pleasure were described by several of the participants (Section 4.1.2) as they began to grieve for the death of their old lives.

For some participants, feelings of depression were severe enough to lead to suicidal feelings. Suicidal feelings are believed to be quite different to suicidal thoughts and have been described as existential feelings in the sense that they involve changes to the core structures of experience that form the background for ordinary thinking, feeling and acting (Benson, Gibson, & Brand, 2014). Benson et al. (2014) argue that, rather than actually wishing to die by one's own hand, being towards suicide represents a reorientation towards bringing an intolerable mode of existence to an end. Evidence of feelings of such intolerability towards their current lives and ways of being in the world were described by most of the participants in their interviews. Interestingly, in the study by Hoban et al. (2015) patients with DFUs also exhibited more suicidal behaviours using the suicidal behaviours questionnaire than those without diabetic foot complaints. However, being a quantitative study the reasons behind this were not explored further.

It is important to remember that the diagnosis of Charcot foot appeared alongside a background of diabetes mellitus. The duration of the participants' diabetes diagnosis ranged from 5-34 years at the point of interview. Therefore, it is argued that the experience of living with the condition was already deeply embedded in their lives and sense of being. All participants had had time to adjust to their diagnosis and medical management, with no reports that the diabetes diagnosis had negatively impacted the meaningfulness of their lives or their ability to carry out day-to-day tasks. However, it should be noted, that this question was not directly asked. Whilst there is a significant evidence base to suggest that depression, anxiety and diabetes distress are more common

amongst those with diabetes than in comparable samples (National Collaborating Centre for Chronic Conditions, 2008; Young-Hyman et al., 2016) (Section 2.12), there was no evidence to suggest that participants in this research were depressed directly prior to Charcot foot symptom onset. Whilst this could be due to the relatively small sample size necessitated by an IPA study, it is perhaps more likely due to the magnitude of life changes following the diagnosis of active Charcot foot, rendering all previous physical and psychological impairments trivial in comparison. Also, as Corbin (2003) points out, simply being diagnosed with a chronic illness does not necessarily lead to feelings of being ill or the construction of an illness identity if one can still perform life's daily activities as they did prior to diagnosis. Certainly, looking back at their lives prior to Charcot foot diagnosis, the participants retrospectively felt that their lives had been very meaningful. However, it could be argued that the difference here lay in the shock and biographical disruption (Bury, 1982) (Section 2.14) of having just received a Charcot foot diagnosis versus the acceptance of their chronic condition of diabetes mellitus.

Chronic illness can result in a variety of stressful outcomes that have negative psychological effects on the individual and how they begin to adjust to their diagnosis (Dobbie & Mellor, 2008). Half of the participants reported feelings of depression at some stage between diagnosis and the time of interview (Section 4.1.3), and whilst levels of depression were not formally measured within the current study, the reported levels during interview were worryingly high. These accounts are strikingly at odds with findings suggested in previous literature, as discussed in Section 2.11, where most studies suggested that QoL was only negatively impacted in the physical domain and not the psychological or mental health domains (Chapman et al., 2011; Dhawan et al., 2005; Pakarinen et al., 2009; Pinzur & Evans, 2003; Raspovic & Wukich, 2014; Raspovic et al., 2015; Sochocki et al., 2008; Vileikyte et al., 2008; Willrich et al., 2005). Most of these

studies postulated that the tools utilised may not have been sensitive enough for their intended purpose, as only Srivastava et al. (2016) found any significant reduction in the MCS of people with Charcot foot using the SF-36. Chapman et al. (2014) found significant evidence of disease related depression using the HADS scoring and Vileikyte et al. (2008) found emotional burden using the Neuro-QoL measure. Whilst this level of reported depression is not noted in published literature, the levels of depression reported by participants with active Charcot foot in the current study suggest that this issue may also be under-reported in clinical practice.

Whilst evidence documenting the psychological burden of Charcot foot in the literature is lacking, it is clear that there is a large quantity of evidence highlighting the high prevalence of psychological ill-health in people with diabetes (National Collaborating Centre for Chronic Conditions, 2008) and closely related sequelae. Perceived worsening of health status is independently associated with diabetes distress and depression (Young-Hyman et al., 2016) and studies have linked the presence of DSPN to depressive symptoms and reduced QoL in people with diabetes (Vileikyte et al., 2005, 2008; Vinik et al., 2005, 2008). Moreover, the consequences of the management of DFUs such as restrictions in ADLs and diminishing self-resources have also been linked to reports of depression (Brod, 1998; Carrington et al., 1996; Hoban et al., 2015; Ismail et al., 2007; Kinmond et al., 2003) (Section 2.12). Such factors could all be viewed as risks to populations such as those with Charcot foot in spite of the lack of association with depression in generic health scores, further indicating the lack of sensitivity and specificity of these measures and the need for further in depth exploration.

Whilst reflecting on the embodiment of Charcot foot, three of the participants considered life with amputation as a possible future outcome (Section 4.1.3). For people with DFUs, LEA can be among the most feared complications (Barg et al., 2017). Such a reaction of fear and panic was exhibited by Colin. Conversely, for Stacey and Bill, the idea of amputation was perceived as potentially preferable to living with the consequences of Charcot foot in the longer term. They each perceived a QoL improvement without the confines of a foot that they were unable to ambulate on and that caused so many disturbances to their lifeworld. This appeared to be a consequence of the idea that life with an amputation had more certainties than a life with Charcot foot, and could potentially offer an avenue back to the lives that they felt they had lost with the onset of Charcot foot. This has resonance with findings from Barg et al. (2017), Brod et al. (1998) and Carrington et al. (1996) where the psychological status of mobile amputees was actually reported to be better than that in people with DFUs, as they were encouraged to be mobile rather than remain non weight bearing (Section 2.13).

Neither the current study nor other studies advocate the notion of amputation to improve QoL in patients with Charcot foot. Nonetheless, it is very important to note this finding, because it indicates the need to find ways to offer much-needed psychological support to these patients and to improve their experience of living with Charcot foot and other, related pedal pathologies. Whilst participants appeared certain that their QoL would improve with amputation, assuming that they would have more mobility, not all patients regain full ambulation following LEA. A study by Norvell et al. (2011) found that only 37% of patients achieved mobility success at 12 months follow up after their first major unilateral amputation in a cohort of people with diabetes and peripheral vascular disease. Should amputation occur, people with diabetes are also twice as likely to have a subsequent amputation of the contralateral limb as those without (NICE, 2015). Mortality

rates following DFU, Charcot foot and amputation are also high, with up to 70% of people dying within 5 years of having an amputation (NICE, 2015; Baal et al., 2010). Misconceptions regarding post LEA outcomes may be a result of increased positive media coverage of those with disabilities, such as amputees, in arenas such as the Paralympics, the Invictus Games and other major sporting events. More research is needed in this area to provide clarity and highlight the need for improved quality of psychological support in this vulnerable patient group.

5.1.2. Temporality

There was a strong focus on temporality throughout the transcripts of all eight participants in this research, as highlighted in the first master theme of the findings (Section 4.1). The temporal disturbance experienced by the participants following their Charcot foot diagnosis clearly separated their lives into discrete sections, those which came before and after diagnosis and a static period of uncertainty which overwhelmed their present-day experiences. Such accounts have not been previously noted in research exploring diabetic foot problems. However, this is similar to an account by Scannell (2000), who after hearing of her possible cancer diagnosis noted how her life was suddenly split into ‘a sharply divided “before” and “after”, with “cancer” cleaving the middle’ (p. 56). Similarly, Frank (2002) wrote of how the loss of his future complimented the loss of his past, whilst contemplating his own cancer treatment.

Post-diagnosis, the participants’ altered sense of time-consciousness increased their intentional focus on the lost freedoms of their past. Memories of a happy, healthy past often then become objects of yearning, which it has been suggested can encompass a

sense of discontinuity (Bury, 1982). This seemed to be the case for the participants in this study. Most participants used the photo elicitation aspect of the research to help ground the discussions in the previous projects and interactions with the world which they no longer felt were available to them. Fuchs & Detmers (2017) suggest that time often expresses itself, not only through the processes and events of life, but also through our aspirations and a longing for the past. Similarly, Van Manen (2007) asserts that the temporal structure of all lived experience cannot be grasped in its full richness and depth in the present moment, only reflectively as a past presence. Indeed, the participants were strongly inclined to reflect on their lives pre-Charcot foot (Section 4.1.1), focusing on the retrospective ease and joy of life pre-diagnosis.

As ‘the past derives its meaning from the present’ (Sartre, 1958, p. 558), it is likely that the participants’ intent focus on their past was a reaction to their present-day restrictions and loss of freedom. Carel (2016) suggests that it is the sense of meaninglessness and despair caused by diagnosis of an illness that initiates a reflection on life, which can then cause a sense of distance from a person’s previous life. This is particularly true of the Charcot foot where, in addition to a prolonged period in a TCC, participants also require regular long-term follow-up within a specialist podiatry service and ongoing changes to their footwear and activity levels. Therefore, past events may seem more significant, depending upon their orientation towards the future and where people feel their life journeys are heading (Ratcliffe, 2012). It is in this sense that Sartre maintained that ‘it is the future which decides whether the past is living or dead’ (p. 520).

Brough (2001) describes our experience of lived time as taking an elastic form, which can often appear to either expand or contract dependant on what content it is filled with.

Unfortunately, during spells of sickness people sometimes find it difficult to imagine themselves going beyond their current situation (Charmaz, 1995) as their sense of biographical temporality appears to shift. The revelation that one has a serious illness, such as Charcot foot, can strand them in the now, precisely because of their significance to the past and the future (Brough, 2001). Participants appeared to enter a state of confusion and grief for what was lost in their present-day lives (Section 4.1.2). In such states of uncertainty and anxiety, the sense of the *now* can also be intensified and concentrated in a way that threatens to implode (Svenaesus, 2014), as demonstrated by Stacey's fears of going "*senile*" (20, 10) and Bill's reference to life consumed by the "*black hole*" (30, 25) (Section 4.1.2). However, boredom and sadness highlight feelings of time as infinitely stretched out and inert (Svenaesus, 2014), similar to the participants' experiences of stasis and depression (Section 4.1.3) further disturbing life's temporal flow.

The biographical disruption caused by chronic illness also often involves an altered recognition of pain and suffering, and sometimes even of death. Such notions normally are only seen as distant possibilities or the problems of others in the pre-conceived acceptance of everyday life (Bury, 1982). Morris (2008) suggests that, in chronic diseases the idea of death as a biological demise 'becomes thematic as a matter of time' (p. 16) and something against which all other clocks are measured. Such aspects of disease progression can be frightening, as not only do they curtail possibilities but also because they may actually be part of dying (Carel, 2016). In this study, life with an active Charcot foot brought thoughts of mortality to mind (Section 4.1.3). This resulted in an alteration to participants' taken-for-granted awareness of and interaction with other objects, a disrupted corporeal identity, a disturbance in relations with others and a change in the character of temporal existence similar to those described by Toombs (1995). Arguably

these changes are more prevalent in chronic than acute illness, where acute illnesses are generally isolated to one bodily area and respond to treatment (Murrow & Oglesby, 1996). This may be one reason why some participants compared the experience of being diagnosed with active Charcot foot as more disruptive to their life journeys and temporal experience than potentially life-threatening conditions.

The biographical timing of illness can also influence the effect of its perceived disruptiveness (Charmaz, 2002). In the current study, the participants who spoke most fervently regarding both their immediate and longer-term concerns for the future were those who were still employed or had a larger number of meaningful projects and responsibilities, such as Bill, Stacey and Steve. Interestingly one participant who did not appear to exhibit any signs of biographical disruption was Graham. This may be because he had experienced a major life change with his retirement less than 2 years prior to diagnosis. In a grounded theory study, Jonsson, Borell, and Sadlo (2000) found that the experience of retirement caused participants to adopt a new temporal structure and to develop a slower rhythm to their lives, which, in many cases, caused a sense of emptiness that they did not know how to fill. They also reported that the participants felt they were entering a period of their lives which was moving slowly downwards into decline (Jonsson et al., 2000). These reports bear a striking resemblance to the accounts which some of the participants gave regarding their experience of active Charcot foot, and if Graham went through something similar when he retired, this may at least in part help to explain the divergence in experiences amongst the participants. However, this assumption was not explored in the interview.

Just as participants pondered on their future narrative path to make sense of the past, some reflected back on the past to try to make sense of their futures. Charmaz (2002) notes that whereas a practitioner may be able to look at and make sense of a patient's future prognosis, a patient will look over the present but may be unable to see into the future, looking into the past for frames of reference (Charmaz, 2002). As the participants' projected sense of their future lives appeared reduced, their entire lifeworlds were thrown into question. The sense that their futures were unknown subsequently caused a sense of fear and trepidation. Both Brian and Bill recalled and compared their own experiences with those of their aging parents as they struggled to envisage what their future lives may subsequently hold (Section 4.1.3).

The lifeworld that the participants had previously taken for granted and the expectation that their future experiences would continue as they always had, became invalidated. This meant that the expectations and plans they had previously had for the future needed to be re-examined. This was expressed by several of the participants, though most notably in Steve's lament about missing the possibilities that his future life presented, given his former expectation that old age would be "*better*" (17, 4) and more rewarding than his middle years (Section 4.1.3). The future draws us in towards it, with a disposition towards activity and the presupposed attitude that it will contain a sense of meaning. However, when these assumptions are disrupted, that future takes on the form of dread and can appear as a conspicuous threat rather than a taken-for-granted arena full of possibilities (Ratcliffe, 2012).

With their sense of freedom, autonomy and possibility seemingly so restricted by the onset of active Charcot foot management, several of the participants described how their

futures were suddenly uncertain. Jobs and relationships had become threatened and their sense of self and social contacts diminished, shattering their anticipated futures. Changes to the participants' bodily intentionality derailed their future aims and objectives leaving them with a sense of loss and anxiety about what may lie ahead.

5.1.3. Spatiality

The disruption to participants' lived bodies, engendered by loss of mobility as a direct result of the onset of active Charcot foot management, caused a change in the character of their surrounding space and an alteration to their feelings regarding their entire lived worlds. It is understood that the experience of illness can cause a disruption to the lived body, which can in turn interrupt the relationship between a person's body and their environment (Carel, 2012). As a person's concepts regarding their familiar environments alter, a sense of alienation may emerge as the ill person experiences the physical world as less welcoming, increasingly difficult to navigate and as full of obstacles. Thus, in illness, it is not only a person's body which is modified, so too is their sense of space (Carel, 2012).

In health, we mostly live with a body-world connection pre-reflexively, acting on autopilot and using our procedural memory for routine tasks (Finlay, 2011). Inherently, these bodily habits presuppose a form of understanding that the body has of the world which it experiences day-to-day (Moya, 2014) and are essential if a person is to dominate their engagement with their environment (Bannan, 1967). However, when a person becomes ill, they may experience both an altered consciousness of their whole body and an altered experience within the world (Finlay, 2011). As the participants' habitual bodies were inhibited, it was the environment which appeared to dominate their existence, as

everyday activities were suddenly fraught with hazards (Section 4.2.1.). This caused the environment around them to look and feel different to that which was so familiar pre-diagnosis, thus rendering their being in the world uncomfortable.

A person understands their environment in terms of their behaviours, in much the same way as they understand their body as requiring certain actions that they have the power to perform (Romdenh-Romluc, 2011). Following onset of Charcot foot management, the participants became transformed into individuals ill equipped to cope with the demands of their pre-diagnosis lives, even within the safety of their own homes. This notion of the meaning of home was touched upon by Merleau-Ponty: ‘My flat is, for me, not a set of closely associated images. It remains a familiar domain round about me only as long as I have “in my arms” or “in my legs” the main distances involved, and as long as from my body intentional threads run out towards it’ (1962, p. 130).

When a person is able to move around familiar spaces with such ease, movement possibilities emerge between the body and the space which can be said to co-create an ‘experiential unity’ (Evenson & Standal, 2017, p. 2) between the two. When this occurs the boundaries between the lived body and its world become blurred. However, if this unity is interrupted and something destroys this ease of movement, the spatial interplay and experiential unity is lost (Evenson & Standal, 2017). If our body is indeed our ‘anchorage in a world’ (Merleau-Ponty, 1962, p. 144), then it makes sense that any bodily disruption would cause the participants to feel adrift in that world. This notion can be seen in some of the participants’ statements, in particular Roy’s statement about feeling “*unsteady*” and having his balance taken away (Section 4.2.1). Such statements could be

seen to reflect not only a sense of physical unsteadiness but a psychological unbalance regarding how he now viewed himself in relation to his lived, spatial world.

Toombs (1995) describes her own experiences of living with multiple sclerosis (MS) as more than living with the actual bodily disorder. Rather, illness is experienced in simple daily activities such as ‘the impossibility of taking a walk around the block or of carrying a cup of coffee from the kitchen to the den’ (Toombs, 1995, p. 10). Van Manen (2007) describes the difference between space as objective geometrical points and the subjectively experienced space that is spatiality. Whilst some spaces may appear to be physically close by, they can still be experienced as feeling far away when the body becomes incapacitated (Van Manen, 2007). This experience can be seen in the participants’ transcripts, in particular that of Stacey, for whom getting up the stairs to kiss her children goodnight was just too much, despite the emotional distress that not performing this action caused both her and her sons (Section 4.3.3).

For a patient, the greatest impact of any disease often lies in the effect it has on their ability to continue with such small, yet important, aspects of normal daily life, and this will often become their focus of interest (Hale, Treharne, & Kitas, 2007). Indeed, it was the inability to compensate for decreased independence and functional status caused by management of DFUs which was responsible for the decreased QoL status in the research by Brod (1998) and Barg et al. (2017) (Section 2.13). Home in particular, reserves a special space experience that links to our sense of belonging within the world. Home is where people can go to ‘be what we are’ (Van Manen, 2007, p. 102). Seamon (1979) refers to this usually unnoticed, taken-for-granted situation, of being comfortable in and familiar with the everyday world in which we live, as a sense of at-homeness. This

feeling is present mostly in the dwelling place of individuals but can occur in any location where we are comfortable (Seamon, 1979). As people, we are beings whose experience of home is an essential and inherent background to our lives. It houses patterns of regularity and is a place of refuge both of and for the self, providing the security and space for self-reflection that is essential to our development (Jacobson, 2009). However, in the face of such disruption to the participants' experiences of their lived places and spaces, their sense of at-homeness in the world appeared to be replaced by a sense of fear and isolation.

This research indicates that not only did participants lose their sense of at-homeness within their home environments, they also lost this feeling within the wider world. When presented with such bodily change, entire lifeworlds can appear to lose their sense of order and meaningfulness (Carel, 2016). Participants reported not being able to engage with the world in the ways they did prior to their Charcot foot diagnosis, presenting photographs of cars, bicycles, green space and holidays that they were no longer able to be a part of, as revealed in Section 4.1.1.

When people feel joined to and akin with the world, they can be said to experience a sense of heightened contact towards it (Seamon, 1979). Seamon (1979, p. 112) cited Searles (1960) referring to this phenomenon as a person's 'relatedness with the environment'. Searles (1960) argues that, for a psychologically healthy person, such relatedness to one's environment can assuage various painful and anxiety laden states of feeling, foster a stronger realisation of self, deepen one's sense of reality and generate a stronger respect for one's fellow men and women. Certainly, more recent research policy and public opinion has also considered contact with the natural environment as a

fundamental human need and as an essential constituent of the ideal, healthy environment (Thompson et al., 2011). Bowler, Buyung-Ali, Knight, and Pullin (2010) asserted that activities in nature could have more positive effects than similar activities in a different environment. They also found, in their research based on self-reported measures of moods or emotions, that levels of emotions such as anger, fatigue and sadness were lower, and of pleasurable emotions such as tranquillity could be higher after exposure to a natural environment.

As people become experientially bound to their localities, their QoL can be reduced when these bonds are broken (Seamon, 1979). The loss of ability to negotiate the outside world (Section 4.2.2) and of the meaningful pastimes previously undertaken within the wider world, as described in Section 4.1.1, provided a marked source of distress for the participants in this study. Similar reports were also commonly reflected in the experiences of patients being treated for DFUs (Section 2.13) (Barg et al., 2017; Brod, 1998; Carrington et al., 1996; Kinmond et al., 2003; Livingstone et al., 2011). Therefore, increased understanding of the impact of such losses might help HCPs, family and friends to offer extra support and either find ways to cope with the loss of, or to retain, this important contact with the world. Theoretically, this could help to improve people's experience of living with active Charcot foot and decrease their sense of social isolation, although further research would be required to fully explore this.

To have a satisfying human existence, a person must experience links with the wider locality in which they live. This can increase their sense of personal satisfaction and community, as these are both also firmly grounded in place (Seamon, 1979). When the ill person can no longer continue to participate in the world of work and play as before, their

familiar world is lost to the demands of the disease. The wealth of opportunity which life had previously afforded, was no longer within the participants' grasp and life's experiences went from dynamic activities such as road trips and weekends away, to simply watching life through the television and Internet. In chronic and debilitating illness, technology can take on another dimension, becoming an outlet to the outside world, an extension of the self and also something, upon which patients' lives come to depend (Corbin, 2003). That was certainly the case with the current study and was highlighted in several areas, for example, participants' need to shop on the Internet and Colin's swapping of the experience of driving for driving games on his PlayStation, as highlighted in Section 4.2.2.

Toombs (2001) describes a sense of 'existential fatigue' (p. 253) regarding the ceaseless and ongoing effort required to maintain contact with the world following bodily dysfunction. In response to the extra effort required to perform even the simplest of everyday tasks, there can be a powerful impulse to withdraw and begin to curtail involvement with the world (Toombs, 1995). As life becomes a burden of conscious and deliberate action, even the simplest outing or activity is a major occasion of planning and expedition, leading to social isolation and dependency (Bury, 1982). This sense of isolation was experienced as a direct consequence of active Charcot foot management and featured in the accounts of all of the participants to varying degrees. Participants discussed this in terms of their lives being involuntarily closed off from them, as discussed in Section 4.2.2. Such reports of social isolation were also common in the research exploring the experiences of those with DFUs (Barg et al., 2017; Brod. 1998; Carrington et al., 1996: & Kinmond et al., 2003) (Section 2.13), adding further weight to the importance of addressing this area with patients receiving management of diabetic foot pathologies.

Whilst all participants in this study experienced feelings of isolation, some reported further self-induced isolation. Many also reported that they did not have sufficient understanding of the disease to explain it to others. The perceived need to explain what was felt to be inexplicable, expressed by both Steve and Colin (Section 4.2.2), made going out into the world even more difficult. Similar findings were reported by Barg et al. (2017) as participants' feelings of self-consciousness and anxiety increased regarding the occurrence of unwanted conversations related to their condition. Where public knowledge is lacking, especially in the face of ambiguous or intrusive symptoms, people may require more information to validate that they have a legitimate illness (Charmaz, 2002). In this case, an inability to grasp or fully understand the illness and its meaning in their lives made it difficult for participants to articulate their diagnosis. Individuals may then restrict their terrain to local and familiar territory where they are least likely to be exposed to the gaze and questions of acquaintances and strangers as they struggle to come to terms with their diagnosis (Bury, 1982).

Similarly, feelings of separation from others who may not be able to understand their current position, caused some participants (most notably Linda and Bill) to withdraw from even watching favourite activities in which they could no longer take part. When the things we have in common with others are disrupted and recede from view, we can begin to feel like strangers and feelings of alienation arise reducing our sense of belonging within our intimate social worlds and with significant others (Todres, Galvin, & Holloway, 2009). As Carel (2016) notes; 'I feel more alone now because others cannot understand the contours of my world. I no longer walk in their tracks, share their freedom, take for granted the commonality of health, its hegemony, its normalising force' (p. 118).

Social isolation without the perception of choice can lead to loneliness and if ignored can cause damaging effects to both mental and physical health (Cacioppo & Cacioppo, 2014). Loneliness in this context consists of ‘the distressing, depressing, dehumanising detached feelings that a person endures when there is a gaping emptiness in their life due to unfulfilled social or emotional life’ (Killeen, 1998, p. 764). This description clearly has some resonance with the participants in the current study. If this sense of isolation can cause such a myriad of negative feelings, exacerbate depression and anxiety (Holley, 2007; Cacioppo & Cacioppo, 2014), and induce a negative impact on mortality (Berkman & Syme, 1978; Biordi, 2006), then this clearly needs to be addressed by both those living with active Charcot foot and the people around them.

5.1.4. Project

The management of active Charcot foot was found to be particularly intrusive in terms of project disruption, as participants were suddenly no longer able to carry out activities to which they were committed and which they regarded as central to their lives. The loss of both simple, obligatory ADLs and of valued or meaningful activities was an area discussed by all participants in the current study. The effect of their condition on important projects appeared so significant that it negatively impacted every other aspect of the participants’ lifeworlds. Notably, the loss of ADLs as a result of the non weight bearing regimen in DFU treatment was also a prominent theme throughout the related research in Section 2.13.

Occupations have a purpose but also often have a powerful sense of meaning and can be rich with personal significance (Molineux & Rickard, 2003). They are experiential,

socially valued and organised. They constitute adaptive skills, and are essential to the QoL experience and have the capacity to influence health (Yerxa, 1993). Occupations are the mechanism by which individuals demonstrate their value and worth to society and the world through their achievements, using these activities to demonstrate what they are or what they hope to be (Wilcock, 1993). ‘Doing’ is said to be so important in people’s lives that it is impossible to envisage them without it (Wilcock, 2006). As seen in the findings of this study, the very idea of losing valued occupations had effects on more than just highly prized projects, it affected participants’ individual sense of selfhood, spatiality and temporality, seemingly leaving no aspect of their lifeworld unscathed. Even when people are free of obligation or necessity, they ‘do’ daily tasks, including both things that they must and things that they want to do (Wilcock, 1998).

Participants not only had to deal with the frustration that they were unable to do the things that they wanted to do, they also experienced the indignity of depending on others to do things which they perceived that they should be able to do for themselves. The doing of valued occupations with and for others often fosters a sense of connectedness and belonging, bringing purpose and meaning that affirms the worth of the individual (Hammell, 2014). Activities such as caring for children, loved ones or animals offer expressions of connectedness through the occupation of sharing oneself (Hammell, 2004b) and were mentioned frequently throughout participants’ interviews (Sections 4.1.1 and 4.3.3). The need to belong and contribute to others is an important dimension for QoL (Hammell, 2014). There is a cultural importance to this sense of belonging and to being enmeshed in reciprocal relationships with others (Hammell, 2014).

Several examples of this can be seen throughout the transcripts. Most notably, this is reflected in the utter loss experienced by Brian upon his enforced retirement from driving. The loss of this activity alone affected not only his employment status and therefore his anticipated life journey (Section 4.1.3), but his ability to drive for his wife and be the husband he had previously been (Section 4.3.3), looking after her and sharing meaningful time away on minibreaks and day trips (Section 4.1.1). Being cut off from these activities and responsibilities left him feeling lost and depressed (Section 4.3.3), grieving the loss of his old more fulfilling life (4.1.2), as he found himself unable to replace them (Section 4.2.2). This led him to question his very sense of self and his new place in the world (Section 4.3.1).

The undertaking of meaningful activity represented ‘who’ the participants each felt they were as individuals. Some activities acted as an outlet for specific personality traits, such as the martial arts undertaken by Bill as an outlet for his competitive nature. Many of the types of meaningful activity discussed in the current study (dog walking, cycling, driving, arranging music collections) also symbolised meaningful time alone for the participants, where they could think their own thoughts away from the stresses of life and their obligatory duties. They could be viewed as cathartic activities designed to give the participants time to reflect, process their own thoughts, breathe fresh air and simply be themselves. Each of these activities could be argued to represent a state of ‘being’ described by Hammell (2004a) as the time taken to reflect, be introspective, savour a moment and rediscover the self. It is an important component of living and encompasses appreciation of nature, art or music in a contemplative manner (Hammell, 2004a). ‘Being’ in this sense is about being true to one’s self and to our essence and our nature, to think, to reflect or to simply exist (Wilcock, 1998). Notably these are occupations distinguished by pleasure, enjoyment and appreciation. They are occupations freely and actively chosen

which do not always have to be purposeful to be personally meaningful (Hammell, 2004b).

The loss of ability to maintain projects and occupations also affected participants' sense of agency and control over their own lives. Toombs (2004) argues that one of the most powerful barriers to retaining a sense of dignity in illness is the prevailing cultural perspective on autonomy and the cultural message that we should be able to stand on our own two feet and look after ourselves. The loss of ability to cope with roles such as chief cook (Steve), and the challenges brought by children and pets (Stacey), as discussed in Section 4.2.1, were as a direct result of life in a TCC. The change came suddenly, leaving participants feeling out of control of their actions and experiences, which again, until diagnosis would have been undertaken without thought or recognition.

This sense of being can also be ontologically linked to Heidegger's notion of Dasein. Heidegger believed that we are fundamentally part of a meaningful world and that the meaningful world is fundamentally part of us. Therefore, we can only be properly understood as a function of our various involvements within that world and vice versa (Larkin et al., 2006). Dasein consists wholly of and is ontologically characterised as being towards its own possibility (Inwood, 2000; Morris, 2008). We are always *to be* something, entwined with and directed towards our future projects (Morris, 2008). With the onset of active Charcot foot management, the participants' freedom and ability *to be* their own greatest possibilities, appeared thwarted. The autonomy and independence to pursue projects and freely make choices regarding many aspects of their lives was removed from them quite suddenly, derailing their preconceived life journeys. Nevertheless, the loss of a life story is not merely a consequence of losing a set of life

projects perceived as being fundamental to a person's life, it is caused by the loss of the *possibility* of engaging in any such projects in the future (Ratcliffe et al., 2014). This loss of life story led to feelings of the present day existential death of participants' old lives (Section 4.1.2). Existential death is not an actual biological event, but a step towards the impending possibility of Dasein's own impossibility or its possible non-being. Whilst it is distinct from the cessation of biological functioning, it is closely linked to the loss of ability to continue with commitments, which constitutes a person's social demise (Rouse, 2016). Feelings of biological demise were also noted in some of the participants' accounts, with Steve in particular focusing on his feelings of having entered a state of decline with the onset of Charcot foot.

Where the performance of routine tasks or meaningful activities is no longer possible, they must either be given up, replaced by new habits, or a different way to perform old tasks should be found (Carel, 2016). At this stage in their journey, few of the participants had been able to make this adjustment and reported struggling to replace meaningful activities (Section 4.2.2) or to feel that they were managing adequately with daily tasks (Section 4.2.1). It is the perceived meaningfulness of life that mainly affects people's will to live. Therefore, the importance of reconstructing a life worth living following such biographical disruption, and filling time with meaning, cannot be overstated (Carel, 2012). The meanings of illness can also shift as embodied experience changes (Charmaz, 2006) and it is possible that once the active stage of Charcot foot is over and the participants' prognosis is more certain, their futures may not feel so threatening. It might therefore have been interesting to hold secondary interviews with this group of participants as they prepared to rehabilitate using footwear, or even a year after management for active Charcot foot had ceased.

5.1.5. Selfhood

Almost all participants reported a destabilisation of their sense of self post-diagnosis. Merleau-Ponty stated, “only in the world does he [man] know himself” (1962, p. xi). However, with their lived worlds so dramatically altered, participants’ innate sense of self also shifted and became something unknown. The onset of a serious or chronic illness can undermine the unity between body and self and can force identity changes (Charmaz, 1995). This is especially damaging to the self when experienced as unpredictable, uncontrollable and overwhelming, as it paralyses the person’s ability to plan and manage their life (Freund & McGuire, 1995).

Charmaz (1987) defines the concept of ‘self’ as an emergent structure or organisation that changes as individuals reflexively interpret the identity that they imagine their self and others confer upon them. This is predicated on the taken-for-granted ways of feeling, thinking and acting that can become a person’s defining characteristics. Chronic illness disrupts these taken-for-granted notions about self (Charmaz, 2002) due to the inseparability of embodiment, perception and action (Carel, 2016). Previously constructed conceptions of self were challenged by participants’ disrupted sense of embodiment. Such a diagnosis can usurp individual understanding regarding the self and cause people to start to question aspects of their own biographies (Strickland, Worth, & Kennedy, 2017). The participants subsequently appeared to experience an acute awareness of the ‘inescapable embodiment’ (Finlay, 2003a, p. 167) of their active Charcot foot.

The bodily impairment caused by the onset of management with a TCC is arguably experienced as a profound loss of wholeness, wherein, the integrity of the self becomes threatened, causing an ontological threat to a person’s very being in the world. Charmaz

(2002) notes that experiences of loss and all the negative emotions surrounding them can inundate the self and can cause it to sink and shrink. With their intentionality impaired and ability to influence the world and to perform effectively in many areas of life reduced, the participants felt that they had shrunk and become diminished to lesser people. Participants recalled viewing themselves as “*now at risk*” (Steve, 1, 12-13) and as feeling “*inadequate*” and “*less of a man*” (Colin, 35, 17-21) (Section 4.3.1.). Chronic illness has been shown to cause identity dilemmas for men in particular, and to threaten stereotypical taken-for-granted masculine traits, such as, dominance, control, physical strength and emotional restraint. The inability to measure up to such ideals can cause many to experience feelings of subordination, marginalisation and to receiving greater scrutiny and stigma (Evans, Frank, Oliffe, & Gregory, 2011). Indeed, it was the male participants in this research who spoke more expressively regarding their perceived reduction and lesser sense of self. It has been suggested that women often show greater resilience towards their illness experiences than men, as men tend to place a higher emphasis on recapturing the past and with it their past identities (Charmaz, 1995). This does appear to be the case within our small sample but further research would be required to assess whether this was in fact always the case.

Similar reports of research participants’ feelings of inadequacy, worthlessness and insignificance were highlighted in an exploration of spinal cord injury experiences by Dickson, Allan, and O’Carroll (2008). Kinmond et al. (2003) (Section 2.13) also reported participants experiencing discredited definitions of self, as the self became both altered and diminished by the daily losses they encountered as a result of DFU management. Similarly, participants in the current study frequently reported that their inability to engage in activities which previously, at least in part, had defined their sense of self, left them reduced and at a loss. Reports of participants feeling reduced to a “*lesser me*”, “*a*

ghost” and “*a different kind of me*” are also noted in a phenomenological exploration of mistrust by King et al. (2008). This sense of mistrust was said to involve a perspectival shift, associated undermining of self/identity, embodied emotional turmoil, a pervasive spread of unease, an attempt to recover self-identity and an attempt to recover social grounding (King et al., 2008). There are similarities with the participants in our study whose sense of trust in their bodies and worlds was shaken by their shock at the diagnosis and subsequent limitations placed upon them as discussed in Section 5.1.1.

Whilst participants were aware that they had been given a definite diagnosis of active Charcot foot, the effects on their current lives seemed neither permanent nor fully reversible. Whereas many other studies describe how new biographies occur following diagnosis of diseases – such as MS, with those affected successfully negotiating a new self with MS (Strickland et al., 2017) – the participants in this study appeared unable to do this. This inability potentially left the participants in a no man’s land, unable to be the able-bodied people they were previously, yet not permanently disabled. They therefore appeared unsure of whom they were and where they now fitted into the world, finding themselves caught between their old and new sense of self, pre- and post-diagnosis. When a person struggles to accept their illness, they can view it as the enemy and cling to the hope that they will be able to regain their former missing sense of self. Only once a person starts to accept their chronically ill body can they stop objectifying and distancing themselves from it and start to reintegrate it into their self-concepts (Charmaz, 1995).

When exploring the stages of grief in relation to patients with LEA, Speiss et al. (2014) (Section 2.13) suggest that the final stage of acceptance be described as feelings of stabilisation and resignation, as patients become ready to be an active participant in their

lives again. This may be an important area in which patients with LEA differ from patients with Charcot foot and DFU. It may also help to explain the recurring finding that patients with LEA often have a better health related QoL in some aspects than Charcot foot and DFU populations. It is arguably the case that what is absent from the DFU patients accounts in the published research are feelings of stabilisation and resignation with regard to their foot complaint. Most recall only anxiety, uncertainty and confusion. (Brod, 1998; Nabuurs-Franssen et al., 2005, Watson-Miller, 2014). Equally, patients are not encouraged to be active participants in their lives, because of the requirement to seriously limit weight bearing activity. Without a sense of finality, adequate information or any idea of what the future might hold, patients with active foot problems may remain unable to reach acceptance stage in the cycle of grief. Therefore, the earlier stages of denial, anger, bargaining and depression may continue to feature highly in their accounts as they grieve the lost sense of self.

Habitual ways of thinking and feeling about the body are rarely readily relinquished, and as such, self-concepts can partially remain in the past causing a disjuncture between past and present that is too great to integrate immediately (Charmaz, 2002). With this confusion and reduction in their sense of self, many of the participants began to refer to themselves as temporarily disabled (Section 4.3.1). Providing a biographical time limit possibly allowed the participants to hold onto the hope of returning to the self that they knew pre-diagnosis. Participants were then left struggling to find a ‘liveable relation’ (Van Manen, 1998, p. 3) between their bodies and selves.

A lack of medical knowledge and an inability to know whether the health professional looking after them can actually heal them and to what extent, erodes the ill person’s

ability to make rational choices (Toombs, 1990). Participants reported feeling stuck and confused (Section 4.3.1) as they lacked the resources to make sense of the situations in which they found themselves post-diagnosis. The clinician, on the other hand, does have such knowledge but may be unaware of how the patients conceive their illness and the personal meanings that they ascribe to it if this is not directly discussed. Moreover, the ways and means which the physician uses to characterise the patient's illness are significantly different to those of the patient (Toombs, 1990). Therefore, recognition of this by HCPs is ever more important, as they are in the optimal position to assist their patients, providing timely information to help them to improve their understanding of what is happening to them and thus to begin adjusting to those changes and come to terms with their changing sense of self. Themes of powerlessness were generated in research exploring patient experience of LEA (Section 2.13). This powerlessness was reported to be directly related to increased worry and anxiety caused by confusion and uncertainty regarding procedures, treatment plans and future prognosis (Foster & Lauver, 2014; Livingston et al., 2011). Both papers recommended that improving information and understanding of patients at all stages of their disease management, would help to reduce anxiety levels and negative emotions.

Ill people with failing bodies can also experience feelings of guilt because they share cultural standards of bodily perfection and ideals regarding outward appearance. Shame and humiliation may then follow as their visible disability testifies to a failure to meet those standards (Benner, Janson-Bjerklie, Ferketich, & Becker, 1994). Today's culture places inordinate value on independence, beauty, health and physical fitness and when people observe those who are physically impaired, they make immediate judgments that their situation is negative and that their intellect is likewise affected (Toombs, 2004). Such negative responses from others are demeaning and reinforce the sense that disability

reduces personal and social worth. This was certainly the case for participants in this study, who felt that where their physical impairments were visible they were treated as if they were also mentally impaired (Section 4.3.2), highlighting once again how their own lived experience of active Charcot foot clashed with the views of the outside world.

Bodily appearances affect social identifications and self-definitions, and therefore, how individuals experience an altered body (Charmaz, 1995). Several participants in the current study reported preoccupations with their outward appearance with regard to their Charcot foot, not just in the present day but in their fears about future limitations and signposts towards their condition. Roy and Stacey both recalled their concerns regarding the potential future requirement to wear custom made, orthopaedic footwear (Section 4.3.2). Personal lack of choice over how to present oneself to the world may further impair a person's ability to project an individual identity and self-image in a satisfactory way. Wearing custom made shoes, for example, can be regarded as a highly visible activity with further associated stigma and embarrassment (Johnson, Newton, & Goyder, 2006). Such negative feelings regarding visual aspects of a disability can further alter a person's identity goals (Charmaz, 1995).

This resonates with the small body of research found exploring identity and footwear which highlighted that, as selfhood begins with the body, there necessarily exists a concern with the internal-external dialectic of identification and embodied experience in social environments (Hockey, Dilley, Robinson, & Sherlock, 2013). Rather than being objects of merely functional necessity, shoes emerged, within this collection of research, as items that position us both socially and culturally (Dilley, Hockey, Robinson, & Sherlock, 2014). The relationship that a person has with their shoes may even be seen to

cause additional angst when they consider that they will be judged by their footwear choices (Morriss-Roberts, 2014; Williams & Nester, 2006).

Hockey et al. (2013) placed the presence of footwear firmly within the traditions and life course transitions of the average person: childhood to adolescence, entrance to university, baptism and marriage. This was perceived to give footwear a level of importance which transcended its functionality. They argue that a transition between pairs of shoes can enable, disable or orient individuals in very distinctive ways and can contribute to the movement between diverse aspects of identity within the flow of everyday life. For example, research has shown that women of all ages report feelings of femininity engendered by wearing high-heeled shoes (Dilley, Hockey, Robinson, & Sherlock, 2015). In addition, some women even experienced an inability to wear high-heeled shoes as a problematic dimension of their identity, as they felt painfully excluded from displaying femininity or embodying this notion in the future (Dilley et al., 2015). This resonates with reports by Stacey in Section 4.3.2 where her inability to go out in “*a heel*” on the non-Charcot foot spoilt the rest of her outfit and left her feeling less “*dressed*” (Stacey, 8, 3-6). This may also be supported by Morriss-Roberts (2014) who found that women who were wearing strappy or high heeled shoes were associated with femininity and power by groups of men, whereas more masculine or clumpy styles were perceived as being unattractive.

The provision of custom made footwear is advocated for people with diabetes, DSPN and foot deformity to prevent ulceration and further complications (Bakker et al., 2012). For diabetic footwear to be most effective, however, it should be worn at least 60% of the time (MacFarlane & Jensen, 2003). Adherence to wearing custom made footwear in the

diabetic population is often poor, with reasons postulated for increased adherence cited as the perceived value of the shoe, more severe foot deformity and more aesthetically appealing designs (Waaijman et al., 2013; MacFarlane & Jensen, 2003). This is supported by Naidoo et al. (2011) whose IPA study explored patient perception of footwear in patients with RA. They found that female participants wanted womanly footwear in order to portray a more acceptable body image, and that choice of footwear impacted self-esteem and self-confidence and could exacerbate feelings of isolation and embarrassment (Naidoo et al., 2011). When comparing perceptions of footwear in a group of patients with diabetes and a similar patient population with RA, Williams and Nester (2006) found that people with diabetes felt that style was their biggest priority whereas comfort was the main concern for the RA population. Williams and Nester (2006) postulated that, as most diabetic patients had normal foot structure, issues with ill-fitting retail footwear may not be as important as for those with RA deformities. The presence of peripheral neuropathy may also reduce a patient's ability to sense poorly fitted shoes, and they must justifiably pay more attention to the appearance of the shoe. This may slightly conflict with the findings of the current study. Whilst all participants had peripheral neuropathy, many also had deformity associated with their Charcot foot.

It has been suggested that where patients feel that their lives and choices become too restricted by medical management, they may consider 'reasonable risk taking' and ignore medical advice in order to limit some of the restrictions on their lives, regardless of the risks to physical health (Kinmond et al., 2003, p. 14). This may warrant exploration in the future to assess whether participants' views on interventions such as footwear are the same once they get to the chronic stage and are ready to start the rehabilitation process.

5.1.6. Sociality

The meanings of chronic illness are not simply personal. They are the result of shared experiences and interactions with others, which may involve re-negotiating existing relationships (Bury, 1982). The innate sense of ease within participants' close home relationships was disrupted by their Charcot foot (Section 4.3.3), with some participants reporting that tensions at home had increased since the onset of active Charcot foot management. Relationships and social interactions within the wider world also became strained as feelings of shame and stigmatisation prevailed (Section 4.3.2).

This can be linked, at least in part, to Sartre's (2003) philosophy, wherein we become aware of ourselves only when we are confronted by the gaze of another: 'by the mere appearance of the other, I am put in the position of passing judgement on myself as an object that I appear to the other' (p. 246). Sartre (2003) describes the experience of shame as 'shame of oneself before the other' (p. 46). This shame is not a direct evaluation of our behaviour in a relational situation, it occurs purely as an 'immediate, unreflective, inarticulate response' (Ratcliffe, 2008, p. 113) that transforms our feelings of belonging and ways of being in the world (Ratcliffe, 2008). Toombs (2001) elaborates on her experience of shame in response to the reactions of others as her bodily function declined. She reports that shame was not merely a matter of what she perceived others felt about her, it was the experience of peoples' gestures and facial expressions, averted eyes and irritation in response to her embodied self. This bears some resemblance to the account from Steve who felt he was being taken less seriously after starting to use a wheelchair (Section 4.3.2). As the body becomes increasingly conspicuous, the rest of the world appears to fall away (Ratcliffe, 2008) and the increasingly passive, corporeal experience of embodiment becomes the person's primary focus (Fuchs, 2003).

When we become aware of the gaze or look of another person upon us, we can no longer adopt our natural pre-reflective attitude; we see ourselves as the other person views us and our bodies are viewed as objects (Carel, 2016). The body becomes conspicuous, which can then alter the person's relationship with the world as a whole. This bodily conspicuousness can occur to varying degrees and the increasingly conspicuous body can begin both to withdraw from within-world activity and experience an altered sense of belonging (Ratcliffe, 2008). As Sartre (2003) goes on to say: 'This is why the effort of the shy man after he has recognised the uselessness of these attempts [to suppress the embarrassment of shyness/blushing] will be to suppress his body-for-the-other. When he longs "not to have a body anymore" to be "invisible" etc., it is not his body-for-himself which he wants to annihilate, but his inapprehensible dimension of the body alienated' (p. 377).

Evidence of feeling as though they either wanted to disappear, or were disappearing against their will, could be seen in the accounts of some of the participants. An example of this is Colin's extreme distress at being publicly observed in a TCC (Section 4.3.2). The felt dimension of these interactions can subsequently induce feelings of shame (Toombs, 1995).

Debilitating illness can also bring about dependency and a division of labour that results in one person carrying the burden of work (Corbin, 2003). Dependence on others can be perceived as weakness, generating further feelings of shame when they need to ask for help and they presume that they are a burden on others (Toombs, 2004). Such illness can also sometimes present as a moral burden, where a request for help is made at the expense of a person's self-sufficiency, as they are made to feel dependent and indebted (Benner et

al., 1994). All of the participants in the current study reported concerns at their inability to complete normal tasks and fulfil their usual roles, and at the consequent burden this placed on loved ones. Both Linda and Stacey were acutely aware of the extra strain that the additional household duties were placing on their families, as their role of housekeeper became reduced. These findings concur with those of Barg et al. (2017), Brod (1998), Kinmond et al. (2003), Livingstone et al. (2011) and Watson-Miller (2005) (Section 2.13) who also found feelings of burden to be commonly reported in those with DFU and LEA, which together with a loss of self-confidence, contributed to negative feelings regarding their dependence on others.

These feelings of burden may not be entirely unsubstantiated, as research exploring caregiver experiences of DFU (Section 2.13) also reported a reduced QoL (Hoban et al. 2015) and high levels of emotional burden and anxiety as a consequence of caring for a loved one (Brod, 1998; Nabuurs-Franssen et al., 2005). Whilst the experiences of the family and caregivers of those with active Charcot foot were not explored in this research, concern for loved ones was frequently mentioned, as discussed in Section 4.3.3, and may therefore be another avenue for future research. Indeed, this was suggested by one of the participants during her interview.

The loss of important roles within the home further diminished participants' sense of self as their autonomy reduced and they could no longer be the mother, spouse or partner that they wanted to be (Section 4.3.3). In their struggle to come to terms with such major changes inflicted upon their whole lives and those of their significant others following the onset of Charcot foot management, some participants appeared to shut themselves away. Chronically ill people need to be able to make sense of how their own condition impacts

upon their social roles and personal identity before they can begin the process of adjusting to it (Yuill et al., 2012). A person choosing to seek solitude as time for reflecting, centring and finding inner peace and strength can at times be healthy (Holley, 2007). However, in this research, the participants' sense of internal turmoil and isolation both led to, and exacerbated, their physical separation from loved ones.

Some participants also reported that they were unable to speak to their spouses about their feelings. In his study of people with a new diagnosis of RA, Bury (1982) also found that patients were hiding the effects of their illness from their family, either actively or inadvertently, due to disbelief and anxiety, when experiencing biographical disruption (Section 2.14). Some participants expressed the need to isolate these feelings from loved ones, not only for self-protection as they attempted to adjust to their new way of being in the world, but also to avoid extra and unnecessary burden to others (Bury, 1982). People may work hard to minimise changes or threats to their relationships with others brought about by their illnesses, hiding them in order to avoid contaminating their self-other relations (Finlay, 2003a). However, their relationships are already implicated and their sense of isolation may be rendered all the more acute where they are unable to share their experiences (Finlay, 2003a). In hiding their true and flawed selves from others, people may cut themselves off to pretend that all is well. This can become a way to cope, a way of fleeing the experience and hiding themselves behind a mask (Finlay & Payman, 2013). However, such hiding may ultimately prove destructive, and several times throughout his transcript, Colin expressed concerns that his marriage may not survive the Charcot foot experience. This finding is partially in contrast to those of Brod (1998) who reported that as well as experiencing increased tension and strain in family life as a consequence of living with a DFU, participants also reported feeling closer to their life partner as a result (Section 2.13).

Research by Charmaz (1994) also found that, following a health crisis, most married men felt affirmation of their valued identities from within the family. In her research, she reported that the men experienced an outpouring of love, comfort, and care from their spouses and that the women's care helped to provide identity validation and implicitly affirmed the men's gender identities as the head of the household (Charmaz, 1994). Interestingly, the very opposite result was noted in this research, where some male participants reported keeping secrets and maintaining physical as well as emotional distance from their loved ones. Merleau-Ponty wrote: 'The communication or comprehension of gestures comes about through the reciprocity of my intentions and the gestures of others, of my gestures and intentions discernible in the conduct of other people. It is as if the other person's intention inhabited my body and mine his' (Merleau-Ponty, 1962, p. 185).

Post-diagnosis, this reciprocity was lost for some participants, and along with it a part of their identities. The presence of health crises and disabilities can cut into a person's pivotal roles, whether breadwinner, provider or sex partner. This can result in the dissolution of previously taken-for-granted identities such as partner or parent (Charmaz, 1995). By creating distance, it could be argued that the participants were avoiding their new reality surrounding the intentional activities that they could no longer undertake and the effects that this was having on their significant others. These parts of their identity may have previously been instituted through the sharing of their lived world with significant others, enduring daily habits and shared rituals and routines (Maclaren, 2014a), things which no longer occurred. The loss of these habits not only increased the work burden on the participants' spouses, but in many cases, joint hobbies and pastimes, such as minibreaks, shared cycling and exercising in the park, were also lost.

Expressive bodily gestures can often reveal the body's lived experience and intentionality. Finlay argues that these gestures are not merely a reflection of a person's subjective feelings, they are those feelings (Finlay, 2006). Therefore, the physical separation whereby Brian and Colin no longer shared a bed with their partners could be interpreted as creating mental and emotional separation. Colin also reported feeling the loss of physical intimacy with his wife acutely. Interpersonal intimacy can be described as a sense of closeness that matters greatly to us and can promote a sense of being at home and okay in the world. Sharing a life with intimate others can actually help inform the sense that we are able to make of the world, and the selves that we become (Maclaren, 2014a). Such intimate bonds are realised with the body-world bond that we each develop with the cooperation of our significant other (Jacobson, 2014). However, such intimate relations may be disrupted as a person's ability to physically embody their loving presence is thwarted (Finlay, 2006).

Interpersonal touching, such as a hug or a kiss, can be seen to represent spiritual closeness (Maclaren, 2014b). It is also an intercorporeal form of intimacy that, in its healthiest form, promotes selfhood and the development of relations between people who recognise each other's otherness (Maclaren, 2014b). Sex may be viewed as an expression of the love or closeness that people feel for their partners (Pontin, Porter, & McDonagh, 2002). With the loss of sex within his relationship as a direct result of the TCC, Colin appeared to feel rejected by his partner. Whilst physical touch and intimacy can be enlivening and vitalising, it can also be experienced as transgressive and alienating (Jacobson, 2014). The same could be said for the sudden loss of touch within a relationship when experienced as rejection, further reducing Colin's relational sense of self in his role as husband and causing increased levels of distress. For those going through illness, physical touch may be especially important as a way to help draw them out into their bodies, to

experience themselves as vital and real and as remaining in communication with reality (Jacobson, 2014). Discussion about loss of important acts of intimacy such as sex may be difficult for both partners due to shyness or embarrassment (Pontin et al., 2002) and could result in increased feelings of isolation and distress for the patient. This is a new finding and many HCPs managing Charcot foot may feel ill-equipped to deal with such issues and may perceive it to go outside of their scope of practice.

Holley (2007) suggests a variety of interventions to help combat such experiences of loneliness and isolation. Peer counselling and support groups are suggested and may have value in this instance due to participants' poor understanding of their pathology and reluctance or inability to explain their pathology to others. Peers can often not only help to meet social needs but can provide a wealth of information and practical advice on how to connect with resources (Holley, 2007). Unfortunately, there were no known current official support groups or programs for people specifically with Charcot foot. However, with developments in technology and social media outlets, it is now much easier to reach out to others in similar situations. Since the start of this research a UK Facebook support group has been started by a person diagnosed with active Charcot foot. At the time of writing it had 96 members. The group appeared to be very active with many posts seeking advice, reassurance and moral support from people in similar situations. Such support networks could be seen as a lifeline, may assist with the sense-making process that is a part of acceptance and could be an important area of exploration in the future. Indeed, research suggests that information seeking and forwarding in online settings can improve patient's perceived coping outcomes (Kim & Lee, 2014). Another study exploring those with mental health issues identified that benefits from interacting with peers online included greater social connectedness, feelings of group belonging, improved coping strategies for day-to-day challenges, improved insight regarding important health care

decisions and personal empowerment (Naslund, Aschbrenner, Marsch, & Bartels, 2016). This type of support may be especially pertinent to this patient group as the majority of the participants reported actively seeking information on the Internet, and physically going out to an external support group may be difficult in light of their mobility restrictions.

Holley (2007) also suggests that HCPs should not underestimate the ability that they have to bring patients comfort and hope simply by listening instead of doing. It is important to validate a person's importance with compassionate listening and sharing to find ways to alleviate their suffering. HCPs are often also in the privileged position of being able to discuss and help support family members and increase their understanding of the situation as they may not intuitively know what the ill person needs (Holley, 2007). This may be especially pertinent where patients are hiding their feelings from loved ones as was reported by participants in this study (Section 4.3.3).

5.1.7. Discourse

The discourse used by the participants to discuss their experiences altered markedly when comparing their lives pre- and post-Charcot foot diagnosis. Ashworth (2003) describes the discourse fraction of a person's lifeworld as the terms employed when describing and living a situation. This reflection on participants' lived situation led to a polarity in the discourse used from predominantly positive language pre-diagnosis to negative language representing life post-diagnosis, as discussed throughout master theme 4.1. (life journey interrupted). Post-diagnosis, the participants' lives seemed empty and void of meaning and direction. Therefore, the discourse used with regard to their lives at the time of

interview was that of grief, bereavement and loss. However, it should be noted, that this discourse reflected the time period when the research was undertaken, in the active stage, whilst participants were still adjusting to the diagnosis and management. Consequently, if this population were interviewed during a different time period in which their lived situations had adjusted to the diagnosis and management, the discourse used may be significantly different. Such research should then be considered for the future.

The discourse was particularly forceful with regard to participants' diabetes as a precipitating factor and as background to their Charcot foot. This led them to reflect on feelings of blame for their current lived situations. Attempts to find the cause of illness may heighten moral feelings of responsibility, blame and shame, as taken-for-granted understandings regarding the responsibility and causation of illness can heighten the sense of one's own responsibility for remaining healthy. A person can therefore be seen to be responsible for their own sickness and for having brought it onto themselves (Benner et al., 1994). This sense of blame and causality in the accounts given by the participants occurred particularly in relation to food, as discussed in Section 4.3.3. Similar themes were also reported in all research exploring participants' experiences of both DFU and LEA (Section 2.13) and in the qualitative study by Tanenbaum et al. (2016) exploring experiences of diabetes distress in people with type 2 diabetes (Section 2.12).

Broom and Whittaker (2004) argue that the language used by HCPs regarding control and surveillance of blood glucose, discipline with medication regimens and responsibility for disease management forms a key part of the moral discourse in diabetes. These implicit judgements blame people for their own health problems, possibly as part of perceived unhealthy lifestyles, obesity, poor diet and lack of exercise. Diabetes is frequently

represented in everyday society as a self-induced ‘lifestyle’ condition of those who live to excess or lack self-control. This can lead to beliefs that people are not good enough at their diabetes management and may manifest with feelings of guilt and shame (Archer, 2014) similar to those expressed by the participants in this study (Section 4.3.2). This is congruent with the findings of Schabert et al. (2013) that those with diabetes may feel stigmatised by their diagnosis (Section 2.5), as was the case for many participants in this research (Section 4.3.2). This may be particularly pertinent with the manifestation of secondary complications, such as DSPN, which are pre-requisite for pathologies such as ulceration and Charcot foot. It is important to acknowledge these pre-existing feelings as part of participants’ pre-diagnosis biographies, as these issues differentiate those with Charcot foot as a consequence of diabetes and DSPN from those diagnosed with Charcot foot as a secondary complication of another pathology.

This sense of blame and shame, and feelings of being a ‘bad diabetic’, have been described as playing a major role in the eventual consequences of diabetes self-management (Archer, 2014, p. 102). Diabetes-related distress has also been shown to hamper efforts to self-manage the condition (Peyrot et al., 2005) and a linkage between poor adherence to diabetes management regimes and psychological problems has been demonstrated (Skovlund & Peyrot, 2005; Fisher et al., 2010). Depression management may be meaningful from the perspective of the patients’ QoL, but it also may also have implications for patients’ ability to attain diabetes self-care goals (McKellar, Humphreys & Piette, 2004). Examples of this symbiotic relationship were explored for Stacey in Section 4.3.2 and Colin in both Sections 4.1.3 and 4.3.2.

The management of blood glucose levels is a complex and dynamic personal task and imposing control can often be a challenging process (Broom & Whitaker, 2004). For Colin, there was a potentially very serious concern given his dangerous practice of administering insulin without due care and attention; something he had not, until the point of interview, discussed with anyone. His actions regarding insulin practice felt conscious, even if not entirely within his control, much like those of Stacey who reported knowingly sabotaging control and self-destructing for short periods of time. This potentially dangerous and largely unrecognised side effect was perceived to be an outward representation of the total loss of control and enforced alteration to participants' lifeworld and an indication of a failure to cope. A similar reaction to diabetes control was noted by Ågård et al. (2015) in a gentleman whose work project had failed, leading to a decreased willingness and ability to take responsibility for his diabetes. It is therefore important to address the present life situation, experiences, backgrounds, attitudes and beliefs of patients in order to ascertain why some people experience these problems maintaining control (Ågård et al., 2015) and to address them directly. This should be highlighted and handled within the clinical setting by any qualified HCP dealing with such patients given the potential dangers of suboptimal diabetes control to morbidity and mortality.

Participants also discussed feelings of confusion throughout the research. A person who is ill may go to a physician seeking a means to communicate and make sense of their disease (Toombs, 1990). 'What he seeks is not simply a scientific explanation of his physical symptoms, but also some measure of understanding of the personal impact of his experience of lived body disruption. In communicating with his physician, he seeks to convey the meaning of his illness in the context of his particular biographical situation' (Toombs, 1990, p. 229). One of the major areas causing confusion and feelings of anxiety for the participants was the inconsistent level of information issued to them by the HCPs

treating them. With so much uncertainty ahead, this vague and occasionally evasive issuing of information, in particular regarding length of time in a TCC and extent of non-weight-bearing, appeared to increase their feelings of anxiety and uncertainty. When patients feel they are given too little or inconsistent information from their HCPs feelings of blame (Foster & Lauver; 2014) and damaged trust can emerge, which can subsequently lead to feelings of powerlessness (Livingstone et al., 2011) as noted in Section 2.13.

Successful interactions between practitioners and their patients lie at the heart of all medicine (Griffin et al., 2004). If bad news, such as a diagnosis, is communicated badly, then it can cause confusion, resentment and long-lasting distress. However, if it is done well, it can aid understanding, acceptance and adjustment (Fallowfield & Jenkins, 2004). Emotional reactions to clinical diagnosis and patients' perceptions of their information needs at this time are therefore vitally important (Peel, Parry, Douglas, & Lawton, 2004). When illness is referred to only in terms of objective disease states the medical encounter is understood only in terms of diagnosis and cure. This approach can remove emphasis on the patients' lived experience and be perceived as dehumanising and promote feelings of isolation, passivity and objectification (Todres et al., 2009). In order to restore some integrity to the patient as a human being some focus should be given to 'the dis-ease of the patient' not solely their disease (Toombs, 1990, p. 230).

It is imperative that practitioners remain aware of this and the importance of patient centred practice by being attentive to the subjective reports of patients and adapting and tailoring responses so as not to unwittingly alienate them. For example, what Brian felt was a "*flippant*" (Section 4.3.1), seemingly throw-away comment from a HCP regarding his management instantly left him disillusioned and not knowing where to turn. The

power dynamics between patients and professionals can be critical within health care communication (Thorne, Harris, Mahoney, Con, & McGuinness, 2004) and should not be underestimated. With so many changes to the participant's lifeworld occurring as a consequence of this diagnosis, retention of good rapport and communication with practitioners was felt to be a vital link in optimal, patient centered care. Disengagement from medical practitioners could be detrimental to patients and prevent them accessing the help and facilities they require. In most instances, people with a chronic condition report that relationships with professionals were critical to their ability to access much needed information and assistance, to trust its quality, and to feel confident that their self-care management practices were appropriately informed (Thorne et al., 2004). When discussing a new diagnosis, time spent sharing information at an early stage has been shown to help support patient care in subsequent weeks (Bryant, 2008).

This section has explored the findings of this study in relation to existing literature and philosophical theory. Living with both the diagnosis and management of Charcot foot appeared to have a profoundly negative impact on every area of the participants' lifeworlds in the early 'active' stage of the disease. Consequently, the seven fractions described by Ashworth (2003) – embodiment, temporality, spatiality, project, selfhood, sociality and discourse – were employed as a useful way of structuring discussion of the findings and were explored in relation to the participants' experiences.

5.2. Critical evaluation of the strengths and limitations of the study

The unique aspect of the methodological approach utilised within this research, when compared with other studies on Charcot foot, is that participants were invited to talk

freely about their experiences and concerns. This afforded individuals the opportunity to prioritise and highlight areas of importance to them, an approach that has largely been disregarded in previous studies. These accounts revealed the extent to which participants' lives were altered by the diagnosis of active Charcot foot and suggest a key set of issues that affect them. These issues contrast with those identified in predominantly quantitative published research which it has been suggested is neither sensitive nor specific enough to capture the effects of this rare and complex complication. It may also be shared by other patients and may have theoretical transferability to others in whom active Charcot foot is being managed by TCC. If future therapies are to be successful and demonstrate a patient centred focus in line with government and health care policy (Darzi, 2008; Department of Health, 2010, 2013; Francis, 2010; NICE, 2012, 2015), it is necessary to address the global sense of deterioration seen to permeate the patients' everyday life, as demonstrated within this research.

The study design, utilising IPA as the methodology, meant that a small sample size was required in order to focus on the in-depth idiographic responses of the participants. The adoption of the idiographic approach facilitated rich, textual accounts and insights into the experiences of a small group of individuals living with active Charcot foot as a consequence of diabetes and DSPN. However, the necessarily small sample size of such research means that the results cannot be considered representative of wider populations. All of the participants in this research were recruited from the same foot clinic which is very specialist and recognised as a centre of excellence. Therefore, the experience of other patients at different centres may vary in terms of different protocols for assessment and review, different availability of tests and specialist doctors, and experience and opinions of differing HCPs and doctors. Every patient interviewed was also treated with TCCs which, whilst recognised as best practice, is not offered at all clinics due to

differing resources and is not always accepted by the patients. Therefore, the experiences reported within this research may be different if the study was duplicated with participants who were treated with removable or generic devices such as Aircast boots or CROW walkers.

The study may also be limited by the exclusion of chronic Charcot foot patients and patients who had previously been treated in a TCC for alternative issues such as DFU. It is also well recognised that many patients have concomitant Charcot foot and ulceration, especially in the presence of foot deformity. These patients were excluded in line with the need for a homogeneous sample and to focus purely on the experiences of those with active Charcot foot. The QoL impact of DFU is far better recognised and it was felt may skew the results away from the Charcot foot experience. Each participant was only invited to one interview, allowing them to explicate their experiences, thoughts and feelings at one very specific stage. It is possible that the results may have been different if either multiple or follow up interviews had been carried out at a later stage. Follow up interviews may have also given more insight into participants' experiences over a longer period of time.

The dual role of the researcher as both researcher and practitioner could be considered both a strength and a limitation. This was recognised at the outset and was one reason for adopting the photo elicitation (Section 3.13.3) aspect of the interviews in order to readdress any potential power imbalance. Whilst aware that participants may limit or modulate their opinions, it was felt that all participants were very honest and open about their experiences, as discussed in the findings reflexivity (Section 4.2). Participants could have felt uncomfortable disclosing negative information, fearing that it may affect future

treatments. This was combatted by assuring the patients that they would not be treated by the researcher on their subsequent visit and would have the option not to be treated by the researcher at any point in the future if they felt uncomfortable after disclosing personal information. This was an area also directly discussed and reflected upon with the PPI group prior to commencing the research (Section 3.10.2). They felt that the dual role would bring more benefits than negative influences to the research as participants may have felt less comfortable discussing the effects of living with Charcot foot with an outside researcher who did not have any prior knowledge of the complaint.

The fact that the researcher is also a highly specialist podiatrist within the clinic with a specialist interest in Charcot foot could be viewed as a bias. However, IPA recognises the central role of the analyst in understanding the experiences of participants via a process of double hermeneutics (Pringle et al., 2011). It is believed that prior experience of treating this condition enabled the development of rapport with the participants and helped to make sense of their experiences more effectively. Good qualitative research should always show the hand of the researcher (Altheide and Johnson, 2011), and reflexive statements have been present throughout the thesis to make my position explicit and add to the transparency of the study (Yardley, 2008).

5.3. Theoretical contribution to knowledge

This thesis has presented and explored the lived experience of active Charcot foot through phenomenological philosophy. It has informed many new insights into life with this condition through examination of the three main master themes: life journey interrupted, the hindered body in places and spaces, and the diminishing self in a restricted lifeworld. Many of these phenomenological insights have not been noted in previous literature and

some stand in stark contrast to findings of the established, quantitative research base in the area. This quantitative bias to the existing knowledge base perpetuates the Cartesian dualism originally postulated by Descartes, namely that the physical changes that occur as a consequence of Charcot foot and its management are not considered to have any impact on psychological well-being. The current qualitative study however, identifies a wide range of strongly negative psychosocial effects which were able to emerge due to the phenomenological nature of the enquiry.

The current research has identified for the first time the profoundly temporal effect that a diagnosis and management of active Charcot foot had on the participants perceived life journeys and personal life stories (Section 4.1). It has demonstrated how this was viewed by participants not merely as a one-off episode of illness, but as a life altering autobiographical event. When illness experience occurs, it can cause a rift in human life stories, making them appear chaotic, necessitating re-examination of the past and a re-visioning of the future (Svенеaus, 2011). In this thesis, the onset of this experience occurred with the commencement of management rather than the diagnosis of active Charcot foot. However, disruption was exacerbated by both the uncertainties surrounding the length of objective time the participants would need to be ‘stuck’ in their TCC’s with limited mobility, and those surrounding their potential outcome once the active stage of Charcot foot had passed. Such a disruption caused by illness experience can be particularly oppressive and difficult to endure where rates of progression are variable or outcomes remain uncertain (Carel, 2016) as was demonstrated in this research. This exacerbation of subjective temporal disturbance in response to objectively temporal uncertainties may be seen to build on the work of Toombs (1990). Toombs (1990) described illness through four stages of temporal experience, from the inner time of the subjective lived experience of illness symptoms, to the objective temporality of a disease state biologically researched and treated by physicians. Such a duality of experience may

be confusing to the patient, who, whilst experiencing illness as a pre-reflective suffering, must conceptualise it as a disease state, which may be viewed as something apart from themselves, with more objective temporal parameters (Toombs, 1990).

Throughout this research participants reported feeling unable to access reliable information or consistent advice from HCPs, regarding prognosis and time to resolution. This was frequently described as exacerbating uncertainties, anxieties and temporal disruptions (Section 4.1.2) as the decisions made regarding their management failed to recognise the impact to their life path and lived experience. A growing body of work by Livneh (Livneh, 2013; Livneh, 2016; Livneh, McMahon & Rumrill, 2019) explores the link between chronic illness and disability, and an altered sense of temporality. They suggest that successful temporal adaptation following traumatic life events such as chronic illness or disability may improve coping mechanisms and mental health issues such as anxiety and depression (Livneh, 2013; Livneh, McMahon & Rumrill, 2019). However, this still remains under recognised in the field of clinical practice, particularly in the field of Charcot foot where the current thesis has built upon this theory of the duality of human experience by identifying poor temporal adaptation leading to reduced quality of life.

Similar to the work of Toombs (1990) this research highlights how patients and HCPs attend to this disease from fundamentally differing ontological viewpoints. Practitioners naturally tend to address the pathology in terms of objective, calendar time, basing all treatment plans and consultations on months to resolution rather than considering the patients' lived experience, or how their previous, current and future selves may be affected. Equally, it may be difficult for patients to share their subjective experience of inner time, especially in the highly transactional space of a medical consultation in a busy clinical setting. Patients may also then revert to the common, shared language of

objective time as they grasp to ascertain answers regarding how long they must continue to live with such restrictions caused by the management of their condition. This disjuncture in perspective and approach to illness as it is lived may exacerbate feelings of unhomelike Being-in-the-world, whereby the very otherness of the bodily experience is brought to the fore and the very sense of self brought into question (Svenaesus, 2011). This interlinking effect of the lifeworld fractions (Ashworth, 2003) as noted in the findings and discussion chapters has not been previously recognised in the management of Charcot foot and is not currently well attended to in the biomedical health care arena.

As the participants' situatedness and Being-in-the-world became suspended with the onset of casting and the enforced limitations on their mobility, they reported reconsidering their very sense of self (Section 4.3). As we are ontologically characterised as being towards our own possibility (Inwood, 2000; Morris, 2008), the potential loss of so many future prospects led to feelings of the present-day existential death of participants' old lives and selves. Participants then began to grieve both for their lost former selves and the lost future selves whose potentials may never be realised. This is a new finding in research exploring health related QoL of those with Charcot foot. However, many of the Kubler-Ross (1969) stages of grief (denial, anger, bargaining, depression and acceptance) can be independently noted in related research (Brod, 1998; Kinmond et al., 2003; Livingstone et al., 2011) (Section 2.13). Reports of grief were highlighted in one phenomenological paper by Foster and Lauver (2014), describing the lived experiences of patients with lower limb amputation as a consequence of diabetic foot ulceration. Such similar subthemes may highlight potential transferability of these findings to comparable groups of patients living with similar restrictions. However, whilst this re-occurring subtheme was noted, it was not explored as grief was simply ascribed to the loss of health and physical and financial independence (Foster & Lauver, 2014). As it is increasingly evident that such feelings of grief can manifest not only through loss of

life but also from loss of personal meaning and alteration to life world, it is argued that we need to begin to explore this further from a different perspective.

In a novel paper by Spiess et al. (2014) the five stages of grief (Kubler-Ross, 1969) are explored in relation to the experiences of those living through limb loss and amputation as a consequence of diabetes from a psychiatric viewpoint. Whilst participants of the current thesis did not have an amputation, they did have a limb which, whilst it remained physically present, was no longer fully functional, and which from a phenomenological perspective altered their Being-in-the-world in a similar way. As such, it is argued that a similar focus on the grief experience should be given to this vulnerable patient group. As was suggested in Section 5.1.5, grief may only be overcome once patients reach the final stage in the grief cycle, that of acceptance. This stage has been described as encompassing feelings of stabilisation and resignation (Spiess et al., 2014), as patients become ready to be an active participant in their lives again. In the early stages of active Charcot foot, patients are not encouraged to be active participants in their lives, because of the requirement to severely limit weight bearing activity and may not have found ways to adapt or replace meaningful activity. Without adequate support or information regards what their futures may hold, patients may remain unable to reach the acceptance stage. Therefore, without recognition, support and guidance from those around them, the earlier stages of denial, anger, bargaining and depression may continue to be experienced as those with Charcot foot grieve their lost lives and sense of self. This may therefore prolong patients' suffering and place them at higher potential risk of ongoing mental health issues. As this finding has not been shown in the Charcot foot population previously, it is suggested that it should be studied in both in research and practice with a level of importance in the future.

Reports of depressive symptoms featured highly in the accounts of half of the participants (Section 4.1.3) in this research in direct contrast to the majority of published papers examining Charcot foot and health related QoL, where it is suggested that the health related QoL in this cohort is not reduced. In addition, participants experienced a high incidence of suicidal ideation which has never before been highlighted. Whilst not measured formally, or diagnosed using validated tools, such reports in some cases appeared to be severe and this should be recognised by all HCPs managing this patient group. This is the first research to have highlighted the extent of depressive thoughts and feelings in this population. Few participants reported ever mentioning the negative psychological impact of life with an active Charcot foot to any doctors or HCPs. In instances where they did, it was not felt to have been taken seriously. Several participants reported feeling that the psychological impact of Charcot foot was generally under recognised and rarely approached. This is perhaps unsurprising when considering that tools currently used to assess health related QoL have been demonstrated to lack the sensitivity to either capture or measure changes in experiences of this cohort (Section 2.11). Additionally, as the existing evidence base predominantly suggested that mental health is not adversely affected in those living with Charcot foot, this is under recognised in our evidence based clinical guidelines and protocols. The extent of depressive thoughts highlighted by this research demonstrates the importance of phenomenological enquiry to explore patient experience, rather than trying to categorise their experiences into the validated measures and questionnaires called for by our reductionist, biomedical systems and hierarchical research values.

A further area discussed by the participants in this research was that of shame and stigma (Section 4.3.2). Phenomenologically, shame has been described as manifesting when we are confronted by the gaze of another (Sartre, 2003) and can be experienced through both

verbal and non-verbal gestures in response to the embodied self (Toombs, 2001).

Similarly, stigma is a social process. It is characterized by blame, rejection, or devaluation as a result of the experience, perception or anticipation of an adverse social judgement based on a feature of a person's identity, often conferred by a health-related condition (Scambler, 2009). Such feelings can transform our sense of belonging and very Being-in-the-world (Ratcliffe, 2008) increasing feelings of loss and alienation.

The current study highlighted how feelings of shame were intensified with the experience of wearing the TCCs as participants sense of visibility within the world was altered, highlighting their deteriorating health and lives to both themselves and others.

Participants reported feeling devalued as those around them appeared to infer a degree of mental diminishment alongside their physical impairment. Such feelings were particularly prevalent within the work place for some of the participants as they felt that they were deemed less valuable and less able to cope post diagnosis. As participants reflected on their experiences they were forced into self-evaluation, corporealizing their lived bodies and searching for answers as to how this had occurred. Attempts to find the cause of illness can heighten moral feelings of blame and shame, as taken-for-granted understandings regarding the causation can heighten the sense of responsibility (Benner et al., 1994). Indeed, in today's society many of the perceived 'lifestyle' diseases such as diabetes, which is often viewed as stemming from obesity and inactivity, come to be understood by the general population as a physical manifestation of problematic, or morally flawed character traits (Bock, 2012). Such systematic devaluation of people associated with certain labels, such as diabetes, can have very real health implications (Saylor, 1990). In this thesis such feelings were directly linked to increased issues in blood glucose management in some participants. This increased dysregulation was felt to be outside of their control and further added to their feelings of shame, blame and stigma, creating a perpetually destructive cycle. For others, such feelings exacerbated their felt

sense of isolation as they increased both physical and emotional distances between themselves and loved ones. Each could conceivably reduce health outcomes where individuals do not receive or feel that they are unable to seek out the care that they require. Whilst such notions of shame, blame, guilt and stigma are commonly noted in research surrounding the medical management of diabetes as noted in Section 5.1.6 and 5.1.7, this recognition is far less notable in diabetic foot research, even within the qualitative paradigm.

Language is a powerful tool which can have a marked impact on both behaviours and perceptions (Dickinson et al., 2017) and is a key area in the background of systemic stigmatisation. The discourse surrounding diabetes places a heavy emphasis on language of control, surveillance, personal responsibility, compliance and discipline (Broom & Whittaker, 2004). However, much of the language surrounding diabetes as a progressive condition is inaccurate (Speight, Conn, Dunning & Skinner, 2012). A perceived internal locus of control regarding past events and behaviours can lead to negative outcomes and create feelings of guilt, remorse, and depression (Norwicki & Duke, 2016). Certainly, within diabetes the use of the language of control indirectly suggests blame in incidences of suboptimal management and secondary complications. This could potentially have an additive detrimental effect on the sense of self, particularly when the self is already in turmoil and revaluation following the manifestation of secondary complications.

The need to reframe such stigmatising discourse in practice is already being highlighted by large organisations such as Diabetes Australia (Speight et al., 2012), the American Diabetes Association (Dickinson et al, 2017) and the British National Health Service (NHS England, 2018). Whilst awareness of the need to improve the discourse surrounding this vulnerable patient group has advanced in recent years, further

improvements need to be made in order to empower and protect this cohort from further psychological harm. The findings of this thesis highlight how such stigmatising discourse may be particularly evident in those with secondary complications such as the active Charcot foot.

These powerful findings emerged as a consequence of the phenomenological nature of the enquiry. This enabled the study to explore, from a person-centred perspective, what it is actually like to live with active Charcot foot rather than trying to fit participants' experiences into convenient tools. Such tools may meet the criteria of the 'gold standard' quantitative style of research on which our medical system relies. However, their attempts to generalise people and their experiences in to mass group are undoubtedly causing us to miss what is truly important to those we are trying to treat. We need to go back to the patients and attend to what is important to them in the first instance if we are to achieve truly patient led health care and not to be approaching illness from ontologically differing viewpoints.

5.4. Implications for practice

The novel findings of this study have practical implications for the future practice of all clinicians and HCPs who come into contact with patients diagnosed with active Charcot foot as a complication of diabetes.

5.4.1. A lifeworld led approach to practice

- Following the finding that participants sense of temporality was so altered with the onset of Charcot foot and its management, it is recommended that HCPs require increased recognition of their patients as storied beings, whose present situations are bound within their past experiences and future hopes. Increased

understanding of this would assist HCPs when individualising patient care in areas of importance to the patients themselves. The aim is to assist them to retain a strong sense of meaning in their lives. A more lifeworld-led approach advocated by Todres, Galvin & Dahlberg, (2007) should be considered as valuable approach to humanising health care, empowering the patient and giving credibility to their experiences.

- To develop a lifeworld-led, patient centred focus in practice would include making time for patients to discuss their experiences and concerns at every visit in order to empower them to become active participants in their care. Patients should be encouraged to tell their stories wherever possible. Grossman et al. (2000) describe story telling in this context not only as describing the facts of the story, but also the thoughts, feelings and behaviours that ascribe meaning to it. A practical way to initiate this may be to include a section in any paperwork or assessment forms as a reminder to HCPs to ask patients about their experiences and if they have any specific concerns, and space to record any responses. Goals, care plans and action points may then be mutually agreed and negotiated during these visits.

5.4.2. Temporal disruption and education

- The recommended lifeworld led approach differs from the traditional, practitioner-led health care interaction. As such it may expose some unexpected, very sensitive and emotive issues not previously explored in clinical practice. Further training may therefore also be required for HCPs to assist them in how to manage any potentially difficult conversations, which could arise from the patients concerns. This may initially be explored in those working with high risk groups such as those with diabetes and other long-term health conditions. Such training may take

the form of workshops or sessions at professional conferences or in-house training sessions. Further training implications are noted in Section 5.3.5.

- The temporal disruption experienced by the participants was exacerbated by the uncertain parameters surrounding treatment time and outcome. Therefore, increased effort is required by all HCPs to try to reduce any ambiguity in these areas. HCPs should remain prepared to explain the Charcot foot, the treatment rationale and potential timeframes as many times as is required by the patients. The issuing of information may also need to be staged and given gradually if this is what the patients prefer or feel more comfortable with. The rate and method of information dissemination should be guided by patient preference wherever possible.
- The delivery of any advice and information offered to patients throughout their journey with active Charcot foot should be uniquely tailored. Nonetheless, all literature given to patients regarding the pathophysiology and treatment rationale should be standardised to avoid unnecessary confusion. Given the extent to which uncertainty and confusion have been demonstrated to negatively affect the experience and health related QoL of patients both in this research and related literature, access to accurate information is key. Information dissemination should be improved to include tangible information that patients can review or revisit in their own time. Leaflets could be developed locally or nationally and would be a practical and easy way of delivering verified information. With increasing reliance on the Internet, as a way of finding information, the development of a reliable web-based information source or an app in conjunction with a recognised group such as Diabetes UK would be very valuable. Therefore, links with groups such as Diabetes UK should be explored.

5.4.3. Enhancing Psychosocial support

- Isolation was a well-recognised factor, which the novel methodological approach brought to the fore. It has also been noted in studies exploring similar areas such as diabetic foot ulcers and lower limb amputations. The provision of support groups for people with Charcot foot at all stages, to include, active, chronic and post-surgical reconstruction, would be useful in providing peer support and advice and should be considered. These could be in person, or given the relative rarity of the pathology and the issues in mobility that it causes, could be considered in an online forum. Again, support from established and recognised sources could help this to gain credibility and reach wider audiences. Therefore, an application for the Diabetes UK clinical champion role is being considered following on from this piece of research in order to try to bring this to fruition.
- Participants, for the first time, articulated the profound impact which their diagnosis had on others and the potential burden that life with a Charcot foot may place on family and friends. Previous research has also indicated that caregiver impact and burden can be prominent (Brod, 1998; Hoban et al. 2015; Nabuurs-Franssen et al., 2005). Practitioners should therefore offer advice and support to caregivers attending alongside the patients. Future support groups should consider inclusion of caregivers as this may also assist in opening lines of communication between all of those affected by Charcot foot.
- The extent of depressive thoughts and feelings was a new finding in this research and requires further exploration as a potentially very damaging consequence of active Charcot foot. Current evidence has suggested that in some instances the health related QoL and the psychological impact of those with a Charcot foot may actually be worse than those undergoing lower limb amputation (Section 2.11). However, those undergoing any level of amputation currently have far superior

access to counselling and psychological services due to the recognised potential impact which this intervention will have on their lives and well-being. As such this should be highlighted as an important area on which to focus improvements in current practice, awareness and clinical guidelines. Further research into this area may also be required in order to affect clinical guidelines and highlight potential improvements in patient reported outcomes following the interventions provided by psychological services.

- Screening for depression and diabetes-related distress should be considered following diagnosis of active Charcot foot in line with the American Diabetes Association guidelines (Young-Hyman et al., 2016) which recommend assessment after the onset of complications, any significant changes in treatment, or alteration to life circumstances. Practitioners need to remain aware of this risk and consider further integration of psychological support into the multidisciplinary team. Referral to counselling or to the GP for management of depression should be discussed with patients and considered on an individual basis.
- Since this research commenced, at the hospital where the study was undertaken, an initiative has been started to identify those who may be suffering with anxiety or depression prior to their clinical session which I have been involved with since its conception. A paper-based pilot has already been undertaken which resulted in the identification of several patients experiencing depressive symptoms who would likely not have otherwise been captured and who were subsequently referred to their GP. Funding has been secured for its ongoing clinical use. Patients will be offered the opportunity to fill in a simple questionnaire on an iPad in the waiting room prior to their clinical session. As suggested, the questionnaire includes free text areas for patients to note their aims and concerns and an area for HCPs to subsequently complete with mutually agreed goals and action points.

Conversations within the clinical session can then be approached in a more patient centred way, and if required, onward referrals made in a timely manner. Should this continue to prove successful in the new format, the initiative could potentially be rolled out to other clinical centres.

- The alterations to the sense of self as a consequence of active Charcot foot management provide insight into difficulties in adjusting to life following diagnosis and subsequent depressive feelings. Most specifically in this research participants appeared to enter a state of grief following their loss of sense of self and meaningful interaction with the world. This sense of loss requires increasing recognition by HCPs and by those close to people diagnosed with Charcot foot in order to allow patients to recognise and begin to deal with these complex emotions. This may require increased specialist training for HCPs in how to recognise such feelings and onward referrals for psychological support.
- Feelings of guilt, blame and shame were noted throughout this research and such notions have been frequently noted in many areas of diabetes care (Section 5.1.7). In some, such feelings may also negatively impact diabetes self-management. Discourse should be addressed by all HCPs interacting with those with diabetes in general, and especially in the face of secondary complications, in order to reduce the stigmatising nature of the messages which patients receive about their condition. Language used should preferably empower patients rather than demoralise and insinuate blame. Guidelines such as the Language Matters document by NHS England (2018) should be increasingly promoted and made widely available to all clinicians. Updates on correct terminology should be made mandatory in NHS settings.

5.4.4. Developing the multi-disciplinary team

- The impact of the loss of meaningful and significant activities on participants' lives and sense of identity was demonstrated in both this research and studies in other active foot problems. Finding ways to help patients regain active participation within their lives may help to improve their illness experience and overall health related QoL and reduce the intensity of their grief. The integration of occupational therapists to the MDT may be one practical way in which to attempt to help manage the impact of diagnosis on daily, meaningful occupations and is strongly recommended.
- Increased physiotherapy presence in the MDT is also recommended to assist with issues associated with offloading, such as those experienced with the use of crutches which were also discussed by participants. The potential for feelings of unsteadiness to predict depression as noted in the literature review also highlights the importance of involving physiotherapists in the team. By helping patients to improve their mobility, health related QoL may potentially be increased.

5.4.5. Education.

- Education of undergraduate HCPs should encourage increased holistic explorations of health and well-being in line with the recommended lifeworld led health care. This may help to reduce over reliance on the biomedical model, promote focus on the importance of understanding patient experience within health care and improve patient centred practice. It may be particularly pertinent to podiatrists who will spend more time with this subset of patients and those in similar situations than many other members of the MDT. Areas such as how to navigate potentially difficult conversations such as those surrounding depression, anxiety or social issues may be usefully added to the syllabus as well as to standards of education and training.

- Ongoing education of specialist HCPs in multidisciplinary team settings regarding the psychosocial impact of active Charcot foot is deemed very important. Continued interprofessional education could help professionals to work together to meet patients' holistic needs surrounding information delivery and to provide an improved patient centred focus to care. This could occur via specialist interest groups, publication of papers in diabetes focused journals and presentations at conferences and CPD master classes. Further interprofessional education through organisations such as CAIPE (Centre for the advancement of interprofessional education) or similar groups may usefully be considered with the objective of cultivating more collaborative practice.
- Further education of primary care physicians regarding the impact of a Charcot foot diagnosis is advised to improve knowledge and ways of identifying those deemed at high risk of developing difficulties in coping with the diagnosis, (as increased understanding in secondary care may result in increased referrals for psychological interventions). This could also be undertaken through targeted publications in journals aimed at GPs and training sessions via webinars.

5.5. Recommendations for future research

The extensive findings of the current research indicate that further work is required to explore the impact of living with Charcot foot at all clinical stages, on the lives and health related QoL of those with this diagnosis. The following suggestions for future research are made:

- The current project focused on exploration of active Charcot foot, and for the first time employed a qualitative methodology. The findings highlight the need for further research into the lived experience of Charcot foot at different stages,

including the chronic stage which may be beneficial to assess whether the issues raised as concerns for those with active Charcot remain or change. Such research could help HCPs to try to better understand the meaning of the diagnosis for their patients, in terms not only of their present-day experiences, but also the subjective meanings pertaining to past experiences and future anticipations. Such important insights into this under recognised area of patient experience may assist in more effective holistic treatments to this vulnerable patient group.

- The current project uncovered the extensive impact that the diagnosis of Charcot foot may have on care-givers and relatives. As this area has not been formally examined previously, exploration of the experiences of those living with people diagnosed with active Charcot foot, and their caregivers may usefully help to identify the main issues affecting patients' main support systems so that any future interventions are more holistic.
- Further qualitative research exploring the in-depth experiences of depression and grief in this cohort may be usefully considered in order to more fully understand these complex emotions and how to target any therapy required. The ongoing use of phenomenological enquiry may be considered here given the richness gained from the current thesis and its idiographic focus on lived experience.
- Studies exploring shared discourse between patients and HCPs could be considered as the effects of discourse have been highlighted as significant in this patient group. Exploration in to more empowering discourse may be used to help frame future guidelines and clinical interactions more specifically and may help to reduce feelings of shame, blame and stigma in this vulnerable patient group.
- Developing a Charcot foot specific health related QoL tool to standardise and easily assess the detrimental psychosocial effects of active Charcot foot in a

clinical setting should be considered. A focus on areas of importance to patients as evidenced by the results of qualitative research could be used to do this. Subsequent validation studies would firstly be required potentially by comparing with currently validated instruments such as the SF36 or EuroQoL 5D. This work should then be followed by larger scale research to better determine the impact of Charcot foot on QoL and the effect of new therapeutic models of intervention

- An exploration of how practitioners view the experience of treating patients with active Charcot foot should be carried out to obtain their assessment of patient concerns so that potential gaps and opinions might be addressed and student and practitioner education may be targeted to therapeutic need.
- Research exploring the effect of any future interventions designed to improve patient experience, such as support groups (recommended in Section 5.3), on patient experience and health related QoL should be encouraged. Such research may also promote ongoing development in these areas and ensure that these interventions are helpful and remain based on what the patients actually need.
- Research exploring the effect of adding in additional professionals to the multidisciplinary team such as physiotherapists and occupational therapists may also be useful in securing ongoing funding for these important interventions. Results demonstrating their successful inclusion may also help these to be rolled out to wider audiences.

5.6. Discussion reflexive statement

This study was the first experience I have had with qualitative research. Whilst it has all made sense to me and definitely appealed to what I was trying to achieve by giving my patients a voice, it has certainly not come naturally. At undergraduate level it took a long

time to find my academic voice and writing style. Subsequently, entering the realm of qualitative research has required a similar re-teaching. Whilst my knowledge has expanded greatly in the areas of qualitative research, phenomenological philosophy and my patients' and participants' lived experience, my skill and confidence at managing and collating all this information have grown far more slowly. I do however, feel that I have come a long way in the time since this research began and am now far more able to articulate my knowledge in this area. Having completed this thesis, I now hope that this skill and confidence will continue to gain strength as I move towards further dissemination and publication.

Whilst my skills as a researcher have taken some considerable time to blossom, the effect which the research has had on my clinical work has been far more immediate as my pre-understandings changed with each interview and with the ongoing analysis. Conducting this research has impacted the way I interact with new Charcot foot patients in particular. I have found myself making a more conscious effort to give patients the opportunity to talk, and to assist with onward referrals to GPs that I would not have done prior to the research. One patient approached me in clinic to thank me for my help and for referring him to his GP for depression and with a request for counselling. I had also ensured, from the outset, that our doctor within the foot clinic provided him with a sickness certificate for his employer to reduce the weight bearing elements of his manual job. I had done this as an automatic action following my increased understanding of patient experience and had not remembered doing so until the patient approached me. This positive effect on my clinical practice has given me a much less one-dimensional focus on physical outcome alone. This has strengthened my resolve to disseminate the findings and educate HCPs about the impact that our interventions have had on the lives and psychosocial well-being of participants.

Others in my team have also informed me that, on hearing my presentations regarding the wider clinical impact of Charcot foot and the effects of its management on the lives of those we are trying so hard to help, they have also tried to alter their approach. Evidence demonstrating previous presentations of the findings of this research are shown in Appendix 17-19. In order to further ingrain these findings within our clinical practice, the hospital where I work has secured funding to start a project to screen patients for depression whilst they are in the waiting room. This may help HCPs to pick up those most in need of support and who may not otherwise have been recognised.

This research has also highlighted to me that, whilst we do strive to achieve gold standard treatment for the majority of our patients, we may not always be getting things right for all of them. For some, such as Colin, maybe a removable cast for a period of time would have been a better short-term option, at least worthy of discussion, given the extent of his unhappiness and the pressures this that was causing in his relationship and more immediately, concerning his diabetes control.

Completing this research has altered my ontological and epistemological positions in relation to the construction of knowledge. More than anything I believe that patients' voices need to be heard far more than they currently are, both through further research, which I intend to undertake, and during clinical sessions. In a busy and highly pressurised clinical environment, it is easy to see how the person on the end of the foot can be forgotten, particularly where many have such complex medical complaints. However, the effect of the management of active Charcot foot is indeed far greater than just having an ankle out of action. The entire lifeworld of an individual can be affected and this needs to

be recognised. The power of this type of research to affect change is very strong, compared to quantitative work in this area, especially considering the findings of most existing studies in the field that mental health in Charcot foot is not affected. I believe that the co-construction of research is the way forward if we are to ensure we as clinicians are addressing the correct issues for patients and not privileging our own perspective over those we are supposed to be helping.

Chapter 6. Conclusion

It is believed that this research is the first to explore in-depth patient experience of active Charcot foot from a qualitative perspective. Prior to this research being undertaken, there was arguably a large gap between the existing quantitative evidence base and the anecdotal reports of the impact of a diagnosis and management of active Charcot foot on patient lives. The existing evidence base exploring the health related QoL and the mental and emotional impact of active Charcot foot was variable in part, but overwhelmingly indicated that the mental components of health related QoL were unaffected by this diagnosis. Most studies concluded that there was a lack of sensitivity of the research tools used for this patient group, leaving the research of limited utility when trying to find ways to improve patient care. Equally, no studies were found which focused solely on patients with active Charcot foot. This is an important area of focus given the severe potential consequences of suboptimal management and such minimal available management options. As the options for management are so restricted and simultaneously so restrictive to patient lives, attention should be focused on improving the experiences of this vulnerable patient group.

The aims of this study were to:

- To explore the lived experience of active Charcot foot on patients' lives.
- To interpret, synthesise and align data from emergent themes pertinent to patients' views of the Charcot foot and to use this information to identify areas to enhance patient care and improve QoL.

The approach adopted in this study was designed to privilege the participants' experiences and give them a voice with which to explore the impact of active Charcot foot in the areas of most importance to them, thereby co-creating knowledge that could be used to improve health care practice. The use of IPA has helped to provide a deeper understanding of patient experience. Importantly, it has also taken what has previously been a very biomedical approach to patient experience, 'back to the things themselves'. Its idiographic approach involves a highly intensive and detailed analysis of the participants' interpreted experiences, allowing for rich, textural and nuanced accounts to be generated. Whilst it is acknowledged that these findings were based on the experiences of a relatively small number of participants, there were many similarities in the participants' accounts. It is suggested that there may then be some theoretical transferability (Smith et al., 2009) to the experiences of other people with diabetes, being treated for active Charcot foot with TCC. Overall, findings indicate that there is a far greater impact on patients' QoL than has been previously suggested and improvements in patient focus on the care of these vulnerable individuals is required.

In contrast to much of the previously published literature, the current study found that the lived experience of active Charcot foot was predominantly one filled with confusion and uncertainty. The participants' sense of temporality was disturbed by the time-bound yet uncertain parameters of the active phase of Charcot foot and the losses they suffered due to the enforced reduction in their mobility. With the onset of TCC therapy, participants appeared to look back on their lives before Charcot foot with renewed appreciation. They longed for their lost lives and mourned for them, expressing this loss in terms of death. Participants felt mentally and physically overwhelmed by their diagnosis to the extent that it consumed their everyday thoughts. Reports of depression were made by half of the participants within this research and suicidal thoughts were also mentioned. This is in

stark contrast to the findings of previous, quantitative research and is an important reminder of the significant psychological impact this condition may have on individuals. The participants' futures were consequently viewed with fear and apprehension, seeing only further demise and decline ahead of them as they struggled to adjust to life with a active Charcot foot.

Participants reported ongoing problems negotiating their lived environments following the onset of management with a TCC. Their familiar home environments were fraught with hazards as a direct result of the embodiment of active Charcot foot. Their sense of at-homeness was negatively affected both at home and more generally within the world. As they struggled to find a liveable relationship with their bodies and the world, the participants' sense of isolation increased. They reported being less likely to go out following onset of Charcot foot management due to the physical restrictions encountered. The requirement to try to explain the inexplicable pathology of Charcot foot was perceived as a further barrier to going out. Feelings of loss and reduction in the sense of belonging also inhibited participants from wanting to watch or interact with others taking part in activities from which they were now excluded. Both internal and external isolation occurred as participants' sense of spatiality rendered even their familiar environments more difficult to manage.

Participants found themselves at a loss to know who they were or where they belonged in terms of their being in the world following diagnosis, bringing into question everything that they previously felt they knew about themselves and their lives. They appeared to feel like lesser individuals as their worlds and their identities shrunk and distorted into something almost unrecognisable. This was exacerbated by the lack of understanding they

each had with regard to Charcot foot and what this meant for their lives and prognosis in the longer term. Diagnosis brought with it an overwhelming and shattering impact to the fundamental roles which the participants took within their own lives. As participants could no longer undertake their previously valued life roles they also experienced a fundamental shift in their relational sense of self. This appeared to induce a sense of biographical disruption and feelings of burden. Self-image and perceptions of visibility in the world were also affected. With their visibility altered, feelings of shame, guilt and stigma prevailed in terms of their diabetes. This in turn further impacted diabetes control in some. With the body-self-world so inextricably bound, each participant's entire lifeworld appeared to shift on its axis causing a deep sense of ontological disturbance.

Much of the impact of the active Charcot foot centred around participants' loss of mobility and independence, and the cascading effect that this had to every area of their life world. This was similar to findings reported in the DFU population as discussed in Section 2.13. In this thesis, this global impact to the participants' lifeworlds was discussed and represented using Ashworth's (2003) fractions. It is argued that holistic management of such a global effect on patient lives would require the involvement of more members of the MDT such as occupational therapists and physiotherapists. Such recommendations have been noted in Section 5.3.

Participants also reported high levels of confusion caused by the variation in advice following diagnosis and the findings of this study clearly highlight the powerful need that some of them had for more guidance and support. It was recognised that psychosocial issues were often not alluded to or openly addressed. Given the paucity of published research in the area of patient experience or health related QoL in active Charcot foot it is

also reasonable to assume that recognition of the effects of active Charcot foot on patients' lives is generally under appreciated. An increased psychosocial awareness is required for effective patient centred treatment so that timely conversations with patients can be had and onward referrals made.

Although it is generally accepted that qualitative research is less robust in terms of research hierarchy, I would argue that it is this type of research which has the most impact and power to change practice in terms of patient experience and QoL. Indeed, presentations of these results to the diabetic foot specialist community have been very well received, causing a level of shock amongst many of the attendees at the severity of the patient impact reported. In addition, as has been previously noted in Section 5.4, this research has already led to changes in practice both for myself and other members of the King's College Hospital diabetic foot clinic team. It is felt that this research has the potential to have a further influence on practice following dissemination through publication. It is my hope to continue with post-doctoral study in this area in order to continue to improve patient experience and HCP knowledge in this important area.

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Appendix 1. University of Brighton FREGC acceptance letter

01-Aug-2013

Dear Miss Lucas:

It is a pleasure to approve your application entitled "The Lived Experience of Active Charcot Foot - Enhancing Patient Care." which has been approved by the Faculty of Health and Social Science Research Ethics and Governance Committee. The comments of the reviewer(s) who reviewed your manuscript are included at the foot of this letter.

Please notify The Chair of FREGC immediately if you experience an adverse incident whilst undertaking the research or if you need to make amendments to the original application.

We shall shortly issue letters of sponsorship and insurance for appropriate external agencies as necessary.

We wish you well with your research. Please remember to send annual updates on the progress of your research or an end of study summary of your research.

Sincerely,

Prof. Julie Scholes

Chair, Faculty of Health and Social Science Research Ethics and Governance Committee

J.Scholes@brighton.ac.uk

Appendix 2. NRES acceptance letter



Health Research Authority

NRES Committee London – Camden & Islington

North East REC Office

Room 002

TEDCO Business Centre

Rolling Mill Road

Jarrow

Tyne & Wear

NE32 3DT

Telephone: 0191 428 3566

Facsimile: 0191 428 3432

02 October 2013

Mr Simon Otter
Principal Lecturer, School of Health Professions
University of Brighton
G5, Robert Dodd Building
49 Darley Road
Eastbourne
BN20 7UR

Dear Mr Otter **Study title:**

**The Lived Experience of Active Charcot
Foot in Diabetes Mellitus - Identifying ways
to enhance patient care.**

REC reference:

13/LO/1314

Protocol number:

N/A

IRAS project ID:

129701

The Research Ethics Committee reviewed the above application at the meeting held on the 23 September 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Joan Brown, nrescommittee.london-camdenandislington@nhs.net.

Ethical opinion

It was observed this was a very detailed and interesting proposal.

It was queried if participants who were not happy to provide photographs or take photos would still be able to take part in the research and Miss Lucas confirmed that this would not invalidate them from taking part. The Committee accepted this clarification.

It was queried how participants would be instructed to select their photographs and it was explained that they could choose to select a good photograph or a bad photograph. It was really up to the participants and they could literally choose anything. The idea was to encourage them to talk about whatever was on their mind and to help them to express their feelings in relation to how their treatment and pathology was affecting them in their everyday life. The discussion would be around photographs of their choice that for them depicted the meaning of what it was like to have Charcot e.g. a picture of a patient at a family party where the patient could not participate as they

wanted to. People's experiences were very different. They would be asked to bring along between 3-5 photographs to discuss. The Committee accepted this clarification.

You explained that when this application was originally submitted there were 3 academic supervisors but one of them has now left and been replaced and you queried what action you should take in relation to this. You were advised to wait for the REC's response letter and then apply for a substantial amendment.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	1	05 August 2013
Covering Letter	Dr Simon Otter	14 August 2013
Evidence of insurance or indemnity	Zurich Municipal Policy No NHE-17CA04/0043	05 August 2013
Interview Schedules/Topic Guides	Patients, Version 1	05 August 2013
Interview Schedules/Topic Guides	Clinicians, Version 1	05 August 2013
Investigator CV	Miss Jody Lucas	05 August 2013
Investigator CV	Dr Simon Otter	03 July 2013
Investigator CV	Professor Adrian Bone	
Letter from Sponsor	Professor Julie Scholes	
Letter of invitation to participant	Patients, Version 1	05 August 2013
Letter of invitation to participant	Clinicians, Version 1	05 August 2013
Other: Photography Guidance	1	05 August 2013
Other: Demographic Data Collection Sheet	1	05 August 2013
Participant Consent Form: Patients	1	05 August 2013
Participant Consent Form: Image Usage (Patients)	1	05 August 2013
Participant Consent Form: Clinicians	1	05 August 2013
Participant Information Sheet: Patients	1	05 August 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- _Notifying substantial amendments
- _Adding new sites and investigators
- _Notification of serious breaches of the protocol
- _Progress and safety reports
- _Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/1314

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the committees best wishes for the success of this project

Yours sincerely



**pp Mrs Rosie Glazebrook
Chair**

Email: nrescommittee.london-camdenandislington@nhs.net *Enclosures:*

List of names and professions of members who were present at the meeting and those who submitted written comments

“After ethical review – guidance for researchers” SL-AR2

*Copy to: Professor Julie Scholes, University of Brighton
Dr Zoe Harris, Kings College Hospital*

Appendix 3. Site specific approval to commence research



29th November 2013
Jody Lucas
King's College Hospital
Diabetic Foot Clinic
Denmark Hill
SE5 9RS

The Research Office
Kings College Hospital NHS Foundation
Trust
First Floor 161 Denmark Hill,
London, SE5 8EF
Direct tel: 020 3299 1985
Direct fax: 020 3299 5515
www.kch.nhs.uk/research
kch-tr.research@nhs.net

Dear Jody,

Study Title: The Lived Experience of Active Charcot Foot. Version 1

Ethics ref: 13/LO/1314

Sponsor: University of Brighton

Campus: Denmark Hill

Study duration: 12 months

Target Recruitment: 15 patient's participant and 8 practitioners (staff)

Protocol Version: 1 dated 09/08/2013

On behalf of **King's College Hospital NHS Foundation Trust**, I am pleased to inform you that your project is approved and you may proceed at the Denmark Hill location.

The study has been registered as **KCH13-165**. Please quote this reference in any communications with the Research Office regarding your project.

All approved documents are listed at the end of this letter. Please ensure that any amendments to the documents or changes to the study team are notified to the office.

Investigator Responsibilities:

- You are expected to recruit to time and target. A condition of the approval is to notify the Research Office of the date of first recruitment at the above email address.
- The approval is conditional on the project being conducted as described within the application. The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures - especially those relating to research and data management.
- You must notify the office of all changes to the project, such as amendment to protocol and changes in study team. An end of study report and copies of the yearly REC report should be submitted to R&D.
- You are responsible for ensuring that good research governance, conduct and practice, are maintained throughout the duration of the study.
- The Trust maintains oversight of all active projects and you may be subject to review and audit at any point by internal or external bodies.
- If the project is a clinical trial under the European Union (EU) Clinical Trials

Directive the EU legislation must be complied with.

If appropriate it is recommended that you register with the Current Controlled Trials website; <http://isrctn.org/>

The Research office will support you throughout the duration of your project. Please contact us at the address above if and when you require further information or guidance.

We wish you every success with your project.

Yours sincerely,



Abdul Babalola

Research Governance Coordinator

cc. Chief Investigator: Dr Simon Otter, University of Brighton, G5 Robert Dodd Building, 49 Darley Road, Eastbourne BN20 7UR

cc. Sponsor: Professor Julie Scholes, Nursing and Midwifery, 132 Mayfield House, Falmer, Brighton BN1 9PH

Appendix 4. Invitation to join PPI group

King's College Hospital 

NHS Foundation Trust

King's College Hospital
Diabetic Foot Clinic
Denmark Hill
SE5 9RS

Dear.....,

I would like to invite you to become involved in the planning of a new research study, which I hope to take place in the diabetic foot clinic at Kings College Hospital. The research aims to find out what it is like to live with an active Charcot foot from your perspective, to discover how this diagnosis affects your everyday life and how people cope. I hope to interview patients in the diabetic foot clinic who have been given a diagnosis of Charcot foot for at least 3 months and who are still in the initial stages where the foot / ankle is still hot and inflamed.

I am also planning a second stage where I hold focused group discussions with practitioners treating the Charcot foot, in order to discover their perspective of the patient experience. Once all my data has been collected I will compare the findings from both my patient interviews and practitioner focus groups in order to find ways to enhance patient care.

You have been approached because you have had a previous diagnosis of Charcot foot or ankle and have received treatment. Having experienced the process of diagnosis and treatment for Charcot foot your opinion on the study design will be invaluable. In order to ensure that I am designing the research in a way that focuses around the issues most important to patients I would value your insight and experience into this condition.

My aim is to speak to 4-5 people in a group discussion during one afternoon at King's College Hospital. I anticipate this to take approximately 1 hour. I will provide you with some information about my proposed research design; a participant information sheet and 2 consent forms for you to consider prior to the meeting. I will reimburse the cost of any travel you incur and will provide refreshments on the day. Initially I anticipate only a single meeting but if you did not mind I would value being able to contact you again to ask your advice.

Should you wish to take part in this stage of the research I would be grateful if you would contact me at the foot clinic on 0203 299 3223 or lucasjody@hotmail.com. Alternatively leave a message at the foot clinic with your contact details and I will return your call.

Thank you for your consideration,

Yours Sincerely,

Jody Lucas

Appendix 5. Flow chart depicting course of the study

Patient participant arm of the research: The Lived Experience of the active Charcot Foot. Protocol Synopsis:

Potential participant identified as suitable in DFC KCH and issued invitation to participate. If participant is keen to proceed or for further information a participant information sheet issued and discussed with a member of the clinical team. Contact details exchanged.



Participant contacted via their preferred method within 2-7days by the student researcher. If keen to take part a meeting will be arranged at a suitable location for the participant.



Participant meets with student researcher to take initial consent. Issue the photography prompt sheet and participant with a disposable camera if required. Arrange interview date here.



Meet for Interview at KCH at an agreed time. Discuss and sign photography consent form and demographic data collection sheet. Recorded interview to take place for approximately 1 hour.



Interview Data to be transcribed verbatim



Data analysis of individual transcript



Interpretive Phenomenological Analysis of individual interview data.



Once several transcripts analysed individually, Interpretive Phenomenological Analysis to commence for group theme identification.



IPA data ready for discussion within framework of existing literature.



Write up thesis

Appendix 6. Recruitment poster

King's College Hospital 
NHS Foundation Trust

University of Brighton

PARTICIPANTS INVITED TO HELP WITH RESEARCH IN TO THE EXPERIENCE OF LIVING WITH ACTIVE CHARCOT FOOT.

We are looking for volunteers to take part in a study of what it is like to be diagnosed and live with active Charcot Foot.

Do you have a diagnosis of active Charcot Foot?

No current or history of ulceration in relation to the Charcot?

Aged 18-90 and a good command of English Language?

Would you like to have your voice heard?

As a participant in this study, you would be asked to take part in an interview at King's College Hospital.

Your participation would involve 1 session, which should last approximately 1 hour.

For more information about this study, or to volunteer for this study, please contact:

Jody Lucas, Professor Edmonds or any member of the Diabetic Foot Team.

Diabetic Foot Clinic,
King's College Hospital,
SE5 9RS

Tel: 0203 049 3223

Email: lucasjody@hotmail.com

This study has been reviewed by, and received ethics clearance through a University of Brighton and NHS Research Ethics Committees

Appendix 7. Invitation to participate

King's College Hospital 
NHS Foundation Trust

King's College Hospital
Diabetic Foot Clinic
Denmark Hill
SE5 9RS

Dear,

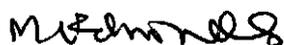
Study exploring the lived experience of active Charcot foot.

As a patient currently attending the Diabetic Foot Clinic at King's College Hospital, Miss Jody Lucas, a podiatrist here, is contacting you in the foot clinic and as a Ph.D student at the University of Brighton, in connection with a research project she is carrying out.

In particular Jody is endeavouring to discover how the diagnosis and management of active Charcot foot affects people in their everyday lives. This information will be collected by holding interviews for approximately one hour at King's College Hospital. Once several interviews have been held and the findings analysed, it is hoped that the information generated will be used to identify ways in which to enhance patient care.

You have received this invitation letter because you have been diagnosed with active Charcot foot and would therefore be eligible to take part. Should you wish to find out more about this project please contact Jody, myself or any other member of the clinical team for more information.

Yours Sincerely,



Professor M. Edmonds
Consultant Physician
Professor of Diabetic Foot Medicine
King's College Hospital NHS Foundation Trust

Appendix 8. Participant information sheet

Participant information sheet.

Title: The lived experience of Active Charcot foot in Diabetes Mellitus – Identifying ways to enhance patient care.

Version 1: last updated 05/08/13

Student Researcher: Jody Lucas

Advanced Podiatrist

Diabetic Foot Clinic, King's College Hospital

Tel: 0203 229 3223

Invitation to take part:

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being carried out and what choosing to take part in the research would mean for you. One of our team will go through the information sheet with you and answer any questions that you may have. This may take approximately 15 minutes of your time.

Feel free to talk to others about the study if you wish.

Part 1 tells you about the purpose of the study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Please ask us if there is anything that is not clear.

Part 1:

What is the purpose of the study?

This study is being carried out as part of a PhD project to explore what a diagnosis of Charcot foot means to patients and how it affects them in their everyday lives.

Charcot is a condition most commonly found in people who have diabetes and nerve damage or 'peripheral neuropathy'. Charcot foot causes pain, swelling and weakening of the bones, which can lead to bone damage. Peripheral neuropathy causes a reduction in the level of pain felt in the foot. The absence of pain sensation often results in continued walking on the affected foot, which can cause fractures and a change in foot shape.

Treatment of Charcot foot involves immobilization, usually in a knee length, non-removable cast for several months. This is done whilst the broken bones heal and to allow the inflammation reduce and bones to strengthen.

Quality of life can be reduced for people with this diagnosis as treatment can typically last 10-12 months, as the breaks in the bones can be slow to heal. Whilst it is generally accepted that this can be a very difficult time for patients, no research has ever been conducted to record patient experience and how exactly living with a 'Charcot Foot' affects their lives. This information is potentially very important both to clinicians treating those with this diagnosis and to other patients. It is hoped that by carrying out this research, ways of improving the current patient care and experience will be identified. As such this research could potentially have an impact on improving care for those diagnosed in the future.

The purpose of this study is to explore your perspective of what it is like to be diagnosed with and receive treatment for Charcot foot. We would do this by holding an interview with you.

We will also hold focus groups with practitioners from several hospitals across the UK who are actively involved in treating Charcot foot in order to find their perspectives. This information will be used to identify ways in which we can improve care for patients receiving this diagnosis and its treatment.

Why have I been invited to participate?

You have been invited to participate as you have been diagnosed with Charcot foot, which has developed as a result of your diabetes. We are looking to interview between 10-20 people with this diagnosis and who are still in the early stages of the disease process (your foot is still hot, swollen and inflamed) and receiving treatment at the Diabetic foot clinic or a similar setting.

Do I have to take part?

It is up to you to decide if you would like to take part in the study. We will describe the study and go through the information sheet with you. If you decide to take part, we will then ask you to sign a consent form. You are free to withdraw at any time without giving a reason. We would like to reassure you that not wishing to take part or subsequent withdrawal from the research will not affect the standard of care you receive in the foot clinic.

What will happen to me if I take part?

If you decide to take part in the study you will be given this information sheet to keep. You will then arrange a date to speak with the principle researcher to ask any questions you may have and asked to sign and date a consent form. An interview date will be agreed at this stage where you will be asked to attend for approximately one hour for interview.

The interview will take place in King's College Hospital. Only you and the researcher will be present to ensure confidentiality. The interview will be tape-recorded so that it can be transcribed word for word onto a written document for analysis at a later date.

As part of the interviews you will be invited to bring between 3-5 photographs or pictures with you, which will be used to help the interviewer to understand more fully how your Charcot Foot affects you in your day to day life and to tailor the interview questions accordingly. These images should represent what the diagnosis of Charcot foot and its treatment means to you in your everyday life. You will be able to discuss this with the principle researcher prior to interview if you wish.

The images can be old or new and can be brought in already printed or on some form of digital media such as a digital camera, laptop, i-pad, mobile phone. Alternatively a disposable camera can be provided and we can arrange for images to be printed prior to interview.

On the day you attend for interview you will be shown a separate consent form detailing how the photographs can be used following the interview. The images will remain your property throughout the research and it will be up to you if they can be reproduced for the purposes of presentations, written publications, in the written thesis itself or not at all. Refusal to sign this aspect of consent will not stop you from being interviewed.

The interview will take approximately 60 minutes. Refreshments will be provided for you on completion of the interview. The researcher will then carry out analysis of the data collected. Once several interviews have been carried out, the data will be gathered from everyone who took part. They will all then be compared, to look for any reoccurring themes or issues that commonly arise.

It is anticipated that the data collection for this research will take approximately one year. All results will be available for you to see once the analysis has been carried out. All data collected will be anonymised and participant identities will be kept strictly confidential. Only the researcher and supervisors/transcribers at the University of Brighton will have access to the transcripts of the interviews.

Expenses and payments.

Refreshments will be provided on the day. All travel costs and photograph-printing costs will also be reimbursed on the production of a receipt.

What will I have to do?

By consenting to take part in this study you are agreeing to attend a 1 hour interview at King's College hospital. This interview aims to discuss your experience of living with an active Charcot foot, how it affects your day-to-day life and how you cope with the treatment. As part of the interview you will be required to bring along a selection of 3-5 photographs. These images should highlight or represent how you feel or cope with your diagnosis and treatment or how it has affected your life. The photographs that you bring in will be used to help make clear to the researcher how Charcot foot affects you and those around you. Each image will be discussed as part of the interview.

What are the possible disadvantages and risks of taking part?

The anticipated risks of taking part in this research are low. There could be a risk of emotional distress during the interview. Should this occur or you wish to stop at any time the interview can immediately be stopped without repercussion. Should you find you become distressed after the interview follow up support can be offered in the form of onward referral to a counselor or psychologist.

What are the possible benefits of taking part?

The possible benefits of taking part include being part of the creation of new knowledge surrounding what it is like to live with an active Charcot foot and its treatment. It is hoped that this new knowledge will be used to improve patient care in the future.

What happens when the research study stops?

When the research study stops the findings will be collated and hopefully presented to other health care professionals through conferences and publications. You will also be provided with a copy of the results. Your treatment in the Diabetic Foot Clinic will continue according to need.

What if there is a problem?

If there is a problem or you have a question or concern about the research at any point from receipt of this information sheet to the end of the study you can contact a member of the diabetic foot team at any time.

Will my taking part be kept confidential?

Numbering participants instead of using names will help to anonymise all documentation and taped voice recordings throughout the study. Only the principle researcher and project supervisors will know the true identities of the participants. For the purposes of presentation and publication of the results pseudonyms will be used in the place of your real name and any identifiable factors will be removed to avoid possible identification. All records will be kept in a secure location at Kings College Hospital in a locked cabinet. All electronic data will be stored on encrypted files. You will be able to decide how any images will be used. Should any images containing faces be used in any documentation or presentations faces will be blurred beyond recognition.

Part 2.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time. Withdrawal will not affect your treatment in the Diabetic Foot Clinic in any way. Information collected up to the point of your withdrawal may still be used in the final analysis.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher on 0203 299 3223, who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital.

What will happen to the results of the research study?

The results of the study may be published in a scientific journal and presented at research or healthcare conferences. You will not be identifiable in any report or publication generated. You will also be sent a copy of the research findings as a whole once the research is complete.

Who is organizing and funding the research?

The University of Brighton will pay the podiatrist conducting the study for her time during the duration of the research, which is being carried out as part of a PhD.

Who has reviewed the study?

All research in the NHS is looked at by an Independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the University of Brighton Faculty of Health and Social Science, Faculty Research Ethics and Governance Committee and NHS Camden and Islington Research Ethics Committee.

Further information and contact details.

Should you require any further information at any point during the research, please contact: Jody Lucas – Diabetic Foot Clinic, Kings College Hospital. Tel: 0203 299 3223, email: lucasjody@hotmail.com

Alternatively the study supervisor: Dr Simon Otter, University of Brighton, Tel: 01273 644543 , Email: s.otter@brighton.ac.uk

Appendix 9. Photography guidance

The Lived Experience of Active Charcot Foot – Identifying ways to enhance patient care. Photography Guidance.

Thank you for agreeing to take part in this research project to explore your experience of living with an active Charcot foot.

We are interested in discussing some photographs that show how Charcot Foot affects you and your life. For example this might be activities that you can no longer participate in or an area of your life that has changed since your diagnosis.

We do not expect you to take pictures of your feet.

An example from a previous discussion group is shown below:

One participant in the group brought in a photograph of his grandchild's 3rd birthday party. The participant was sat in the middle of the photograph smiling happily but felt frustrated that he could not participate in all of the ways he would have liked to.

Another example from previous research:

One participant for a study exploring motivations for attending cardiac rehabilitation courses after a heart attack brought in a photograph of an ambulance. This was a motivating factor because the experience of being in the ambulance was frightening and it was an experience he did not want to repeat.

On the day:

You can bring in the photographs in an electronic format such as on a phone or i-pad, or you can bring in the actual paper copy of the photograph.

During the interview each photograph will be discussed one at a time in order for you to explain to the researcher what each image means to you. This will allow the researcher to more fully understand how the diagnosis and treatment of Charcot foot has affected your life.

How the photographs are used after the interview will remain up to you and a separate consent form will be signed on the day in order to make this clear to all parties.

Appendix 10. Consent form

Centre: Kings College Hospital, Diabetic Foot Clinic

Patient Identification Number:

CONSENT FORM

The Lived Experience of the Active Charcot Foot in Diabetes Mellitus – Identifying ways to enhance patient care.

Student Researcher: Jody Lucas

Please initial box

1. I confirm that I have read and understand the information sheet dated 05/08/13 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that the data collected during the study, may be looked at by the researcher, individuals from the University of Brighton, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

5. I agree to take part in the above study.

Name of patient..... Signature.....
Date.....

Name of Person
taking consent..... Signature.....
Date.....

Once consent completed:

1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix 11. Image usage consent form

Centre: Kings College Hospital, Diabetic Foot Clinic

Patient Identification Number:

IMAGE USAGE CONSENT FORM

The Lived Experience of Active Charcot Foot in Diabetes Mellitus – Identifying ways to enhancing patient care.

Student Researcher: Jody Lucas

Please note that the rights to these photographs will remain your property at all times.

Please initial box

Storage of Photographs:

I agree to allow the researcher to have an electronic copy of my photographs, which will be stored in an encrypted file, and will have no identifiable labels attached. These files will be kept confidential.

2. I agree to allow the researcher to keep a hard copy of my photographs, which will be stored in a locked cabinet and will have no identifiable labels attached. These files will be kept confidential.

Use of Photographs:

3. I give consent for my photographs to be reproduced as part of the researcher's Ph.D. thesis (write up).

4. I give consent for my photographs to be reproduced for use in potential publications or medical conference presentations on the understanding that recognizable features e.g. faces, will be blurred beyond recognition.

Name of patient..... Signature.....

Date.....

Name of Person

taking consent..... Signature.....

Date.....

Once consent completed:

1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix 12. Interview schedule

The Lived Experience of Active Charcot Foot – Identifying ways to improve patient care.
Interview Schedule

Can you tell me what you understand about Charcot foot? (This question is designed to provide some background information as to participants understanding of their condition and how this understanding has been arrived at in terms of lay perceptions, advice from professionals or education from other sources).

Can you tell me about your journey to the diagnosis of your CN? (This question appears because studies have indicated that later diagnosis is associated with poorer outcomes and this may or may not be reflected in the thematic analysis later on).

Can you explain to me what you know about any treatment that has been recommended for your foot problem?

Do you know the purpose of these treatments? Has this ever been explained to you?

How long do you expect this particular treatment to go on for?

(The last 3 questions are designed to show what participants have understood with regard to treatment options and rationale).

Can you tell me about picture 1/2/3/4/5 please and what they represent to you?

Appendix 13. Demographic data collection sheet

The Lived Experience of Active Charcot Foot – Identifying ways to enhance patient care. Demographic Data Collection Sheet

Centre: Kings College Hospital, Diabetic Foot Clinic
Patient Identification Number:

Gender

Age

Ethnicity

Socio-economic status (Education & Occupation)

Type and duration of diabetes

Method of control & prescription

Smoking status

Co-morbidities

Condition specific data:

Symptoms Onset

Date of diagnosis

Previous treatment and centre

When referred to KCH?

How long receiving treatment at for active Charcot foot KCH to date?

KCH treatment history?

Appendix 14. Transcript analysis Steve

Emergent Themes	Original Transcript	Exploratory Comments
<p>Future risk / vulnerability</p> <p>At risk person - identity shift Sense of self</p> <p>Annual event - Future fear</p> <p>Knowledge + understanding vs uncertainty + fear</p> <p>Shock</p> <p>Lack of general knowledge / awareness of condition</p> <p>Fault / Blame?</p>	<p>1 Ok so today's mostly going to be a bit of a one-sided conversation, as I think I said. So I'll ask you... I've got a few sort of preliminary questions and then we'll talk about your photographs and go on as long as you want it to. It's just for me to find out what it's like for you being diagnosed with Charcot Foot. So just to start off with... can you tell me what it is that you understand about Charcot Foot?"</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6</p> <p>7</p> <p>8 "I understand it to be a hyperaemic-inflammatory reaction due to lack of... due to sensory-neuropathy-to-the-small-vessels. My understanding of it is... because I think, if this is wrong, it's important to the risk of the future, so I've been told if and when I get over this, that I'll be the end of that, but now clearly I'm an at risk person and therefore my understanding of how it actually happened to me is very important because I need to take laborious measures and do not want this to be an annual event for the next ten years. And my understanding was that it followed what in other circumstances would be an appropriate inflammatory reaction because I stressed my foot, I was limping, and that it had got out of control and won't stop. I don't know if that's right, but I think it is. And what shocks me about it is two things: 1, I've never heard of it, and I'm a doctor, and nobody of my vintage has heard of this. We've all heard of Charcot joints, but that's not what I have yet. That's a massive deformity, I guess this is the start of it, and it can be aborted, and the other was how quickly it came on, very quickly, over a weekend, and that's a shock. Interestingly I knew I was doing a few things wrong that weekend. I knew that."</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p> <p>21</p> <p>22</p> <p>23</p> <p>24</p> <p>25</p> <p>26</p> <p>27</p>	<p>very specific clearly how medical knowledge - well educated, can explain what he believes this means to him in the longer term - Risk factor however!</p> <p>Some doubt? Uncertainty about what time means for him in reality?</p> <p>Repeat of my understanding + Risk -> exposure to danger / harm / loss, probability to damage / injury</p> <p>fearful that if understanding is not correct may have negative consequences? Use need to take laborious measures - work / effort to ensure does not return. Fear of return - do not want to be an annual event - Time association</p> <p>Reaction no longer appropriate. awareness of disease staying not what I have yet - things more repetition of shock - still get worse? repetition of query unexpected</p>

Descriptive (Face value - Paraphrase, insights)

Linguistic (Pronoun, Pause, metaphor, tone, laughter, repetition)

Conceptual, interrogative

no longer possible to manage / would / usually / carried around / feeling / seems certain / with medical language but then starts, / don't know if that is right - more uncertain - what is reality / Sense of blame - fault. / 1 of fear situation

<p>Blame (walking + shoes)</p> <p>anxiety/fear</p> <p>guilt</p> <p>Effect on relationships - secrecy</p> <p>Pain</p> <p>anxiety/fear</p> <p>uncertainty</p>	<p>1 "What do you mean by doing a few things wrong?"</p> <p>2 "So I had knee pain because I was awaiting an arthroscopy of my</p> <p>3 knee, it had the MRI, I had a loose body and a benign cyst in my</p> <p>4 knee, it was a bit painful, it was restricting my sporting activities,</p> <p>5 my gym and all the rest of it, and eight days later I was due to have</p> <p>6 a planned arthroscopy in day surgery two days before Christmas.</p> <p>7 And then the weekend before that, when this all happened, I was</p> <p>8 on holiday, I was walking much further than usual, I went to the</p> <p>9 airport straight from work wearing heavy leather shoes, and for</p> <p>10 reasons of not having too much crap with me, I just decided I'd</p> <p>11 wear that all weekend, walked significantly more because I was</p> <p>12 on holiday and sightseeing, and to and from the tram and all that</p> <p>13 sort of stuff, and then halfway through the weekend, my knee got</p> <p>14 much worse, very suddenly, something happened, loose body</p> <p>15 moved, my knee got much worse, and I limped in a very obvious</p> <p>16 limping fashion for the next two days. I was away Friday to</p> <p>17 Monday. And my foot got sore, and unlike ... I was anxious, but I</p> <p>18 didn't share that with my wife, because there's a lot of guilt about</p> <p>19 my diabetes frankly. And what I noticed was my foot was sore,</p> <p>20 but that when I went to bed it didn't get better at all. All other</p> <p>21 minor traumas would feel better once they were non-</p> <p>22 weightbearing and you'd be significantly, if not totally better the</p> <p>23 following morning. I was no better the next day. In fact I might</p> <p>24 have been worse. And the third thing that bothered me about it</p> <p>25 was, I've never had rest pain, but it felt like how I would imagine</p> <p>26 rest pain to feel, it felt like a burning pain, and it... position...</p> <p>27 nothing would shift it and I was anxious about it, I knew there was</p> <p>28 something wrong, but I didn't know what."</p>	<p>Explaining perceived onset</p> <p>Knee complaint already limiting physical activity Very medical then struggle to return on his life.</p> <p>Situating in time.</p> <p>In spite of knee pain?</p> <p>deception of footwear - cause of recommendations for shoes perceived as not ideal, worn for convenience.</p> <p>Real like US recommended practice?</p> <p>Reads a bit like bullet points - summarizing relevant information</p> <p>Power then change of tone + pace live on limping causing change in gait pattern, cause of pathology alongside odd choice of phrase - usual noticed? unusual in presence of neuropathy?</p> <p>Time aware that this was potentially more serious than (it thought quite quickly)</p> <p>Repetition of answers?</p> <p>Justification back to safety of medical language, trying to justify to alleviate fear + anxiety?</p> <p>Repetition of pain, rest pain, burning pain</p> <p>Unable to make sense of situation - Didn't know what was wrong? Encouraging fear?</p>
<p>29</p> <p>30</p>	<p>"Just for the tape, when you say rest pain, you mean like... ischaemic rest pain."</p>	<p>Previous issues with around health complaints (diabetes in particular)</p> <p>Line = Guilt a bone again - own fault he was diabetic?</p> <p>guilt changing his behaviour + causing barriers between him and his wife</p> <p>General issues - Diabetes, knee pain, foot pain.</p> <p>anxiety: suffering / suspense / apprehension / angst / dread / fear or change of misfortune</p>

<p>1 "Ischaemic rest pain, yes. Ischaemic neuropathy... yes, neuropathic pain." 2 3 "So could you tell me about the journey to the diagnosis of having Charcot." 4 5 "So... er... this all happened on a Sunday and a Monday at the end of December and on the Tuesday I came back to work and limped quite a bit, but pressed on. At 8 o'clock on the Thursday morning, which is four days after it seemed to kick in, I was having my annual diabetic review with Professor A and she was examining me and she was beginning her neurological examination and she was doing touch, and as she ran the back her hand down both shins and onto my feet she said your left foot feels warm compared to the right. That's it. She kept saying I'm worried that you might have a Charcot. And I wondered what the hell she was talking about because the Charcot I knew about, I knew I didn't have, mega-deformity and she had previously, on two previous occasions queried it above my right ankle. And I thought I don't know what you're talking about because that ain't a Charcot joint. Acute Charcot, never heard of it. And so she said no this isn't right, your foot feels warm, go straight to the foot clinic. So I saw her almost immediately. He looked at it and said no you don't have a Charcot, and then promptly ordered £10,000 worth of investigations which showed that I did. So within hours I'd had bloods, etc, etc, they didn't show anything exciting at all. Plain x-ray - nothing, and then a bone scan... wow you didn't need to be a nuclear medicine person to say, oh yes, you know, I had two feet, left is black... left is red-hot and the right is quiet, really hot... instant, even I could see it, because when you're having... have you been in the PET scanning, bone-scanning place at all?"</p>	<p>medical terms / encourage Calm, don't want to make a fuss Pressed on: Bruce, So I'd read on but started to lose something with losing previously - why not seeking help? Factual account: diagnosed on the base of the annual review - change of Dr. Shocked that it's there all - just a temp difference - disbelief. language indicates confusion + disbelief. One Dr says yes, one says no, pt does not understand. Tests say yes. - Confusion - what the hell. - don't know what your tests are about. Sleepless. Dr said one thing but did another - adding to confusion. Prompt assessment + review. written hours urgency. impressed? focus on Swift time + cost of investigations. odd choice of words on x-ray? wow - nothing exciting? said bone scan so exciting? visual proof of pathology? validation of pain? recognition of me a HCP? not remarkable. Sweet firm medical perspective?</p>
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Feature to seek help.

Disturbed

Lack of knowledge understanding.

Confusion.

Spoke

Big reaction on Sean's behalf about obvious.

3

<p>Shock Speed Embedment</p>	<p>1 "No." 2 "You see the scintillation cameras picking it up as the acquisition goes on and I was looking at this and I was thinking oh god. That foot... that foot... something's happened immediately... this is the immediate injecture, immediate scan, and that is exactly the point, it was instantly hot and it was hot later on in the bone as well, so the foot was hot. The measured difference was 2 degrees C between the two which is hot. And so that all happened on the same day, on the Thursday. And I was in the plaster cast. Then I made them take it off on my knee on the Monday because I felt, it's bad enough now... by the way climbing the stairs and doing everything at home, the dodgy knee and the plaster cast, that was dreadful and I forced them to take the cast off, do the operation, put the cast back on. That was also tricky because post-op I was very sore, but I got the knee fixed and I, you know, I wouldn't have wanted to continue without it being fixed, the 3, 6, 12 months, so I got them to do that. And er... that's it.. And the other one went out. So I spent a month, with one foot, which is the hot one and we know there was nothing in the other because nothing lit up. The bone scan I think is quite sensitive, if not anatomical, but... and it was I who queried the other foot for no good reason except that I was conscious that now being on crutches with a cast, one good foot, clearly putting more weight now on the good one than the bad one and favouring the bad one, I just had my doubts about that foot, and so Venu do you know him... and then I was called down to see him and he starts twisting it and poking it and examining the joints of the foot in a way that I didn't know could be examined, but he seemed to twist it in an S shape... and he said no it's fine and then the MRI, because I said well we'd better MRI both feet instead of one, the rest is history, it's in both. And um..."</p>	<p>Good - expression of Shock show power, omnipotent being Much more emotional response wider realization. Two foot repetition - repetition to emphasize and that not my separate from himself? Repetition of hot - hot clinically + visiting hot on scan. Repetition of immediate - adding to shock? instant - esp to see - no chance to get words to see see? Dreadful - treatment will be compelling existing problem with the knee. Simple daily tasks not manageable. After initial shock language changes I used a lot I got the knee fixed I made them take it off it was I who - authority - being because I said - authoritative new awareness of risks - I was increased anxiety? link to post-hoc medical background - general from - masculinizing identity? refuting the 'expert' demanded testing of both feet</p>
<p>Taking control</p>		
<p>Knowledge / understanding</p>		
<p>anxiety / blame?</p>		

↳ I was right they were wrong!

<p>Overthinking / Preoccupation taking over!</p> <p>Reflection</p> <p>Cancer fear after limbs.</p> <p>Taking control</p> <p>Panama / Preoccupation</p>	<p>1 "And that was about a month later you said."</p> <p>2 "A month later. Now... the question then is when did that happen?"</p> <p>3 If, for example, I had had Charcot in my right foot say a week, a</p> <p>4 year, ten years before, it might not be hot on the bone scan any</p> <p>5 more but it might still have hallmarks of it, because once I</p> <p>6 discovered what the Charcot was, I began to wonder if I had it</p> <p>7 four years ago. I have a photo. I have a photo of me when I was in</p> <p>8 trouble, and I'll look it up while we're talking, but several years</p> <p>9 ago I had a sore right ankle, very sore. And I went to Australia and</p> <p>10 I was on holiday for three weeks in Australia, (mega) sort of</p> <p>11 holiday and as the holiday went on I could walk less and less and</p> <p>12 less. And when I came back I went to the er... orthopaedic</p> <p>13 department, they examined me, but didn't do an MRI and said</p> <p>14 they thought I had torn my tibialis posterior or anterior??</p> <p>15 Posterior. And the characteristic was I couldn't and wouldn't</p> <p>16 stand on my tippy toes on that side, I couldn't do it. But</p> <p>17 interestingly they put me in one of those Rooney type boots and I</p> <p>18 got better. But if you think about it, that might have been not</p> <p>19 totally inappropriate treatment for a Charcot as well and it's in my</p> <p>20 mind... it's in my mind. Why did I pull this thing? There was no</p> <p>21 injury that I was aware of. And that always... and I had always</p> <p>22 thought my right ankle made her a little concerned to look at. But</p> <p>23 I have very flat feet so they're terribly inverted anyway and I wear</p> <p>24 orthotics, but it was in my mind and I deliberately asked them to</p> <p>25 scan the other foot. Not because I had any symptoms. I claimed to</p> <p>26 be worried about it, but I had no symptoms. Because I had come</p> <p>27 to realise you could have this thing and not really know it."</p> <p>28 "Yeah, absolutely."</p>	<p>Focus on how.</p> <p>Looking for answers / reasons</p> <p>Justification?</p> <p>1. (likely would remain 'hot' on scan - shows 'hot' for a very long time.</p> <p>Justifying on / overthinking</p> <p>diagnosis - trying to make sense of it? Anxiety?</p> <p>Using prior education / he, ground previous claims / worries - has evidence / proof?</p> <p>Repetition of holiday + Australia</p> <p>2nd holiday noted in Spago - important aspect of life?</p> <p>large financial impact.</p> <p>reasoning / justifying - trying to bring me to sea was reasoning, wife looked & also concerned.</p> <p>Repetition of 'in my mind' - becoming a preoccupation?</p> <p>Diagnosis has increased anxiety after foot</p> <p>Claimed to be? but not really concerned - suspicion? - but said wife back to present day issues - dumping through time.</p>
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↓ pulling full focus, becoming paranoid

awareness that this can occur without warning ↑ fear.
 if it was negative - would thus warn warning have continued - ongoing requests for scans?

	<p>1 "So that's why I'm in both. That's why I'm in both." TC's</p> <p>2 "But you didn't have any other CT scans, we don't know if it looks hot now on a... spec CT... because obviously we can see it in the..."</p> <p>3</p> <p>4</p> <p>5 "No, it's too soon. They say it takes forever, for the radiation to go away, is that right? On the Technicum Technicum, on the bone scan"</p> <p>6</p> <p>7 "It takes a while, yes."</p>	<p>Rep. Reputation, forceful in both halves for his own actions.</p> <p>Would not be if he hadn't raised the issue - justifying own preoccupation?</p> <p>Level of trust in medical professionals?</p>
<p>Taking control loss of control.</p>	<p>8 "So I keep saying would you like to do another one of them and they say no you're still hot."</p> <p>9 "OK."</p> <p>10</p> <p>11 "And they don't mean clinically hot, they mean you'll still have... tracer... but I don't know the answer to that, but I'd like it. This is me in Australia, 2007 actually, July 2007 and I'm in... that's me walking down a beach in Northern Queensland. Have you been to Australia?"</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p>	<p>Still pushing for more tests - why? Needs visible evidence (reassurance) to see? To believe? (Again? control?)</p> <p>wants more information.</p>
<p>lack of knowledge / understanding.</p>	<p>16 "Yes."</p> <p>17 "This is a beach called, I don't know, 4 mile beach, 7 mile beach or something, it's in Port Douglas, above Cairns. That's me, that's my brother who we were visiting, that's my sister and you can see my ankle in this, but it's at the wrong <u>chase</u> because the right one is down. But I can't walk here. I am doing it because I want to, <u>foot</u> because I want to be out there and we're having a nice morning stroll on the beach, but actually I'm struggling enormously and I have ferocious pain in the medial aspect of my ankle which is</p>	<p>focus on photos of quilt.</p> <p>ambulation - Soliman on again - putting on in spite of pain - refused to accept limitation.</p>
<p>D. General attitude pre-post diagnosis</p>	<p>22</p> <p>23</p> <p>24</p>	<p>Different reaction to post diagnosis - due to new awareness of risk factors?</p>

Bevel / ruthless Savage

survives on struggle.

<p>Knowledge Understanding</p>	<p>1 the foot clinic... what was...?"</p> <p>2 "Well if you want my medical opinion of them, I don't think</p> <p>3 they're tremendously evidence-based and so I've been told that</p> <p>4 standard anti-inflammatory treatments if you like, or anti oedema</p> <p>5 treatments such as anti-inflammatories, bisphosphonates, you</p> <p>6 name it, don't really work. In other words there's no active</p> <p>7 treatment is the first point. There's no active chemotherapy of</p> <p>8 any sort that has been proven to be effective. Though I was</p> <p>9 wondering why, you know, total cooling and immersion in an ice-</p> <p>10 bath for six hours every day, wouldn't be effective, but that's</p> <p>11 neither here nor there. You have to wonder, if your microvascular</p> <p>12 won't switch off due to the normal nervous control, can it be</p> <p>13 forced to by temperature, or even regional cooling or whatever?</p> <p>14 [That can be your next project when you get to the end... Er...</p> <p>15 second, there are three possible elements to it I think and only</p> <p>16 two seem important. The first is immobilisation, so that's</p> <p>17 obvious, and that has been absolute. So I'm in this and that's that</p> <p>18 They're very comfortable by the way, they have their drawbacks</p> <p>19 of course, but actually they're very comfortable shoes. I suppose</p> <p>20 they're meant to be. The next is relative non-weightbearing, and</p> <p>21 that's very interesting because that's an open-ended thing and I</p> <p>22 have had huge problems with that, and then the third, that</p> <p>23 everybody thinks, including the... what was not made a big deal of</p> <p>24 at all, is elevation. So the first three days that I had this, I</p> <p>25 essentially took off from work completely and I elevated at home.</p> <p>26 And in any event at that stage my foot was sore. But within two or</p> <p>27 three days I've never had pain since and it's... it wasn't sore after</p> <p>28 that. And when I spoke to M... and others they said that</p> <p>29 elevation wasn't a big part of it. But even still, occasionally I still</p> <p>30 elevate, and there was a time when I was working less that I</p> <p>31 would deliberately go to bed in the afternoon just to be on the</p>
<p>want's evidence (proof) but was going to go outside the box - immersion etc - will explore and open - deapertion?</p> <p>Showing medical knowledge</p> <p>Showing opinion - medical (1st than personal understanding)</p> <p>Strong - all encompassing, nothing you could think of would have been shown to work.</p> <p>Nothing can be done.</p> <p>Repetition no active - TCC treatment + time - late passive</p> <p>Less covered as evidence base?</p> <p>Young background to possible other ideas for treatment & underlying aetiology - further evidence of overthinking? Control?</p> <p>Seeing me as researcher again?</p> <p>State immobilisation obvious - acceptance? Absolute - not relative or comparative Total, not qualified or diminished 'body'.</p> <p>No room for questioning or debate</p> <p>Final decision. Final statement feels stuck 'intuitive'.</p> <p>Finding positive - comfort</p> <p>Relative non-weightbearing (unrestricted).</p> <p>Head-pain tense?</p> <p>huge problems with open-ended advice?</p> <p>Pain gone - OSRN.</p> <p>→ Stronger out medical opinion but wanting to accept elevation wasn't help - trying to remain central? To mean uncertainty?</p> <p>Crashing at stresses? Anything that might possibly help worst a try? Still doing, actively trying to improve this situation? Possible line to blame guilt?</p>	

Thus account is very methodical.
Everything in lists: 1st CASHING
2nd Non-w/B
3rd elevation.

Taking control	1
Talking over w/ my head!	2
Consequences of offending	3
Control 'I got	4
Confusion	5
Streak	6
Frustration	7
Deportation	8
Level of knowledge	9
Uncertainty	10
Environments dominating	11
ward altering isolation	12
LOSS	13

1 horizontal. I worked very effectively from home for the first three days that this happened, and had to stop doing that because I thought I'd be in pain or have a sore bum or a sore back, or a sore something, but actually I was able to make myself very comfortable on a couch in the living room and on my bed. But within days my neck was killing me and my shoulders are still not right. From holding the iPad like this and my head like this in the couch, typing 52 million emails, and my shoulders are still sore and my biceps tendons are still sore after that, aggravated by the wheelchair. I got the wheelchair, nobody told me to get it, because when I first said to M..., they gave me crutches, it was one foot and they gave me two, and you know, if both feet are with crutches you can't be non-weightbearing. On two feet it's not possible. So he said... I said how much weightbearing? He said as little as possible. And I wanted to say, but I was too shocked well as little as possible is lie in bed the whole time with your feet in a sling and, you know, so clearly... So I got the wheelchair. And then a month or so later I said to M., you didn't tell me to get a wheelchair. I did that. And she said yeah, we didn't tell you. But I got it myself because if you can do something, setting a limit is very difficult. How far can I walk? How far can I stand? How do I add it all up? Can I stand for... you know, can I walk a mile a day? In otherwise 50 x 20 yards, or can I stand for a minute, or ten minutes or 25 minutes? Would I be better for 2 minutes an hour, or 20 minutes total or where does that begin or end? So I got a wheelchair. And I go the wheelchair for two reasons, here in the hospital, to stop me going the length of... it's a long corridor. To stop me going the length of the corridor and further around the hospital, to go in the wheelchair. And then at home, not in the house, it's useless in the house, to have a mild social life by which I mean ^{the extent of} going to the supermarket once a week, and going to the shops, once a week, which I haven't achieved by

changing route to accommodate General Park
repetition of same - various body areas
neck killing him - Frustrating him
Environments - impact of General Park + consequence of offending
aggravated - implying never ending amount - limiting all pressures to keep going? Where responsibility to
Repetition 'I got the wheelchair' - blame
- Accusatory? Why not advised? or accusing power + control
advice to get better and advice to advice to not realistic.
advice to vague - as little as possible? Not enough support?
Crutches repeated
lack of tangible advice relating to level of shock - used to more prescriptive
talking what is suggested very medical
literally - i.e. in bed + legs in sling -
aggravating to make point? So clearly: obvious to anyone else?
Questions highlight confusion + desperation - made something more to hold on to. Frustration
Just nouns or whole situation
could be talking about parts + whole?
Breakdown of offending strategy
wheelchair allows access to outside world but 'useless' indoors
Several allow social access to shops but still unable to achieve
them. Don't usually visit supermarket as
usual - dominating

Social life reduced to once a week supermarket visits - still not achieving. Unaccessible - dominating
- ironic? hint of sarcasm?
9

1	Loss of mobility
2	Shrinking world
3	Shrinkage
4	Life line into
5	outside world.
6	
7	
8	
9	Shock
10	(identity transformation)
11	Displacement
12	Lack of information
13	
14	
15	
16	Deprivation
17	
18	Reverse perception
19	Through the eyes of others
20	
21	
22	
23	Life contained
24	Loss of old life
25	
26	
27	Reverse perception
28	
29	
30	Lack of understanding
31	
32	deprivation

the way, but that's ~~not~~ enough. So that's what it's about. And to be able to get long distances, through an airport, through the train station. I was on holidays ten days after this happened to me and I thought your only chance is to get a wheelchair, so I did. Other interesting thing is, once you've hired a wheelchair for a month and then you ring up and say I want to extend it for another month, and maybe another month, they say, OK, you'll make that expensive, you're better off buying it... I own the wheelchair. Something I never thought I would... I own a wheelchair. Brand new, lock stock and barrel. I'm not happy about that. Never wanted to own a wheelchair, but I do. I think I would have benefited from more specific advice about weightbearing. And even if it was bullshit and you don't really know the answer, but made it up, a few rules would be better. So I'm not confined to a wheelchair, I never was, but at work I was mostly seen in a wheelchair. The day people saw me even walk to the bathroom, they said oh god, oh, oh... they were all on my side here, every one of them, or against me, whichever way you want to look at it, and they all said, oh don't, you're not supposed to be doing that... but the answer's actually... and nobody ever told me I couldn't walk to the toilet you know, but everyone here said whoah... Then more recently I have used the wheelchair much less here, don't go very far... and I've managed to contain my life anyway and I don't go far, and I've essentially stopped using the wheelchair for the last week or so, and everybody congratulates me on the improvement. Oh, you're more mobile, great to see you up and around, oh you're getting better and I just say actually, no I'm not, I just chose not to use the bleeding wheelchair. And oh god, I should have come out with a list of lies, what's wrong with you? Were you skiing? Yeah. Both feet? Yeah right. Or did you break your foot? Were you in an accident? What's wrong with you? And then you tell them what's wrong with you and they

Seems actually to be very important + to be having a large impact. Radiation in size of the world.
 More habitats? Living control.
 primitive - being cornered, trapped.
 own choice - cornered, trapped.
 no other option.
 wheelchair, "refine into world"
 financial cost.
 Reputation of never - not a pit he envied himself having - unrecognizable
 Reputation - own a wheelchair - sounds like SHL in shock - what does this mean - who is he now? look, speak... means total (all everything).
 increasing meaning - more than just a new possession - negative connotations life change, image change, loss of independence (pale).
 going back to advice re. w/b
 feeling lost - alone, nothing to grip on to, even if falls/fred - de facto perception of others.
 Sense of confusion - not confined to wheelchair but still uncertain of safe parameters for movement
 still either for or against - unusual way of looking at situations? feeling lost + therefore unable to read situation + reactions of others? Pulling back? feeling threatened in old environment. He used to dominate? managed to contain life - conscious choice?
 Frustration at reactions of others irritation at congratulations - too many misunderstandings, judgments, oversteering

one becomes better to parasitic
 Step - like a horse (animal) - get back in cage/back chair - restricted/trapped.
 has easier to try to explain than Charat foot?
 too many questions he can't answer.
 wrong - not right, not morally good/correct, harmful, unfair

<p>lack of understanding</p> <p>explaining the unscripted</p> <p>Punishment; blame, guilt</p>	<p>1 don't know what the help you're talking about, because I didn't know what the hell I was talking about. I don't know... a script... what to tell people that isn't a lie, but isn't too detailed and you know... God smote me or something, you know! I've been punished for sins in a past life or something."</p> <p>→ God, Biblical, punishment - devalues;</p> <p>"Can I just... when you were talking about the elevation thing you said everybody agrees about elevation, but no-one told you in clinic. Would you...?"</p>	<p>- can't explain to others because still can't understand himself even with medical knowledge.</p> <p>still confused!</p> <p>→ need to lack of advice used to help to explain - a script</p> <p>Quit, punishment - sin - blame for live but still comment (Fearful not worried about him) (Fearful accounts just to make more simple.</p>
	<p>9 "No. Everybody seems to think elevation isn't a significant part of the treatment."</p> <p>10 "Oh OK."</p> <p>11 "Is that true?"</p> <p>12 "Yes, I suppose that is..."</p>	<p>elevation helped.</p>
<p>Taking control</p>	<p>13 "It seemed the right thing to do anyway, because I found my feet a bit swollen for a few days if that makes sense, and actually I was a bit tight in the cast for a day or two and I elevated. But the Chairman of the hospital is a dentist dentist. You probably know that do you? Scripture removed for anonymity removed for anonymity."</p> <p>14 "Oh OK."</p>	<p>Bringing back to main concern.</p>
<p>frustration</p> <p>Pulse perception.</p>	<p>15 "A recent past patient patient He's been in diabetes for the past 50 years. Every time he saw me he said why aren't you at home, why aren't you at home, why are you here, why aren't you at home? Of course the answer is well I'm not actually sick in the</p>	<p>lack of understanding from someone he feels should know better.</p> <p>Repetition - finds questions or concern too much, overwhelming.</p> <p>trying to help but making him feel worse.</p>

→ emphasis on inability to explain + fully understand.

<p>Loss of identity Confusion Lack of understanding.</p>	<p>1 sort of sick sense. What would I do at home except wreck my shoulders, be miserable and be locked up with an incontinent 16 year old Labrador who's dying you know. However... it's people trying to do their best for you, but what is the best? God only knows." emphasis on confusion</p> <p>2 "Was the purpose of the treatments that you were offered explained to you or... because you obviously know quite a lot. Was that something of your own perception?"</p>	<p>Q1 + words in the Sick Sense but not depressing alternative to being fit work. 15 yrs planning computer to work he said himself going. Back breaking, only trying to do best but previously - for or against confusion?</p>
<p>Inaccurate information Lack of understanding</p>	<p>9 "That was explained in one particular domain, which is you have no fractures, you have no permanent damage to your feet. If you take the medicine you will get over this and you will have normal feet again. You will be susceptible to this, but that would be an episodic thing, but won't be continuation and you can be cured. Is that true? So he said... so he said... we will get rid of it. When? I don't know. But take this medicine and we will cure this. I've had more useful information from M and T frankly. And just on a complete aside, you know, I wouldn't pretend for a moment that the treatment I get is typical. Why would it be? It shouldn't be. I'm a senior member of the staff. I believe we all owe each other exemplary personalised treatment. But I'm listening and watching this, seeing what goes on down there and... And one of the things that I really like and am impressed by is that while they all hold M in tremendous esteem, it's actually quite egalitarian. And the podiatrist, the senior podiatrists will tell him what they think, or disagree with him, and he will take their opinion. And basically, in some elements of it they're as expert as he is. And their opinion counts. I like that. I find that a very strong culture. There is no question who is the hero down there. No question about that and er... actually I've found that quite emotional as well, because I have tremendous respect for her</p>	<p>Change of tone - so you impersonal, generic, base to bullet point statements inaccurate, poorly explained by team? reference to my clinical role wants info again - direct question - still wants info diagnosis, doubtful - not offered medicine taking - disbelieving, use will cure - team effort no cure, no medicine - cash only no active -> chronic - usual useful? Practical perhaps? Priority - staff member Priority treatment justified Standard rx? Standard rx? So who should he listen to? Approves of culture of clinic - reward with everything - just not the info he had been given.</p>
<p>Powers</p>	<p>16</p>	<p>cash only declassified as having changed feet</p>

→ Questioned connection to cinema

<p>change in thinking → becoming patients.</p> <p>Fault blame Cult humiliation</p> <p>Lege uncertainty Fear for future affecting work</p>	<p>1 and to think that I am less ^{aggressive} am able to support that service 2 really appeals to me. It's about what we're here for. Only for the 3 sick, I don't give a toss about the rest of it. We treat the patients, I 4 happen to be one now, and I'm a bit more informed about your 5 department than I was, but it's what we're for. And he is 6 definitely the <u>hero</u> down there and rightly so. But he's not the 7 boss and he's not the only opinion in town. That's quite 8 uncommon, it's quite uncommon, and then I hear what they say to 9 the other patients. I hear what goes on and of course there's a 10 little ??? of patients because they're all acute, but chronic and 11 coming back and back. And er... the other thing I like is that I've 12 heard it many times... somebody arrives in acute... whatever... 13 suddenly, not necessary Charcot... ulcers, whatever... and I've 14 heard him say it several times to patients and I've heard others 15 say it as well... you haven't done anything wrong, this happens. 16 Because with diabetes it is either chronic disease of <u>self</u> 17 <u>managements, self abuse, self mismanagement...</u> for me at least 18 <u>guilt is never far below the surface, never, never, never.</u> And I'm 19 <u>not happy with this disease, I'm embarrassed and humiliated by</u> 20 <u>the feet, I really am... I really am. I'm probably jumping through</u> 21 <u>chapters again now...</u> <i>(implying choice)</i></p> <p>22 "No, no, no, that's what we want to be talking about really. 23 The only other... the very last silly question is just how long 24 do you expect the treatment to go on for?"</p> <p>25 "I expect it to go on for eight/nine months. I'm hoping that it will 26 be six, but I'm mentally resigned to it being another three, come 27 hell or high water. If it drags into nine/ten/twelve or eighteen 28 months I really don't know what I'm going to think about it, I 29 really don't. Because it's affecting my job as well, does that not 30 surprise you? And then... do you know <u>what</u>?... so <u>what</u> all along</p>	<p>regaining power / pulling rank giving something back. defiant - hospitals are for the sick, the rest glorify water war rest? his power? Politics.</p> <p>Hero - person admired for great + brave acts. War - character - strong.</p> <p>Happens to be patient now - almost on a side - speaking more broadly about the service.</p> <p>Less certain, suggesting more blaming tone when talking generally - much more certain when talking about himself.</p> <p>Practitioner recognizing feelings of blame, trying to remove focus - no fault blame.</p> <p>Repetition - powerful language identifying / attributing effect of own behaviours to current health state. Self abuse / self harm - knowing that (verbal / improper / offensive dialogue) to bad effect. Powerful sense of blame.</p> <p>understands averages but hopeful it will be over in less time. resigned - realize he out still fearful for the future was not cope if continues in longer term. affecting work.</p>
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↳ challenging me? Am I surprised was work is affected?

the no department on
the junior year's program?

<p>Inaccurate information</p> <p>Confusion</p> <p>Lack of accurate information</p> <p>Fear</p>	<p>1 told me well we've caught this really early and we hardly ever see anybody as early as we've seen you, ergo you'll get over it quicker, I don't think that's necessarily true. I think there's a fallacy in that because there's a pathophysiological process that isn't strictly timed and it takes its own time. If you've got it, it'll take it's time going away. And... but he had said that. It was people who said, immediately on the first day, oh we usually say six to eight months, and then people, who I met a month later.. I bumped into her at the coffeeshop downstairs, said oh you're going to be in those for eighteen months then are you? And I was on my way to the clinic straight away, so I went straight up to her and I said Carol said I'll be in these for eighteen months. And he said harshly he said a bit harsh. I think she's not being fair, that she not be eighteen months, it'd better not. So, what's the average?"</p> <p>15 "Average? From... I think the average in clinic from coming out and into shoes, is about ten months..."</p> <p>17 "That long?" - <i>Shock!</i> Even though just had discussion re longer time frames + aware of averages. Reaffirming hope will be over in less time.</p> <p>18 "...but that's into shoes so... and then obviously if you need those made and things, sometimes that holds things up."</p> <p>19 <i>Superior</i></p> <p>20 "Well, believe it or not my orthotics are being made in two weeks time, which sounds a bit crazy because I won't be in them, but people said yeah but your feet won't change and they'll.. it takes them months to come up with them and get appointments, have it off, get measured, put it back on and you're good to go when the time comes."</p> <p>26 "Because that can be a thing that holds it up."</p>	<p>- Challenging what he has been told. Inaccurate information - placing him trying to make him feel better? recognizing pathophysiological background - back to medical knowledge.</p> <p>Not all singing from the same hymn difference in opinion / advice confusing + distressing.</p> <p>Repetition: it had better not be! or worse? Fear? Apprehension? Harsh? Not fair? Is time longer? time frame? Still uncertain - challenging me as practitioners.</p> <p>Superior Swift treatment due to street status.</p>
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<p>lack of information</p> <p>Timing future</p>	<p>1 "So she was the one who gave me some information about the transition in the future, and boots and L shaped orthotics and ankle support and that kind of stuff. There's no information sheet. Or if there is I don't have one."</p> <p>2</p> <p>3</p> <p>4</p> <p>5 "There isn't at the moment."</p>	<p>Different people giving different information</p> <p>No written info → nothing</p> <p>→ Questioning if missed out. Long, etc.</p>
<p>Taking control</p> <p>Lack of information</p> <p>Timing + Straying info</p>	<p>6 "I've looked it up on the internet, but I've really concentrated on the diagnosis and the topology and I don't know if... I don't know where I'd look or if it exists about outcome, future, duration, rehabilitation. I figure I'd like to be getting better before (worry) about it properly."</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11 "Do you think an information sheet would be something that would be useful?"</p> <p>12</p> <p>13 "I do. I do, yeah, yeah it would... it would..."</p>	<p>Practical/ anatomical structure</p> <p>Actually seeing information internet wasn't accessible - but not always accurate. Acknowledged not sure where to look for info - even with medical knowledge.</p> <p>Straying or drip feeding information - doesn't want to get ahead of himself perhaps</p>
	<p>14 "We are working on it at the moment." → talking as if practitioner! Need to keep focus on researcher.</p> <p>15 "Good."</p>	
<p>identifying activity</p>	<p>16 "So now's the interesting bit really where you get to tell me about what it's like to live with it so... do you want to show me one of your photos and we can have a chat about what the picture represents and how Charcot's affecting your life."</p> <p>17</p> <p>18</p> <p>19</p> <p>20 "They aren't necessarily all the photos I wanted, but that's ^{more?} definitely one that would be. So... late in life, five years ago we both became cyclists. I would cycle to work maybe three out of five days a week and there was a stage, especially in the summer months where I would cycle to everything. I'd cycle to meetings</p>	<p>Given photo selection some thought + consideration.</p> <p>Both (he and his wife) became cyclists</p>

→ everything - absolute, part of daily life.

<p>loss of important activities health image.</p>	<p>1 in town, I always cycled to Guy's and Tommy's and got used to changing in toilets and god knows what and I have all the kit and all the gear and this is 7 o'clock in the morning on the second year that we did a night ride, London to Brighton. This one was for Alzheimers. The previous one was for the Heart Foundation, or maybe that's the other way round... I don't... no that's the recent one... so I can't do any of that. And I liked it, it was healthy, it was good, all the holidays, and I mean all holidays included cycling or we just didn't go. Last May I went to a conference in Minneapolis, preceded by three days in New York, because I had stuff to do there. And then a couple of days of fun in Montreal because we could, and in all three... I cycled around Manhattan on a bike, did you know you can do that?"</p> <p>14 "No."</p> <p>15 "Well we did, both of us, top to bottom, on Manhattan, the whole way, and right down the middle again, through Harlem and Central Park and back to the bike place. And then we cycled all over Minneapolis and we do other little things, we cycle to the restaurant at night. Because you can have a load of drink and still cycle home again. And so we would... we do that here, we would cycle to a restaurant here, we've done it many times, and cycling all over Montreal... all over... though interestingly in Montreal I claimed that because of my knee, but now if I look back I can't remember where the pain was, but I claimed that because of something or other, oh I know I had sciatica, I did have had sciatica at the time, I was in a lot of pain in Montreal, and it was mainly my sciatica. Anyway, I miss cycling. I miss the element of calorie consumption and really missing exercise now. Obesity has always been a huge problem for me and that had been coming under control... slowly, but it had been and I miss the contribution</p>	<p>get used to uncomfortable aspects - that a problem, serious about it.</p> <p>Showing photo of bike ride.</p> <p>Can't do - loss of important ADL - don't like + fun with wife.</p> <p>Positive connotations - healthy, good.</p> <p>Very important positive connotations included in holidays or then "just don't go"</p> <p>old because "we could" phrases open - choice, freedom, autonomy fun, movement.</p> <p>↳ takes user pride about activity - feelings of positivity</p> <p>↳ cycling made life more fun all round. Conversations</p> <p>↳ other ailments impeded cycling temporarily - but still nothing quite stopped them previously.</p> <p>↳ misses cycling - absence of loss enthusiasm + physically creating the activity.</p> <p>↳ healthy, reducing guilt re food + drink consumption?</p>
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loss of important activities
healthy past
life - pre charcot
Chance freedom
pre charcot

loss of important activities
health image.

<p>Health</p> <p>Life span - loss of future opportunities</p> <p>Time</p> <p>Negative effect on relationship w/ wife.</p> <p>loss of meaningful activities</p> <p>Fear + abandonment</p> <p>isolation</p>	<p>1 of the cycling which could be extreme. We used to regularly cycle 2 30 miles every Saturday and Sunday. And also... coming up to 60, 3 I'm 60 in the summer, I felt good about that. It felt a... it felt like 4 older age was going to be better than younger... than middle age 5 was. And of course if you look around you see all these older 6 people doing all this shit now that my parents and others didn't 7 and it's a different life now for older people who are close to 8 retirement now, and that appealed and I miss it badly. And it has 9 big knock-on effects, and also, my wife and I get on very well, but 10 we don't do this anymore. She doesn't do it... it's been winter 11 anyway, but she doesn't do it because I'm not doing. There is no 12 question it's going to be 20 degrees on Sunday. Every other 13 March 30th when the weather is 18 to 20 degrees at the end of a 14 poxy winter, we would have been out cycling. We won't. She 15 could go on Saturday... on Sunday, but will she leave me at home, 16 because she knows I'll feel abandoned, frankly. I might say you 17 should go for a cycle, but she won't do it, not least because she's 18 working all day tomorrow and I'm stuck at home with the 19 incontinent dog on Saturday and if she goes cycling on Sunday, I'm 20 stuck at home with the incontinent dog all Sunday as well. So... so 21 that... shall I email that one to you now?"</p> <p>22 "That would be lovely thank you..."</p> <p>23 "What's your email address...?"</p> <p>24 Email address given</p> <p>25 "So how does that make you feel that you... you know when 26 the sun comes out and you know... you and your wife can't 27 go..."</p>	<p>miss sense of optimism + possibility of world + future.</p> <p>worked hard all his life - feels entitled to his retirement.</p> <p>Life Journey: ↳ exploring life span + looking to the future he previously anticipated - had been optimistic about; can't afford to hold onto younger + middle years ↳ availability of fun exciting things open to do in modern times ↳ extensive ↳ choice + options taken about + removed without consent ↳ craving the options now lost ↳ part of who they were as a couple + less engaging relationship ↳ language of stress - regulator not doing, doesn't do, we won't. All negative. ↳ feels guilty that wife can no longer undertake activity. ↳ can't, instead? ↳ he might say she should go but she can't appear to want her too, ↳ feels fear of abandonment + isolation - only alternative to be stuck with incontinent dog. ↳ terrible picture of life + what it has become. ↳ Contrast to what he expected of older age w/ unfair; would feel's like w/ wife left alone. ↳ cessation of all fun + activity for both he + wife.</p>
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Image	1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32	weight I've been since 1991. And that is actually my official photo and I used to weigh at peak 21 and a half stone. And I went on Lighter Life and two and bit months into Lighter Life, for a totally different reason they were redoing all our photos for the boards in the hospital, they were redoing them all, and as it turns out that's my lowest weight, and it's not that now. It's not 21 and a half either. But that was my lowest weight, the <u>thinnest and best</u> I looked and the photographer who took it had photographed me the year before, for the previous one, and didn't recognise me. And I didn't know it at the time, but that is momentarily my lowest weight. So that is me, better and fitter than I had ever been in the previous 20 years, and that's where I'm going to get to once I get liberated again. That's one element to the photo. The other is I don't think I'm a very egotistical type of person, but I have a very powerful job. There is no denying that, I wanted it. And I've mainly got where I've got on drive and enthusiasm as opposed to being a bastard, I would say. I don't know. You probably don't know me at all, but I believe in what we do here, and I've always been part of it and people know that and whatever. But it is a powerful position and it's a visible one. Two things are going on at the same time. My own... <u>stamess</u> is probably the word for it. That I have ended up in this position I haven't enjoyed. And the second thing is that if you go, in a wheelchair in particular, but look disabled in any event, people subconsciously start to treat you as if you were <u>mentally disabled</u> as well. Not fully but impaired in some way, and they don't have the same... respect is the wrong word, but they just don't treat you with the same seriousness that... Interesting. Since T put this black one on the other day, it's caused much less attention on me than it... very, very subtly interesting to watch that. The big white fluffy one, you couldn't miss it. And the black one... the black one makes people think I'm not as sick as I was. Very interesting. Um... there's an	<p>22 yrs ago - long term struggle with weight,</p> <p>Feels good about photo source of pride.</p> <p>Line with disability again</p> <p>Somewhere in between</p> <p>Hum = healthy? Line = weight issues</p> <p>Prud that photographer don't recognize with. Should've name? Ego!</p> <p>old self - 'Batter' improved version of self - goal to return to self important photo - multiple elements self</p> <p>liberation - prison, punishment - concentration camps. Freedom from etc or from restrictions on life.</p> <p>Eager to return from current self to improved former version of himself</p> <p>Focus on self - self made powerful man - pride, positive previous self image - drive + enthusiasm</p> <p>Enjoys position of power - was strong belief in reward system, work part of belief in reward system</p> <p>Visible device -</p> <p>exaggerating sense of shame</p> <p>Visible - unable to hide.</p> <p>Public paraphor: - infers mental visible disability with less authority / disability - weaker (Rudely / mental impairment) - assumed. Perceived lack of ability to cope</p> <p>Subconscious - not intentional.</p> <p>Black vs white - white more visible - increased attention</p>
Image / Identity			
Loss sense of Self.			
Future + past Self.			
Hope.			
Identity			
Shame / Fault Name.			
Disability physical mental			
Public perception			
increased visibility.			

Previously stated not sick! Previously stated about how to place himself - current identity

1	awful lot going on in the hospital, there always is, but there's some	
2	really big things going on at the moment and I'm absolutely key to	
3	them and I was very determined and at cost to myself, not to go. I	
4	could have gone sick, I could be off sick now. You could argue	
5	that... I'm not sick, but if I said oh I need a certain time off, for	
6	three months, six months or a year, I'm sure people do, I'm sure	
7	they do. I took no time off. Because I didn't want to be edged out	
8	of the system, and I have a real problem with the Chief Executive,	
9	who genuinely means well, and is genuinely sympathetic, but he	
10	doesn't possess the emotional intelligence to deal with me. Others	
11	do. Clinicians do, you do, most of my colleagues do. He doesn't.	
12	So while he talks a really good and supportive game, he will	
13	frankly <u>erase</u> me and he tried to already. And interesting... I know	
14	this isn't paranoia, because my colleague next door, the director of	
15	operations said, you need to <u>delegate</u> more specifically. I have	
16	seven deputies by the way and they had jobs, but most of them	
17	were task orientated, but I have actually delegated a ton to them	
18	which I didn't enjoy very much, but I did, and that's worked.	
19	Because I just don't have the time I used to have. Life is very	
20	difficult now. I don't have the time I had. I can't go to the places I	
21	used to go, as quickly and easily, etc. And it... and I... the biggest	
22	physical problem I have is sleep. I don't get as good a night's sleep	
23	with these two feet that I used to. I have turn over consciously	
24	from one side to the other. Sometimes it's good, mostly it's not. In	
25	an ideal world I would have a nap every day. But I can't because	
26	I'm here. But if I could go to bed for two hours every day, I could	
27	work twice as long and be twice as happy, but I can't. So then I	
28	started working at home one day a week. Jesus Christ, he <u>drove</u>	
29	me crazy, the phone calls, the emails, the texts, the everything. I	
30	was on holidays last week... I almost... I didn't do as much work	
31	here as I would have, but I tell you it was relentless over there. I	
32	got a phone call from him on the bloody ferry! And I've been a	
	insane world	
	Highlighting Personal Importance	
	Eye - identity, key player	
	- at what cost? Personal (family)?	
	- not working sacrifice made to get	
	to position of power.	
	could have gone sick - would be	
	just read - others do. But not technically	
	ill - doesn't fit in any way - not ill	
	but not well.	
	Fear of being edged out + erased	
	due to lack of understanding -	
	- perception that with physical	
	impairment, mentally can't cope.	
	Erase - reducing in visibility	
	Deviously felt very visible - former self	
	Sugarcoats did have the emotional - pure	
	intelligence to cope with -	
	role determined against.	
	- not paranoia, justifying claims	
	highlighting position of power again	
	loss of power - enforced	
	loss of control.	
	release effect on life + freedom.	
	where life difficult, time + space	
	altered, mental focus on restriction	
	reels affect sleep.	
	Turn trying to prove he can	
	cope by pushing himself back	
	early	
	Requirement to change lifestyle	
	start to improve lived experience	
	start to get = increased productivity	
	changed routine - feeling	
	hounded - no space	
	- no escape	
	Still feeling trapped even when	
	pass trying to push him out?	

to steer clear of or prevent from happening

Blame	1	avoidable, but not preventable. Preventable is not have it happen again. Avoidable - it would be avoidable if I had had far better	To avert / impede / anticipate or counter in advance.
Consequence	2	diabetic control, if I had obeyed all of the rules instead of cheating,	Avoidable vs preventable - obviously
Cheating	3	which I did. We probably all do. And it would have been better if I hadn't got to this point. And so those feelings are... it's your own fault... Come on, a lot... a lot... within me and mine... which is public humiliation and shame. And er... it's very interesting... some of these things are worse when people are being nice to you... so one of my colleagues, do you know her Nuclear	Given this some prior thought - don't obey - comply, fulfill, adhere to instructions
Shame	4	Medicine... she does all those body scans and everything... she summed it up for me, so it's very interesting... I've never used the word disabled, because I'm not paralysed and I... well let's assume I'll get better. But I am disabled at the moment, but I've never thought it, and others have used the term and it isn't that it was inappropriate, I am currently disabled, I am now... though I can't get a badge for the car is very interesting, because you have to be disabled permanently for that and it takes six months to apply for it. When I go to the supermarket, my wife or my son, whichever one is driving me, has to park with everybody else and then I have to wheel through the car park and almost be run over. It's not the distance that bothers me that that's a problem, it's you're wheeling behind rows of parked cars that can't see you and want to pull out. It's a very interesting phenomenon. I could genuinely benefit from a disabled badge, but I can't get one... I can't get one. But I am obviously disabled. I am in a wheelchair or on crutches or both. That's what she said. And she said that her brother had lost a limb... it turns out it was his arm, they used to live in Zimbabwe in the bad old days and I think it was where he lost his arm. And she said, even today, 40 years later, he still finds the inability to do certain things and people having to do things for him, humiliating, even still. And I do too. I do too. I deliberately took to the wheel... when I got the wheelchair I brought it in. I	cheating - violating rules deliberately dishonest / unethical.
Public perception	5		Moral language highlighting his shameful + immoral demeanor - he should have been good - all feels like punishment
Disabled	6		Feels that others will judge him as nasty or he does himself - visible compliance why worse when nice? Don't decrease it? Due to reputation of blame + guilt. Still unsure - no guarantee
Disabled	7		Reputation disabled - struggling with categorization - lots of time participants never, currently, now, at the moment, very generalised - one you only disabled if paralysed?
Confusing definition	8		Confusing - others use term disabled - he doesn't live to - official sources society does not do not permanent + can't get help in form of blue badge.
Public perception	9		Not disabled nor able bodied - worse than - what?
Danger	10		Disorder - in more danger without blue badge
Lack of help / understanding	11		General benefit - but not recognized - diminished + ignored
System not working	12		Repetition - implies dishonesty?
Disability	13		change - 'obviously' disabled - previously said never called himself that
Humiliated	14		Confusion in terms of where it belongs
Loss of sense of self	15		Do involuntary audio help in wheelchair? = disability?
Disability	16		But help = humiliation
	17		But help = humiliation
	18		conscious decision.
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no change even after 10 years. Fear for future self? would we be future need?

Found someone to identify with, reputation - relief? not alone?

helping to make sense of feelings? 22 experience?

<p>Control, Glucose + Stone → Food</p> <p>Power</p> <p>decline in health</p> <p>Pre vs Post Charcot Foot life + health damage</p> <p>decline mortality</p>	<p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30</p>	<p>month. And only found it by accident because I wanted to check what my HbA1C and other things were on the diet and they were terrific and I discovered I was in acute renal failure. On a Tuesday morning I had all my... I ordered them all myself. I ordered my own bloods, went down, had them done, had a board meeting that afternoon at 2 o'clock, and at 1 o'clock I sat here to just look at my results and I think ooh, cholesterol's great, ooh yeah, this is good stuff. If you eat nothing you're great, and I thought Christ Almighty and I called one of my deputies who's one of the pathologists, I said you couldn't possibly come up, there's something bothering me and I need to see you straight away. Very interesting. If I walked into you with bare feet, you'd look at my feet, straight away because that's what you do, you'd probably make a diagnosis in a second. He looked at this list of bloods and his eye went straight to the Creatinine nothing else, if you showed me an ECG or a chest x-ray, that's where my eye would go. He said oh my, an hour and a half later, I'm asleep here having an emergency stent put into my kidney and I spent two nights into the high dependency unit. So a lot of tough stuff going on, that wasn't pleasant. I'm also left with the bigger feeling... which is that there is a step-wise decline with my health, which is why I, in some respects, not today, but in the past felt fitter, happier, richer, more enjoying that I'd ever been before, less concerned that there's a step-wise decline in my health. And if somebody were to plot my demise in.. next year, or fifty years, when I die, they'd say oh that's when that and that and that... but this is a big one, this is ??????? what else have I got in the ??? all sorts... I've had four knees operations, all kinds of crap and ?????? subject whispers a lot in this section... but I have a feeling of decline."</p> <p>"And you notice it more with your feet than the other?"</p>	<p>— taking charge of own health — monitoring blood markers in relation to recent weight loss — But was concerned he pain also a contributing factor? Not noted but aware he felt unwell. — using dead he, pain stake — Power — taking control. — In giving things busy + important help eatery? — live again to food + health — have one undertaken — consequence. — Pulling out deputy. — food + blood eat nothing great — recognizing me as podiatrist — recognizing organ status of other Specialist saw problem straight away not too area of expertise. — Emergency situation + surgery — severe — life threatening issue. — Playing down? Not phobias tough sleep? why? pain issue + over it now? — or in comparison to Charcot? — Step wise decline — to Charcot? — systematic decline — → give me recognize moving downwards, deterioration in/out of — Foot self better, happier, all round improvement to current state + on the way down + out — now worried about decline + damage? — personally? Not just in health + previously noted? — Charcot Foot a big step down — bigger than the AHS and other pathologies — in the fracture of life plus event w of major significance.</p>
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1	'Never noticed it with the others, they were bumps in the road.	
2	Currently well this is a decline, not least because it may have been an acute onset, but boys it's a chronic problem and it was clear	
3	two days later I was going to survive the kidney hit, but it ain't clear two days after this, I was only getting into that, so this is also an image of the sort of person I wanted to be back to	
4	being... <u>banging fist on the table</u> ... The other thing that bothers me is this. I indicated... job stress about my career, my position etc at the moment. But the reality of it is, I'm not as strong as I was, I'm not as able to do what I did before, and that bothers me as well.	
5	That bothers me. I am not functioning at the level I was functioning at six months ago, I'm not. And I want to get back to that. I even contemplated retirement, but what would I do in retirement? Christ Almighty! Um... I don't want to do anything rash while I am disabled, but I'm not enjoying it, I'm really not enjoying it... Could you use any more? It weren't so interesting.	
6	This was just a... this is me going round the hospital on a tour of inspection, but I don't go to the wards anymore, not in the same way... there's the cycling... what is this? I wanted one of me, what's driving. I very much wanted one of me driving. I'm not a racing driver or anything. I have two very good cars, but that's because we're old and rich and you know... but I've been driving since I was twelve. I grew up in the country. I've been on the road since I was 15. At 12 I was around the house at home and I just like the <u>minor liberty of going places all the time. All holidays include driving and cycling, cycling and driving, if you said to me right now, have you the time, because I'm desperate, I have to be in Lancaster tonight... I'd bring you. I would love that. That would not be a chore. One day my daughter, the older one whose in Newcastle, was coming down and we were all going on holiday, I'd rented a villa in Italy. At 10 o'clock on the Friday night before a plane the following morning at Stansted at 7, she suddenly came</u>	
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Don't go back to go back.
 emphasis on go back to go back.
 emphasis on go back to go back.
 emphasis on go back to go back.

Repetition of boiler - agenda, intake, intake, paper
 upset by loss of strength + freedom, paper issues?
 out of a felt and then back on to smooth road
 Shake then okay again. After (pulsated) they have been serious at the time but life was able to return to normal
 Acute VS Chronic: this is a chronic
 life altering diagnosis, leads him to quest survival, identity, mortality
 Future now uncertain - altered
 loss of identity - doesn't know who he is anymore - so reduced. Needs to return to the 'sort of person' he was before
 Control - previously powerful driver, in control, of himself - now??? is he's old self able to survive this?
 Keep changing tune throughout through trying to accept the new reality" still not how he sees himself - happens to anxiety? Difficult to do physically + mentally
 Fear of? Future - what will it hold?
 Contemplated retirement - entering new life stage? Christ Almighty - Shock, panic
 Tom, needs time to consider - but the decline
 loss of freedom man, issue? Disoriented
 nothing more to look forward to. Can it be returned? - fears the unknown!
 no matter in control - not in a position to make
 loss of physical or mental freedom? seeking cars as status symbols?
 - thinking - old + new - pride? upstart hard
 driving while life part of life + something he enjoys.
 minor liberty enjoys sense of freedom
 all the time. "worth taken during"
 retirement + live back to cycling, an
 essential aspect of leisure time
 unable to contemplate holidays etc without
 these activities.
 Extravaganza.

<p>longing for old life self activity level.</p>	<p>1 down and she said I've left my passport in Newcastle. Five 2 minutes later I was in the car and we drove to Newcastle all 3 through the night and back to Stansted and met the rest of the 4 family who went to Stansted, we missed the plane, they went 5 ahead, we met them in Rome two hours after that. Didn't bother 6 me in the slightest, it almost made my day, you know, it's the sort 7 of... give me a challenge, and it's nothing... give me a challenge and 8 I'll be twice as happy. And I miss that <u>enormously</u> so I wanted one 9 of my car. This is me in Brussels. Before this happened we had 10 booked a weekend in Europe, as luck would have it on the 11 Eurostar so that bit still worked well. We went to Brussels and... 12 phone vibrates... and they're on their way, your cab is on its way. 13 We went to Brussels for two days and then onto Cologne for New 14 Year's Day and all of that, and of course I was extremely 15 restricted, one foot by the way then, and this is me sitting in the 16 Grand Place at Brussels, have you been?"</p>	<p>Shows telling to demonstrate love of driving - what he misses.</p> <p>loves a challenge - who he is - competitive nature? Challenge being lost? Curious or happy? Taking control? own a mission.</p> <p>↳ maybe he now appears to be a challenge but in a different way - challenge to survive? to achieve the mundane? lives the thrill to stand out? No excitement (adrenaline/urgency)? misses this enormously - emphasis left a long wait gap? early on to find diagnosis.</p>
<p>17 "No."</p>	<p>18 "What you don't see there is I'm sitting with all the geezers and 19 there's a couple of wings beside me because my wife is off looking 20 at the sites and I'm sitting there like some old geriatric. Looking 21 at it... and we... we liked holidays, lots of holidays. I'm interested 22 in all sorts of things, but I'm not used to just being interested on 23 the internet, I'm used to being there, doing it... so..."</p>	<p>Geezers + wings - underestimates, labels + alcoholics, unfamiliar landscape, looking down on others doesn't belong there; stuck on the down + out side;</p> <p>wife is off - feeling abandoned out + dejected? want to stepwise decline? live on old geriatric - skill re-identifying with paraphon</p> <p>↳ shed previously stated needed to include driving + cycling - note self out of date missing but numeral wife takes at sub.</p>
<p>24 "I think you mentioned earlier something about um... 25 shopping, was something that you miss and your weekly 26 shop."</p>	<p>27 "Yeah, so...it wasn't a weekly shop, it was a frequent shop. I do all 28 the cooking... all... I just do... I always have, I do all the cooking at</p>	<p>↳ change in proc - always doing (active) busy - loves a challenge or diff work</p>
<p>29 Strange new surroundings - world alienation</p>	<p>30 Abandonment</p>	<p>31 Loss of old life</p>
<p>32 Stress</p>	<p>33 Restriction</p>	<p>34 Isolation</p>

Now restricted + stuck, world was shrink - the only way he can be interested + see the world is through the internet - behind a computer - loss

Death of adventure, challenge + spontaneity? 26

Now self used internet → craft, loss

1	home, I do all the festivals, I do all the everything... and I'm quite good at it and I like it. I really enjoy it and I would do... my wife can shop, she can also cook, she doesn't get a chance, and she's usually going later than I am... I leave earlier, she's home later... she's a GP and er... I would do all the shopping that's necessary and planning and menus and all of that and I don't anymore. I don't. So I have also lost control, in a small way of my environment... my domestic environment... phone vibrates... your car has arrived... well it's 15 minutes early so he can wait... he'll call me in a moment. Yeah I miss that a lot... I miss mooching, and I miss people... you wouldn't call the supermarket people... and I ordinarily wouldn't, and I miss the shopping centre in London which I normally wouldn't include on my list of things, but I feel isolated at home and I want to be with people, so I like being at work for that reason, I am with people, whereas at home I'm not, not with them at all and er... so just being in a place where there are people cheers me up a bit. For a long time I avoided things that required me to explain myself, so my hair was the longest it had ever been because I wouldn't go to the barber. Now my wife dropped me off at the barber, I pootled in, she'd pick me up again, but I wouldn't go, didn't want to have to tell the barber, all I thought was the 20 minutes, <u>what the hell was going on?</u> Didn't want to do it... did not... There's me reading the guide book at Brussels, looking in the distance at... So... what else have I got? I think that's probably it. Ah... ah... holidays."	more interesting activities loss of control isolation altering outlook new sense of self attraction in relationship outside world. dependency missing out explaining inexcusable
2	"That's beautiful." <u>internal struggle</u> - what is happening, questioning self understanding, trying to get himself together	more interesting activities - holidays
3	"That's New England in the fall. I'm a huge fan of the fall. And apart from the holiday, we had actually booked two holidays, believe it or not, we booked this train trip for New Year and we had booked a week in Lanzarote on the first week of February,	more interesting activities - holidays
4	good! really enjoy - passion. love of food - big part of life. loves all aspects, planning, shopping, preparing, cooking, eating everything. Personally meaningful + sometimes to share with family - highlights festivals etc.	more interesting activities - holidays
5	life outside the house increasing, difficult but also less at home. his house - loss of control	more interesting activities - holidays
6	Missing people - no longer interacting in the same way? missing the buzz of the shopping centre? Seeing life outside? would normally consider such things but perception of the world changing. wonder how smaller? ideas to be around people but not have to explain? used to be anonymous in shopping centre / supermarket. No need to explain himself. Being around people brings happiness	more interesting activities - holidays
7	Avoiding barber - can't explain further impact on image. long hair. Passes shoulders, like a tanktop - like stamping feet + demonstrating can't shift + collected by wife → loss of power + control - barrier to others used to being strong + powerful. - loss of identity - self + confidence. can't explain to others - too difficult, doesn't want sympathy - humiliation, guilt + shame	more interesting activities - holidays
8	more interesting activities - important Pass time.	more interesting activities - holidays
9	more interesting activities - important Pass time.	more interesting activities - holidays
10	more interesting activities - important Pass time.	more interesting activities - holidays
11	more interesting activities - important Pass time.	more interesting activities - holidays
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13	more interesting activities - important Pass time.	more interesting activities - holidays
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28	more interesting activities - important Pass time.	more interesting activities - holidays
29	more interesting activities - important Pass time.	more interesting activities - holidays
30	more interesting activities - important Pass time.	more interesting activities - holidays

more interesting activities? → internal struggle - what is happening, questioning self understanding, trying to get himself together

more interesting activities? → take away? → already had issues re food + weight?

only cooking but feels like something more meaningful. Giving to self? he was family? looking after wife? talked about work previously 24/7 worked to build up the position of power - recognition wife also works long hours - cooking + food his contribution to family life? repetition of 1 day ownership, his feeling with enthusiasm, pride, quite

good! really enjoy - passion. love of food - big part of life. loves all aspects, planning, shopping, preparing, cooking, eating everything. Personally meaningful + sometimes to share with family - highlights festivals etc.

life outside the house increasing, difficult but also less at home. his house - loss of control

Missing people - no longer interacting in the same way? missing the buzz of the shopping centre? Seeing life outside? would normally consider such things but perception of the world changing. wonder how smaller? ideas to be around people but not have to explain? used to be anonymous in shopping centre / supermarket. No need to explain himself. Being around people brings happiness

Avoiding barber - can't explain further impact on image. long hair. Passes shoulders, like a tanktop - like stamping feet + demonstrating can't shift + collected by wife → loss of power + control - barrier to others used to being strong + powerful. - loss of identity - self + confidence. can't explain to others - too difficult, doesn't want sympathy - humiliation, guilt + shame

more interesting activities - important Pass time.

<p>Understanding + knowledge of others</p> <p>opening up the world</p> <p>altered outlook on life.</p> <p>Life on hold</p>	<p>1 which we went to and they put a split cast, on the airline and</p> <p>2 everything. I have by the way been heavily impressed by the</p> <p>3 understanding and knowledge ability of Easyjet, believe it or not</p> <p>4 and Ryan Air have been the same. The customs people... not the</p> <p>5 customs, the security people, brilliant, the training people, all of</p> <p>6 officialdom has actually been informed, capable, intelligent,</p> <p>7 absolutely true. I've had some of the best travelling directions I've</p> <p>8 ever had, it was really good. The ferry to Ireland. I must have</p> <p>9 ticked a box when I booked the ferry because I booked that after</p> <p>10 the event, that was.. we were now... last week.. I must have ticked</p> <p>11 a box which said I have a wheelchair or something... I don't</p> <p>12 remember it. And I looked at the booking and I couldn't see it.</p> <p>13 We pootele up... my wife does the driving, hand in the ticket, but</p> <p>14 they knew who we were anyway, and then she said, hang this on</p> <p>15 your mirror, which says you know, whatever, a bit like the</p> <p>16 Eurostar, and then they said, and put on your hazard lights, which</p> <p>17 is the signal, parking in the disabled bay on the ferry deck beside</p> <p>18 the lift... both times! Just like that! Just like that! She said I didn't</p> <p>19 know it existed, but could have imagined right, what are the</p> <p>20 facilities for the disabled? Did you know there are three disabled</p> <p>21 parking spaces beside the lift on all those big ferries, and people</p> <p>22 are facilitatory. I like my holidays, I like New England particularly,</p> <p>23 we used to live in America and I've made no further plans. I have</p> <p>24 no holidays booked at the moment. I have one particular. I'm 60</p> <p>25 in August and my wife was 60 in January. We had a variety of sort</p> <p>26 of celebratory ideas, but we don't know what we're going to do...</p> <p>27 so we haven't booked it. So a little element of life is on hold."</p> <p>28 "So to go back to it, very quickly, something that you</p> <p>29 mentioned to me on the way in, was the er... just because</p> <p>30 we're recording... the lift... the stairlift...."</p>	<p>Still managed to go on holiday</p> <p>Very pleased with the way</p> <p>he was treated traveling</p> <p>they may not understand</p> <p>patology but possibly have a</p> <p>lot more understanding his</p> <p>physical needs in his less</p> <p>able bodied state?</p> <p>? Gratitude? (Relief)?</p> <p>No questions just helped + accepted</p> <p>Turned what could have been</p> <p>an even stressful situation into</p> <p>a pleasant one.</p> <p>Minor thing - taking abox,</p> <p>made a really major impact</p> <p>- understanding, no judgments!</p> <p>Big difference when people</p> <p>understand.</p> <p>Shore + surprise at disabled</p> <p>cars - Seeing world after</p> <p>new appreciation, could have</p> <p>imagined but didn't with prior</p> <p>able bodied outlook on life.</p> <p>Big life events coming up for</p> <p>both he + his wife.</p> <p>all plans paused!</p> <p>wrote life now on hold to see</p> <p>what the future will bring +</p> <p>what is the available "Synch" was</p> <p>on hold for both</p> <p>Parted - him + his wife.</p>
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<p>Knowledge / understanding</p> <p>explain the inexplorable.</p> <p>uncertainty</p> <p>future fear</p> <p>hope</p> <p>depression.</p>	<p>1 assessment of the whole bit..."</p> <p>2 "A hospital, you would think..."</p> <p>3 "This isn't a clinical area, so they didn't ^{think} It didn't ^{think}... yeah. So..."</p> <p>4 "Fabulous, thank you ever so much for that. I know that you've got a taxi waiting."</p> <p>5</p> <p>6 "No, he'll wait, he's early. He hasn't... they ring when they lose patience. Anything else you wanted to ask?"</p> <p>7</p> <p>8 "Just to say is there anything else that you think I haven't covered or anything that you'd like to tell me about what it's been like to be diagnosed with Charcot Foot and how the treatment and the pathology has affected your life or the way that you feel..."</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13 "It would help in the future, not for me, if it was a more commonly known thing and I didn't have to explain the inexplicable to others, because it's hard to explain. An information leaflet, for somebody like me perhaps a very detailed one or a list of websites, or a chapter in Me's book or something, would really help. And... yeah, yeah, one of the worst features is the thing ^{tapping the desk}... none of you know when this will end. And therefore you can't and won't tell me that. When it's going to end. It's better to have an end than to be permanently disabled I can assure you of that, but er... and that gives me hope, but it's a long way away. I don't have the strongest psyche, I'm prone to depression in the past, and this doesn't help. And quite frankly I was moderately... not deeply depressed, but I was depressed for all January and February and I couldn't do my work properly,</p>	<p>Perception: Them + us again. Staff not patients.</p> <p>lack of information given partly of complaint. Not enough information for patients to obtain + understand. Not enough public knowledge for others to understand.</p> <p>Feeling of impossibility.</p> <p>thing - something apart from himself</p> <p>The worst part - wondering in certain for future making things to hold on to.</p> <p>hope remains just out of reach living through a hopeless situation - despair.</p>
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→ emphasis judgement tapping to point.
 understands that these is an ending, but when will that be.
 Too far away to grip on to - exacerbating factor in diagnosis + depression.
 depression crippling emotional skills to cope.
 30

Depressed	1	more for that reason than any other. I was fed up, depressed, unhappy... unhappy... er... that's much less now, I don't know quite what it is... and that's good... But I was very depressed...	emotional reaction one of the most draining feelings? caused inability to focus on other areas such as work
Family impact	2	very... which worries my wife. Hmm..."	Family care also affected.
	3	"Thank you very, very much for sharing all of that with me. That was very, very useful."	
	4	"There was one particular night... not early on, but earlier on and I was getting really upset and we've nobody at home anymore, rooms everywhere, but no children and I manufactured a minor row and took myself off into one of the kid's bedrooms and the real reason was I wanted to cry. But I didn't want to do it in the bedroom because I didn't want her to, you know, comfort me and say it'll be alright or whatever, I didn't want to do it. I just wanted to crawl under a rock. So I crawled into one of the kid's beds and crawled under that duvet. It hasn't been that bad since, but it seemed the sort of necessary thing, in a way. There's a sort of a bereavement about it all you know. I'd lost my life. The life I had... she didn't... I know I'm not a racing driver or anything, I just wanted to do very ordinary stuff so... let's hope that doesn't come back. I wouldn't bet about what I'd feel if you were to tell me in another seven months, it's not getting better, you'll have to have another year... I really don't know how I'll do... we shall see. So sort of mind-body interaction, not alluded to strongly, though I find M and T therapeutic, it's slightly different why. T because he's a sort of rock of experience and common sense and... sort of manliness and let's get on with it type... but without ever saying it in that way, but you know what I mean? And M I think realises, and I've said it to her, there have been two occasions, at first, and more recently, when M has had to walk me out of the building in the evening because... actually T and M, brought me here the other	not immediately but was poor - so at what stage? children grown up + moved on created an argument to "give her a reading space?" hiding feelings - bereavement emotional + physical distance did not want her to see - further shame + embarrassment - did not want comfort - needed release
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Creating Conflict	9		
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Effect on Family	11		
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Hiding	13		
Secrets	14		
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Grief	16		
Bereavement	17		
loss of old life.	18		
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Fear for future.	22		
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Time span.	24		
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Mind, body interaction	27		
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Mind-body interaction - needs recognition - very important
 T - male, rock, common sense, manliness approach - implied lack of emotion - keep calm + carry on. Strong.
 M - female - wanted me out, more intrusive, think she 'realises' reaching to use criteria - suffers approach, feminine, caring.
 31

<p>Psychosocial Ludan Shock</p>	<p>11 10 9 8 7 6 5 4 3 2 1</p>	<p>And I think some of that needs to be addressed up front, it's a chronic illness... it ain't cancer, but by god it's a shock to the system." ↘ Classification - Chronic illness but not treated as such?</p>
<p>Future Fear</p>	<p>12</p>	<p>"Yeah, absolutely."</p>
<p>Life Savings</p>	<p>13 14 15 16 17 18 19 20 21</p>	<p>"Yeah... there's always cancer to look forward to! (Trust me) you never know... but I'm not feeling optimistic about the future. I'm not. We had one of those interesting two-way decisions about ten years ago, because we had both worked abroad and had been in America and everywhere, we had rather small pensions. We couldn't both afford to pay extra years because of all the kids and everything, so we instantly chose to buy extra years for my wife because she was likely to use them and we didn't for me, which sounds fine and rational but... there's a message in there... I'm there diabetic... I'm the diabetic. I'm the one who's had to pay the higher insurance premium for years and years, life insurance. There's a message in that which you usually put out of your mind. There's a message in there."</p>
<p>Diabetes Blame (Shame Guilt) Mortality</p>	<p>22 23 24 25 26</p>	<p>"Do you think it affects your family dynamic, caring...?"</p>
	<p>27 28</p>	<p>"Yeah it does, yeah. The little one... she's not that little anymore, but she used to be. The little one decided aged 8 that I was going</p>

↑
Effect on Family.

Airs the feeling she knew
 implied recognition that there is an emotional impact. Caring addressed but not adequately addressed.
 Shows we hit hard on Steve.
 ↘ Should be addressed immediately not in the open - needs attention
 Compared to cancer - not to life not deadly but loss of old life Steve to whole system - all encompassing.
 Not optimistic but was previously, because he was at the old age was suppose to be better than younger + middle age. Nothing left to look forward to except further "health & demise?"
 Practicalities + emotional impact did not buy extra years for him as unlikely to need (short future) ↑ risk of death
 Instant - easy choice, obvious, no debate inferred that he was the 1st message of fault + blame - cost ↑ mortality - very negative
 But Charles bringing back to the parent? trigger?
 ↑ will blame/punishment.

<p>Effect on Family</p> <p>Guilt</p> <p>depression</p> <p>physical struggle.</p>	<p>1 to die and that she was personally going to make sure I behaved myself, and she has nagged and badgered me constantly ever since, yeah... Yeah... If you were to say why? Because I care Daddy... but boy that doesn't sound any better does it you know... that's just guilt on guilt on guilt as far as I'm concerned. Yeah... there is <u>no doubt</u> though that here, <u>certainly</u> all through January and February, but now, even now... I could do with a day out of here a week..."</p> <p>Taxi calls</p> <p>"Is that alright?"</p> <p>"That's absolutely perfect, thank you ever so much for all that."</p> <p>"I look forward to reading your thesis when it comes and..."</p>	<p>daughter trying to look after him</p> <p>keep keeping check - sees a nagging - want leave him alone</p> <p>nicer gesture to worry but</p> <p>depression</p> <p>decarbonating negative</p> <p>Guilt</p> <p>side effects</p> <p>Guilt</p> <p>Stress</p> <p>Humiliation:</p>
13		

Appendix 15. Example of table of themes for Steve

Loss of sense of old life That was me	Page/Line	Quote
Identity –Change in sense of self self	1,12-13	...now clearly I'm an at risk person
	13, 3-4	We treat the patients, I happen to be one now
	15, 21-22	So... late in life, five years ago we both became cyclists
	19, 7-9	But that was my lowest weight, the thinnest and best I looked and the photographer who took it had photographed me the year before, for the previous one, and didn't recognise me
	19, 11-13	So that is me, better and fitter than I had ever been in the previous 20 years, and that's where I'm going to get to once I get liberated again
	19, 18-20	I believe in what we do here, and I've always been part of it and people know that and whatever. But it is a powerful position and it's a visible one
	20, 13-15	I'm telling you that and it's true, but I'm not at a motivated point yet, because I'm not... Haven't... the future isn't here yet. It will be a motivating picture for me but only in theory.
	25, 3-7	It was clear two days later I was going to survive the kidney hit, but it ain't clear two days after this, I was only sort of getting into that, so this is also an image of the sort of person I wanted to be back to being... <i>banging fist on the table</i> ...
	25, 9-10	But the reality of it is, I'm not as strong as I was. I'm not as able to do what I did before,
	26, 7-8	give me a challenge, and it's nothing... give me a challenge and I'll be twice as happy. And I miss that enormously
Disabled??	10, 8-11	I own the wheelchair. Something I never thought I would... I own a wheelchair. Brand new, lock stock and barrel. I'm not happy about that. Never wanted to own a wheelchair, but I do

	10, 17-22	they were all on my side here, every one of them, or against me, whichever way you want to look at it, and they all said, oh don't, you're not supposed to be doing that... but the answer's actually... and nobody ever told me I couldn't walk to the toilet you know, but everyone here said whoah..
	11, 24 - 12, 1	I'm not actually sick in the sort of sick sense. What would I do at home...
	19, 23-28	if you go, in a wheelchair in particular, but look disabled in any event, people subconsciously start to treat you as if you were mentally disabled as well. Not fully but impaired in some way, and they don't have the same.... respect is the wrong word, but they just don't treat you with the same seriousness that...
	22, 13-18	I am disabled at the moment, but I've never thought it, and others have used the term and it isn't that it was inappropriate, I am currently disabled, I am now... though I can't get a badge for the car is very interesting, because you have to be disabled permanently for that and it takes six months to apply for it.
	22, 25-26	I am obviously disabled. I am in a wheelchair or on crutches or both
Reflected / diminished in the eyes of others	10, 16-19	The day people saw me even walk to the bathroom, they said oh god, oh, oh, oh... they were all on my side here, every one of them, or against me, whichever way you want to look at it
	11, 22-24	Every time he saw me he said why aren't you at home, why aren't you at home, why are you here, why aren't you at home?
	23, 2-6	And every time somebody new saw me there was always oh god what's wrong with you and it was the talk of the building, there's no denying that, it was. And as I would go into the Mezz and places, you could see it, people's eyes. I could see it in their eyes, they'd think Jesus what's wrong with him?
	29, 27-28	I'll get over it but... you know... and I've already been told several times by the Finance Director how expensive it was. I don't care. I'm worth it.

Loss of ability to perform at work	20, 8-13	I have a real problem with the Chief Executive, who genuinely means well, and is genuinely sympathetic, but he doesn't possess the emotional intelligence to deal with me. Others do. Clinicians do, you do, most of my colleagues do. He doesn't. So while he talks a really good and supportive game, he will frankly erase me and he tried to already.
	20, 17-20	I have actually delegated a ton to them which I didn't enjoy very much, but I did, and that's worked. Because I just don't have the time I used to have. Life is very difficult now.
	21, 6-9	I have to be at his beck and call 24/7 and I'm not able for it anymore, I'm not able for it, and that makes me feel vulnerable. Because I have no wish to be pushed out of my job before my time. It's a big thing for me.
	25, 7-13	The other thing that bothers me is this. I indicated... job stress about my career, my position etc at the moment. But the reality of it is, I'm not as strong as I was. I'm not as able to do what I did before, and that bothers me as well. That bothers me. I am not functioning at the level I was functioning at six months ago, I'm not. And I want to get back to that.
Loss of meaningful activity	16, 3-5	this is 7 o'clock in the morning on the second year that we did a night ride, London to Brighton. This one was for Alzheimers. The previous one was for the Heart Foundation
	17, 12	And it has big knock-on effects, and also, my wife and I get on very well, but we don't do this anymore. She doesn't do it... it's been winter anyway, but she doesn't do it because I'm not doing. There is no question it's going to be 20 degrees on Sunday. Every other March 30 th when the weather is 18 to 20 degrees at the end of a poxy winter, we would have been out cycling. We won't.
	25, 23	I very much wanted one of me driving. I'm not a racing driver or anything. I have two very good cars, but that's because we're old and rich and you know.... but I've been driving since I was twelve. I grew up in the country. I've been on the road since I was 15. At 12 I was around the house at home and I just like the minor liberty of going places all the time. All holidays include driving and cycling, cycling and driving,
	26, 26	I'm interested in all sorts of things, but I'm not used to just being interested on the

		internet, I'm used to being there, doing it
	26, 27-28 - 27, 1-6	I do all the cooking... all... I just do... I always have, I do all the cooking at home, I do all the festivals, I do all the everything... and I'm quite good at it and I like it, I really enjoy it and I would do... my wife can shop, she can also cook, she doesn't get a chance, and she's usually going later than I am... I leave earlier, she's home later... she's a GP and er... I would do all the shopping that's necessary and planning and menus and all of that and I don't anymore
Loss of control/agency	18, 18-25	And the things I miss the most are the really small things. If you tell me I can't go a long distance on a run or cycle I could live with it for a while, but to not be able to turn left or right or choose when I go home, I'm going to have to go home in 35 minutes because a cab is going to turn up here and that was planned. My secretary has booked all my cabs for the next three weeks because she's away. I know where I have to be when I have to be
	27, 5-8	I would do all the shopping that's necessary and planning and menus and all of that and I don't anymore, I don't. So I have also lost control, in a small way of my environment... my domestic environment
Isolation	9, 30-32 - 10, 1	...to have a mild social life, by which I mean it's out...going to the supermarket once a week, and going to the shop etc, once a week, which I haven't achieved by the way,
	10, 23-24	I've managed to contain my life anyway and I don't go far
	27, 10-17	I miss mooching, and I miss people... you wouldn't call the supermarket people... and I ordinarily wouldn't, and I miss the shopping centre in Bromley which I normally wouldn't include on my list of things, but I feel isolated at home and I want to be with people, so I like being at work for that reason, I am with people, whereas at home I'm not, not with them at all and er... so just being in a place where there are people cheers me up a bit
	27, 17-21	For a long time I avoided things that required me to explain myself, so my hair was the longest it had ever been because I wouldn't go to the barber. Now my wife dropped me off at the barber, I pootled in, she'd pick me up again, but I wouldn't go, didn't want to have to tell the barber.

Psychological impact Mind-body interaction	Page/Line	Quote
Grief/ bereavement	31, 9-13	I manufactured a mini-row and took myself off into one of the kid's bedrooms and the real reason was I wanted to cry. But I didn't want to do it in the bedroom because I didn't want her to, you know, comfort me and say it'll be alright or whatever, I didn't want to do it
	31, 16-18	There's a sort of a bereavement about it all you know. I'd lost my life. The life I had... she didn't... I know I'm not a racing driver or anything, I just wanted to do very ordinary stuff so...
Guilt / blame / shame	2, 18-19	there's a lot of guilt about my diabetes frankly
	11, 3-5	what to tell people that isn't a lie, but isn't too detailed and you know... god smote me or something, you know! I've been punished for sins in a past life or something
	13, 16-20	Because with diabetes it is either chronic disease of self-management, self-abuse, self-mismanagement... for me at least guilt is never far below the surface, never, never, never. And I'm not happy with this disease, I'm embarrassed and humiliated by the feet, I really am... I really am.
	19, 21-22	My own... shame is probably the word for it. That I have ended up in this position I haven't enjoyed
	21, 23-27	all I could think of was that I had put my children's future at risk by my own obesity, overeating, whatever and I really... just my mindset... I have this great... my wife keeps saying you're too hard on yourself, whatever it is, it's always my own fault, my own guilt, my own whatever
	21, 28 - 22, 1-6	that's my mindset and I view this as avoidable, but not preventable. Preventable is not have it happen again. Avoidable – it would be avoidable if I had had far better diabetic control, if I had obeyed all of the rules instead of cheating, which I did. We probably all do. And it would have been better if I hadn't got to this point. And so those feelings

		are... it's your own fault... Come on... a lot...
	22, 7-9	public humiliation and shame. And er... it's very interesting... some of these things are worse when people are being nice to you...
	22, 29-31	And she said, even today, 40 years later, he still finds the inability to do certain things and people having to do things for him, humiliating, even still. And I do too. I do too
	23, 10-11	I don't enjoy it. Enjoy is the wrong word, I found it humiliating I think, you know
	31, 15	took myself off into one of the kid's bedrooms and the real reason was I wanted to cry.
	24, 8	If you eat nothing you're great
	29, 20-22	I felt slightly embarrassed and responsible. It isn't my stupidity, but it is my needs that have led to that happening in the first place
	32, 21-25	... there's a message in there...I'm there diabetic... I'm the diabetic. I'm the one who's had to pay the higher insurance premium for years and years, life insurance. There's a message in that which you usually put out of your mind. There's a message in there
	32, 28 – 33, 1-6	The little one decided aged 8 that I was going to die and that she was personally going to make sure I behaved myself, and she has nagged and badgered me constantly ever since, yeah... yeah... If you were to say why? Because I care Daddy... but boy that doesn't sound any better does it you know... that's just guilt on guilt on guilt as far as I'm concerned
Anger	18, 1-6	I had a very angry moment, really angry moment recently. Three weekends ago, it must have been. It was a Sunday and it was beautiful and I just wanted to do something really small, like walk to the park or walk to a coffee shop, sit outside it, have a coffee and walk home. And I was infuriated. Absolutely furious
	18,10-13	I was up for it and couldn't do anything and er.... got angry at my wife, angry at everybody, angry at everything, and threatened to stomp off up the street on my crutches and back home
Depression	30, 24-26 31, 1-4	And quite frankly I was moderately... not deeply depressed, but I was depressed for all January and February and I couldn't do my work properly, more for that reason than any other. I was fed up, depressed, unhappy... unhappy.... er... that's much less now, I don't know quite what it is... and that's good... But I was very depressed... very...which worries my wife

	31, 23	So sort of mind-body interaction, not alluded to strongly
	32, 7-11	And there have been occasions up there where you felt she knew that this wasn't just a physical question. And I think some of that needs to be addressed up front, it's a chronic illness... it ain't cancer, but by god it's a shock to the system.

Appendix 16. Example of table showing groups themes

Isolation World reduced / more insular Life contained	I wasn't allowed to go out or walk for um... The first cast on... Which was two weeks or so... They just said you've got to stay indoors, but luckily enough the weather wasn't with us so... We couldn't go out anyway, Um...	Graham Page 5 lines 16-18 & Page 6, 1
	We used to like do... you know, you'd meet up with your friends and their dogs and you could walk round and round, there's different routes you could take, but now, I just go as far and the bench and sit on the bench	Graham Page 8 Line 14-17
	It's changed my life in a way because er... as I say, I can't drive, not that I'm too bothered about driving, but er... I can't walk, if you like, down to the village um... to the shops and things, you know, so I have to adjust myself	Graham Page 9 lines 9-12
	The only driving I really do... prior to the cast going on is going down... I picked my daughter up from school and I'd take her and we'd go shopping, and I'd take her down the supermarket, and now her partner, he er... She goes down there and does the shopping and waits for him to come and pick her up and er... they bring it round to me and then go home..."	Graham Page 20 line 6-11
	don't see my great-grandson too often, because I can't... she comes up most weekend to her mothers and occasionally they walk from where they live to my place, but um... most of the time they're indoors, so I don't get down there to see them too often... shame really	Graham Page 20, lines 13-17
	...to have a mild social life, by which I mean it's out...going to the supermarket once a week, and going to the shop etc, once a week, which I haven't achieved by the way,	Steve Page 9, line 30-32 & Page 10, line 1
	I've managed to contain my life anyway and I don't go far	Steve Page 10, lines 23-24
	we liked holidays, lots of holidays. I'm interested in all sorts of things, but I'm not used to just being interested on the internet, I'm used to being there, doing it...	Steve Page 26 line 21-23
	I miss mooching, and I miss people... you wouldn't call the supermarket people... and I ordinarily wouldn't, and I miss the shopping centre in Bromley which I normally wouldn't include on my list of things, but I feel isolated at home and I want to be with people, so I like being at work for that reason, I am with people, whereas at home I'm	Steve Page 27 line 10-17

	not, not with them at all and er... so just being in a place where there are people cheers me up a bit.	
	For a long time I avoided things that required me to explain myself, so my hair was the longest it had ever been because I wouldn't go to the barber. Now my wife dropped me off at the barber, I pootled in, she'd pick me up again, but I wouldn't go, didn't want to have to tell the barber.	Steve Page 27 lines 17-21
	It was like my life was... well to be shut indoors really.	Stacey Page 6 line 2-3
	they thought I was going down, until I got the mobility scooter and sort of got my independence back and could pop out... because, like this, you cannot pop anywhere obviously.	Stacey Page 14 line 7-9
	I can't just get in the car and go, because it's my right foot so I can't drive.	Stacey Page 15 line 17-18
	I passed my driving test three days after I was 17, I've always driven, I've always had a car, and now and again something crops up where she wants to go somewhere or... shopping or what have you, and I say without thinking, oh I'll run you down there, but I... you know	Brian Page 9 lines 4-8
	I didn't really know where to turn with it.	Brian Page 11 lines 17-18
	I've got the old travel permit and I live right on top of R station. I've just gone over there and got a train to London Bridge, or a train to Victoria and just like walked round for half hour and come back, just for something to do, you know, but I'd never used the travel card up until having this, you know, but er... yeah that's about it I think there	Brian Page 12 lines 6-11
	I've read quite a few travel books.	Brian Page 12 line 17
	Well we don't really go anywhere now	Brian Page 14 line 20
	I had er... not good friends, but friends in the local pub and that and I used to go down there maybe once or twice a week, so I haven't really been drinking since I've had this at all	Brian Page 18 lines 7-10
	so there's a few... I wouldn't call good friends, but local acquaintances, because I've	Brian

	known them for years, I haven't seen since September	Page 18 lines 27-30
	I keep watching Coast on the television, although I've seen them all numerous times, but er... yeah, I miss that, yeah	Brian Page 20 line 9
	I miss having a walk... I do miss having a walk, yes. Because it gives you... I don't know, you feel so much better when you've been out in the fresh air and... there's nobody around... well there are... there are other dog owners, but you don't... you're on your own and you can think your own thoughts and it's just nice. Yeah, I miss it. (7, 10)	Linda Page 7, lines 10-15
	But you can't do it... what you can't do.. and on holiday I couldn't play tennis with my grandchildren... [] That was... I didn't go up there and watch	Linda Page 9, lines 3-8
	And this is the other bit of the holiday I couldn't join in, swimming. Do you remember I asked you... <i>laughing</i> ... and that was un... that was not fair	Linda Page 11, Lines 14-16
	Oh this is... when we go on holiday we always go to wild places... there's my grandchildren there, but we always walk until we find somewhere and of course I can't get a wheelchair down there, I can't get crutches down there, I can't go... so yes, that is very... I miss that very, very much, my holiday	Linda Page 8, lines 13-18
	I don't go out now as much as I used to obviously, you know, walking round the shops is bad enough now, just to get a few bits, but er... mainly it's indoors now...	Roy Page 24 line 3-6
	I try and do it all myself, you know. I mean um... I mean my mate, he's 60-odd, he's had cancer, he's only got one kidney, so... he does too much anyway, you know what I mean, I'd always help you, you know what I mean, but...I wouldn't think of doing it, I'd rather do it myself, you know what I mean? But er...my niece, as I say, she's probably the only one that keeps in touch with me now and she's on the other side of the river to me, you know, so... So no, really there isn't anybody. Just got to do it myself, you know, one way or another	Roy Page 26 line 18-23 Page 27, lines1-2
	Which means that I know most of them, and most of the guys or a lot of the people look upon it not only as an excellent training session, but a chance to see people who you haven't seen for a long time, so there's pals there that you only get to see once a year or twice a year if you're lucky,	Bill Page 21 lines 18-23

	I mean there's a course in Norway every year, I keep meaning to go up, I've not done it yet, I can go to Japan, I can train in Japan and... I did go to Japan again, but I just went to see friends, [I didn't actually train there um... but basically yeah, it's a big family, and it's... um... a lot... a lot of friends I've known for a long, long time	Bill Page 22 lines 8-13
	I went to Edinburgh... I didn't go this year, er... because I was obviously in a plaster. I didn't go to Windsor in May. I went to Edinburgh last August	Bill Page 23 lines 3-5
	I see Cameron because it's me and him that started the club together, um... Sean I see occasionally. I mean I still go... there's a course in grading every three months, um... so obviously I've got people grading... so I still go along, um... and watch the grading, obviously take care of that, you know, so I still a lot of people every three months so to speak, um... but I'll miss training for... because they're out training	Bill Page 38 line 4-10
	Yeah, I started being away, um... you know, basically while the training's on	Bill Page 38 lines 12-13
	we like to go out for walks in the parks and things like that, you know, we like... we normally take the car and we go miles out... miles away and just have a walk around in the park, you know what I mean, and things like that and we... she loves all that, you know. And er... I love that too, um... but I can't do that now, you know, and I really... I miss that... I miss that a whole heap,	Colin Page 11, lines 2-8
	very nice park, lovely beautifully maintained and everything like that, you know, keep it clean and everything. It's lovely. We love going in there as well, um... but we haven't been there for a while because of my foot,	Colin Page 12, lines 22-25
	I don't know what options there are... um... apart from sitting down indoors and reading, which I do... which I have been doing now, reading, um... or watch television. Um... no, there's nothing else... nothing else that... As for the driving, the only thing I've substituted it with is PlayStation...	Colin Page 16, lines 8-13
	I mean like all the things I've mentioned to you I love doing, and I can't do...	Colin Page 20, line16
	I really do miss driving, I really do. There's a lot of things that I miss. There's a lot of things that I miss like... like I said, just even going for a walk, yeah it's just...something I just can't... it's just not available to me at the moment,	Colin Page 33, line 15-18

Appendix 16. Abstract for oral presentation to 2nd International IPA conference in Glasgow June 2018



University for the Common Good

Names of authors and affiliations:		
Jody Lucas, University of Brighton; Dr Channine Clarke, University of Brighton; Dr Chris Morriss-Roberts, Great Ormond Street Hospital; Dr Simon Otter University of Brighton.		
Title of presentation:		
The lived experience of active Charcot foot in diabetes mellitus		
Preferred type of presentation (please select)		
Oral only	Poster only	<u>Either</u>
Abstract		
Background:		
The aim of this research was to enhance understanding of the lived experience of individuals diagnosed with active Charcot foot. Charcot foot is a rare but potentially devastating complication of diabetes that can result in foot deformities, ulceration and potentially amputation, impacting on quality of life (QoL).		
Methods:		
8 participants were asked to bring in 3 to 5 personal photographs to demonstrate how active Charcot foot had affected their lives. These photographs were used as the basis of discussion in the semi-structured interviews (auto-photo elicitation). Analysis of data was embedded in an interpretive phenomenological framework.		
Findings:		
Three superordinate themes were elicited from the data; ‘lived time’, ‘lived space’ and ‘loss of sense of self’. All patients saw diagnosis of Charcot foot as an immediate marker of overall decline in health and well-being, although by understanding this decline a stronger position of self-reflection evolved.		
Discussion:		
This is the first study to explore the patient’s perspective of living with active Charcot foot. Highlighting that the diagnosis/management of Charcot foot has an immediate and severe impact on patient’s perceived QoL and sense of well-being. This study recommends that a more holistic approach is needed when assessing and treating this patient group.		

Appendix 17. Diabetic foot master class program

The Multidisciplinary and Surgical Reconstruction of Charcot Foot
Kia Oval Cricket Stadium, Kennington, London, SE11 5SS
30th June, 1st July 2016
Day 1

08:40 – 09:10 Registration, Coffee

Session 1: Chairs: Venu Kavarthapu, Mike Edmonds

- 09:10 – 09:20 Introduction- Venu Kavarthapu, Mike Edmonds
09:20 – 09:35 Initial Assessment of a Diabetic Foot - Prashanth Vas
09:35 – 09:50 The Spectrum of Clinical Presentation of Acute Charcot Osteoarthropathy - Mike Edmonds
09:50 – 10:05 What Do We Know About The Pathogenesis of Charcot Osteoarthropathy So Far? - Ines Reichert
10:05 – 10:20 Advanced Imaging of the Diabetic Foot and Diagnosis of Charcot Foot- David Elias
10:20 – 10:35 Modern Emerging Principles of Nuclear Imaging - Gill Vivien
10:35 – 10:50 Is This an Acute Charcot or Infected Diabetic Foot? - Klaus Kirketerp-Moller

10:50 – 11:20 Tea/coffee

Session 2: Chairs: Raju Ahluwalia, Prashanth Vas

- 11:20 – 11:35 The Anatomy of Offloading of Acute Charcot Foot - Maureen Bates
11:35 – 11:45 The Patients' Understanding of Total Contact Cast - Jodie Lucas
11:45 – 11:55 Current Pharmacological Options in Charcot Foot - Nina Petrova
11:55 – 12:10 Principles of Orthotics in Charcot Foot - Matthew McShane
12:10 – 12:25 Antibiotic Principles and Practical Tips - Mike Edmonds
12:25 – 12:45 TCC Workshop for Podiatrists / AHPs – Maureen Bates, Wegin Tang, Tim Jemmott

12:25 – 13:25 Lunch

Session 3: Chairs: Naveen Cavale, Alex Wee

- 13:25 – 13:40 Traumatic Foot and Ankle Fractures in Patients with Diabetes –
How Should They be Managed? - Chris Walker
13:40 – 14:55 Management of an Infected Diabetic Foot Ulcer
13:40 – 13:55 Modern Local Antibiotic Delivery Solutions in Infected Diabetic Foot – Mark Rogers
13:55 – 14:10 Debriding Diabetic Ulcers - Klaus Kirketerp-Moller
14:10 – 14:25 Has This Ulcer Been Debrided Adequately? - Raju Ahluwalia
14:25 – 14:40 The Role of Exostectomy in Charcot- Chris Walker
14:40 – 15:00 Revascularisation of an Ischemic Charcot Foot - Hisham Rashid

15:00 – 15:30 Tea/coffee

Session 4: Chairs: Ines Reichert, Maureen Bates

- 15:30 – 15:45 Skin Coverage Solutions for Diabetic Foot Problems From a Plastic surgeon - Naveen Cavale
15:45 – 16:45 Amputation in a Diabetic Foot?
15:45 – 16:00: When to Consider?- Mark Rogers
16:00 – 16:15: Appropriate Levels, When to Chose - Alex Wee
16:15 – 16:30: Major amputation- When is it Appropriate - Venu Kavarthapu
16:30 – 16:45: Prosthetic issues – Amy Jones

16:45 – 16:55 - Take Home Message on Day 1- Prash Vas

16:55 – 18:00 - Surgical workshops

18.00: Faculty Dinner

Appendix 18. Diabetes UK abstract

P405

Reducing amputations in the UK: a key to unlock the door

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Background and aim: Amputation is one of the most feared complications of diabetes and has an enormous impact on patients' lives. Despite having an integrated care pathway and multidisciplinary foot team, our centre had very high amputation rates in 2007–2010. The aim of our project was to examine the entire foot care pathway, identify areas for improvement and redesign our services to improve outcomes.

Results: A detailed root cause analysis of all amputations over a 12 month period (n=140) identified that at least 20% were potentially avoidable. Key factors were delayed referral from primary care, delays in getting investigations and management of antibiotic therapy. Detailed mapping of the care pathway demonstrated a high level of complexity that was difficult for healthcare professionals and patients to navigate. Using validated service improvement tools, we designed a number of interventions (e.g. foot hotline), resulting in the major amputation rate falling by around 50% from 1.75 to 0.9 amputations per 1,000 people with diabetes (2007–2010 vs 2010–2013).

Conclusion: There is a 10-fold variation in amputation rates across England and many of these are avoidable. It has been suggested that key reasons for this are the lack of integrated care pathways and multidisciplinary foot teams. We have demonstrated that it is not enough to have the appropriate structures in place. Foot care pathways are complex healthcare systems that cross organisational structures. These structures often create unnecessary barriers within the patient journey. By analysing the entire pathway and focusing on the patient journey, we have come up with innovative strategies that are more effective than targeting individual departments or functions.

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The lived experience of active Charcot foot in diabetes: improving understanding and patient care

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Background: Charcot foot is a rare but potentially devastating complication of diabetes that can result in foot deformities, ulceration and potentially amputation. Offloading via non-removable cast for an average of 9 months is the only known effective treatment.

Aim: The aim of this research is to enhance understanding of the lived experience of the active Charcot foot with a view to identifying ways to enhance patient care.

Method: A novel method of auto-photo elicitation and qualitative interviews using interpretive phenomenological analysis (IPA) was used. Participants were asked to bring in three to five of their own photographs to demonstrate how diagnosis and management of active Charcot foot had affected their lives and to use this to form the basis of discussion in a semi-structured, tape-recorded interview.

Results: Eight interviews were carried out: six males and two females aged between 46 and 73 years old, six had Type 2 diabetes, two had Type 1 diabetes, all received treatment at the same foot clinic, time from symptom onset to diagnosis ranged from 3 days to 7 months. All were treated in a total contact cast at time of interview. Identified areas of concern included difficulties of feeling 'disabled', depression, guilt, unwillingness to accept diagnosis, loss of meaningful activity, impact of family relationships and impact on diabetes control.

Conclusion: Active Charcot foot and its treatment have a more severe impact on patients given this diagnosis than has previously been shown in quantitative, questionnaire-based quality of life studies.

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Organisms isolated from diabetic foot ulcers in the inpatient population of a tertiary referral centre: a retrospective analysis over a 1 year period

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Aim: To survey the organisms isolated from diabetic foot ulcers in inpatients under the diabetic foot multidisciplinary team (MDT) at a tertiary referral centre.

Method: 172 inpatients new to the MDT between 1 May 2013 and 30 April 2014 were retrospectively identified. 112 had both swab and deep tissue samples. The organisms grown from each sample and their antibiotic sensitivities were retrieved from the CliniSys[®] WinPath database.

Results: 186 organisms were isolated from initial deep tissue samples. Of these, 65 (35%) were Gram negative bacilli, of which 32 (49%) had intrinsic AmpC production; 46 (25%) were Gram positive cocci including *Streptococcus* spp. and *Staphylococcus aureus*; 38 (20%) were coagulase-negative Staphylococci or *Candida* spp.; 22 (12%) *Pseudomonas aeruginosa*; 15 (8%) were other environmental organisms including *Acinetobacter*, *Alcaligenes*, *Fusarium* and *Stenotrophomonas*. Four of 33 (12%) Gram negative bacilli without intrinsic AmpC production had acquired beta-lactam or aminoglycoside resistance. One of 46 (2%) Gram positive cocci was methicillin resistant. Three of 22 (14%) *Pseudomonads* had anti-*Pseudomonas* resistance. One of 21 (4.7%) Enterococci was vancomycin resistant. 39 of 112 (35%) initial deep tissue cultures grew a single organism, 68 (61%) were polymicrobial and 5 (4%) were sterile. In 69 of 112 (62%) patients there was no overlap in the organisms grown on superficial and deep culture. In 16 (14%) there was some overlap but not all deep tissue organisms were grown on superficial culture. In 20 (18%) identical organisms were cultured. In five (4%) there was no growth, and in two (2%) no data were available.

Conclusions: Gram negative bacilli and Gram positive cocci comprise the majority of pathogens. Superficial swabs are a poor predictor of the pathogenic organisms grown from deep tissue samples.

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An audit of a multidisciplinary foot clinic effectiveness in West Hertfordshire

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Aim: The acute diabetic foot remains the main cause of non-traumatic limb amputations. The importance of a multidisciplinary

Appendix 19. Abstract for poster presentation at DFSG 2016

Aim: The impact of a clinical diagnosis of Charcot foot with/ without deformity and its long-term treatment with a total contact cast on patient's quality of life has not been studied. The aim of this research was to enhance the understanding of the lived experience of the active Charcot foot with a view to investigate patient's acceptance and "life with a Charcot foot".

Method: We carried out a prospective study in diabetic foot patients recently diagnosed with acute Charcot foot presenting to one clinical centre and undergoing treatment with casting therapy. We applied a novel method of auto-photo elicitation and qualitative interviews, which were evaluated with interpretive phenomenological analysis. Participants were asked to bring in 3 to 5 of their own photographs to demonstrate how the diagnosis and management of active Charcot foot had affected their lives. These photographs were used as the basis of a discussion in a semi-structured, tape recorded interview.

Results /Discussion: We studied 8 patients with an acute active Charcot foot (6 males and 2 females; 2 with type 1 and 6 with type 2 diabetes). The mean age was 59 ± 9.8 years (mean \pm SD) and the mean duration of diabetes was 16 ± 12.5 years. All patients were treated with total contact casting. One patient had bilateral involvement and was treated with two casts. Time from symptom onset to diagnosis ranged from 3 days to 6 months (10 ± 9.5 weeks). Three patients had already developed Charcot foot deformity at the time of presentation to the Foot Clinic. Duration of casting therapy prior the interviews ranged from 3 to 7 months (3 ± 1.8 months).

Patients identified several areas of concern including issues surrounding non recognition of symptoms and misdiagnosis of Charcot foot, lack of available information, the challenges of acceptance of the diagnosis, effects on diabetes, depression and suicidal thoughts, isolation, loss of meaningful activity and employment, changing sense of self, effects on relationships, and fear of the future. All patients saw being diagnosed with a Charcot foot as a marker of overall decline in health and well-being.

Conclusion: This is the first study that has explored the patient's perspective of the lived experience of active Charcot foot and its treatment with a total contact cast. It has demonstrated that both the diagnosis of a Charcot foot and its long-term management with total contact casting, have an immediate and severe impact on patient's perceived quality of life and sense of well-being. More patient focus research is required in order to improve patient care.