

Frozen Shoulder: Living with uncertainty and being in “no-man’s land.”

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Abstract

Title

Frozen Shoulder: Living with uncertainty and being in “no-man’s land.”

Background

Frozen Shoulder (FS) is a painful debilitating condition that is a significant burden to those experiencing it and healthcare systems. Despite research investigating the pathogenesis and effective treatment for the condition, there is a paucity of research exploring how having frozen shoulder is lived through and meaningful to persons experiencing it.

Objective

To explore how living with Frozen Shoulder is experienced and meaningful.

Methods

A qualitative research study design using hermeneutic phenomenology methodology was used. In-depth unstructured interviews were conducted with six purposively recruited participants. Interpretive Phenomenological methods were used to analyze the data forming emergent, superordinate and master themes to qualitatively expose the meaningful aspects of living through FS.

Findings

Five Master themes were identified i) “Dropping me to my knees,” an incredible pain experience ii) The struggle for normality iii) An emotional change of self iv) The challenges of the healthcare journey v) Coping and adapting.

The overarching ‘binding theme’ was ***Frozen Shoulder: Living with uncertainty and being in “no-man’s land.”***

Conclusions

This study illuminated the struggle to maintain a normal life whilst living with the significant pain, physical restriction, sleep loss and disability experienced by persons with Frozen Shoulder. Attempts to cope and adapt were impeded by the challenges of the healthcare journey. The uncertainty of these experiences was conveyed as being in “no man’s land” an expression that reflected the existential crisis and impact on persons’ sense of self.

Keywords: Frozen Shoulder; Adhesive Capsulitis; Lived Experience; Phenomenology; Hermeneutics; Quality of life

Introduction

Frozen shoulder contracture syndrome, often known as ‘Frozen Shoulder’ (FS) (Codman, 1934) is a common musculoskeletal condition which affects up to 2.4/1000 head of population (van der Windt, Koes, de Jong and Bouter, 1995). FS is a debilitating, painful, restrictive condition that is a significant burden to individual sufferers and healthcare systems (Lewis, 2015) which costs the National Health Service (NHS) £44 million/year in GP costs alone (Jones, Hanchard, Hamilton and Rangan, 2013). The disease is most prevalent between 40-65 years of age and affects females more commonly than males (Bunker, 2009; Lewis, 2015; Lundberg, 1969; Neviasser and Hannafin, 2010). There is a high incidence and poorer prognosis in persons with other health problems such as Diabetes Mellitus and Dupuytren’s Disease, but these links are not currently well understood and are still being studied (Smith, Deveraj and Bunker, 2001; Zreik, Malik and Charalambous, 2016). FS can occur idiopathically (primary FS) or develop after a recognised shoulder injury, (secondary form) (Hannafin and Chiaia, 2000; Ryan, Brown, Minns Lowe and Lewis, 2016). Inflammation and a contracted shoulder capsule were thought to have an important role in the pathophysiology of FS leading to the nomenclature ‘adhesive capsulitis,’ (Neviaser and Hannafin, 2010). However, later authors have debated whether inflammation is present and questioned the term ‘capsulitis’ (Bunker, 2009). Recent studies on the pathophysiology of the condition have found it to be a complex process of inflammation, stiffness and potential self-resolution with a wide and variable spectrum of presentations (Ryan, Brown, Minns-Lowe and Lewis, 2016; Vastamaki, Kettunen and Vastamaski, 2012). FS was classically described as having three phases (Reeves, 1975). A first ‘freezing phase,’ second ‘frozen’ phase and third ‘thawing’ phase followed by self-resolution from one to over four years (Lewis, 2015; Maund et al, 2012). However, this description has been challenged both in terms of the different phases and the condition being self-limiting in nature (Struyf and Meeus, 2014), as some sufferers are left with symptoms and

disability persisting beyond five years (Hand, Clipsham, Rees and Carr, 2008; Wong et al, 2017). Thus, some authors have simplified the stages to just two, a first ‘pain over stiffness’ phase and second ‘stiffness over pain’ phase, (Lewis, 2015). Much research has attempted to evaluate the most efficacious treatments for FS and though debate still exists this evidence has been collectively formed into guidelines. The U.K. guideline proposes a stepped approach to modifying activity, taking analgesia, engaging in physiotherapy, exercise, an intra-articular steroid injection and finally a referral to secondary care (NICE, 2017). However, the burden to the sufferer with FS can be considerable and little attention has been given to the qualitative aspect of what it is like to experience it and what this may mean for healthcare.

Understanding the experiences of persons receiving care is important in improving healthcare, yet in relation to their health encounters patients often feel they are not listened to and their experiences are not considered (Mulley, Trimble and Elwyn, 2012; Verbeek, Sengers, Riemens and Haafkens, 2004). Qualitative research conveying the ‘patient voice’ may resonate with clinicians and researchers working in the field and prompt them to reflect on how they care (Gillespie, Macznik, Wassinger and Sole, 2017; Hutting et al, 2014; Minns Lowe, Moser and Barker, 2014). However, only one qualitative study has aimed to explore the experience of FS (Jones, Hanchard, Hamilton and Rangan, 2013). Using thematic analysis this study aimed to explore sufferer’s perceptions and priorities related to FS. The data was epistemologically driven seeking knowledge about the condition. Four main themes were generated: the inexplicable severe pain, issues around awareness and expectations, issues around treatment and inconvenience with disability. To date no study has explored how the experience of FS is lived through and meaningful (with an ontological focus). Therefore, this study aimed to explore and uncover rich new insights into FS by studying the lived experiences of those with the condition.

Research Methodology and Methods

Methodology

This study used interpretive (hermeneutic) Phenomenology to explore the lived experience of FS. Phenomenology can explore a collective kaleidoscope of subjective individual experiences by drawing out the similarities and variation in what is meaningful to persons who have experienced the same phenomenon (Harrison, Kinsella and DeLuca, 2019). This methodology aligns with the authors' epistemological and ontological positions that knowledge about being and existence is relative to the individual (relativist philosophy).

Phenomenology originated with the philosopher Husserl who sought to reduce the experience of a phenomenon down to its core features (essences) as perceived by the experiencer in their unique lifeworld, (Koch, 1995). This form of phenomenology now known as Descriptive Phenomenology (Georgi, 2009), was epistemologically driven, seeking knowledge about a phenomenon and being by using a person's detailed descriptive accounts of their lived experience. Phenomenology took a different direction with Husserl's student Heidegger, who shifted the emphasis of the methodology from the epistemological to the ontological by focussing on what it was like to be, to exist, with an experience in the context of the person's lifeworld (the relative world in which people perceive their life) (Lindseth and Norberg, 2004). Heidegger saw interpretation as an inseparable part of the transfer of the experience between the experiencer and the researcher (Horrigan-Kelly, Millar and Dowling, 2016). The authors of this study drew on Heidegger's philosophy, by focussing on the existential aspect of experiencing phenomena, and embraced interpretation throughout the process. The authors also drew on the work of Hans-Georg Gadamer, using Hermeneutics (the theory and methodology of interpretation), by continuously moving back and forth between the parts and the whole of the experience layers of meaning were unearthed; a technique referred to as the Hermeneutic

Circle, (Gadamer, 1989). Using Gadamer's approach the interpretations and experiences of the authors could potentially be married with the accounts of those experiencing the condition where appropriate, to reach a "fusion of horizons" (Gadamer, 1989).

Methods

Prior to the research the author assumed a phenomenological attitude. This meant having an awareness of the prior understandings, thoughts and feelings (fore-conceptions) of the lead author towards the phenomenon and at the same time approaching the research with genuine curiosity and openness (Finlay, 2014; Fitzpatrick and Finlay, 2008). To help with engagement in the hermeneutic circle and to reach a fusion of horizons, the first author completed a reflective fore-conception statement (See Appendices document 1) and kept a reflexive diary through the research process.

Patient and Public Involvement (PPI)

A PPI group with lived experience of shoulder pain was asked to feedback on study aspects such as participant information, recruitment, interview styles and practicalities prior to the studies acceptance and commencement. A pilot interview was also completed with a person suffering from FS. This helped to craft prompts and exposed a feeling that interviews should be as unstructured as possible to allow the data to arise from persons with FS not an interview guide.

Participants

The study purposively recruited six participants (see Table 1 below). A small number of participants was used as the study sought to elicit rich, in depth descriptions and search for hidden meaning through prolonged engagement with the data; an approach congruent with phenomenological studies exploring individual's lived experience (Finlay, 2012).

Table 1 Participant Demographics

Participant Pseudonym	Ethnicity	Gender Female/Male/Other	Age	Duration of symptoms	Arm affected	Dominant upper limb
April	White/British	Female	52	10 months	Right	Right
Ezra	White/British	Male	60	24 months	Right	Right
Rex	White/British	Male	35	12 months	Right	Right
Leah	White/British	Female	66	11 months	Left	Right
Lance	White/British	Male	56	18 months	Bilateral	Right
Tadgh	White/British	Male	60	18 months	Bilateral	Right

Persons attending a Musculoskeletal Assessment and Triage Team outpatient service at a community hospital, who had been diagnosed with FS by upper limb specialists in the team, were considered for inclusion and were invited to take part. Potential volunteers were given information about the study. For those who expressed an interest, inclusion and exclusion criteria were applied and verbal consent was gained to pass their contact details to the lead researcher who invited them to an interview at a hospital. Written informed consent was gained prior to interviews commencing. Ethical approval was granted by the West Midlands Regional Ethics Committee (Solihull) and approvals were gained from the Health Research Authority, a University in the South of England and the local NHS trust site.

Data Collection

Data was collected using loosely structured in-depth interviews conducted by the first author and opened with styled question “**can** you describe in as much detail as possible what was important and meaningful to you in your experience of living with frozen shoulder?” If participants were deviating from the focus of the research or struggling to articulate their experience, similar styled questions brought them repeatedly back to what was meaningful to them about their lived experience of FS. For example, “thinking about a meaningful experience

related to Frozen Shoulder can you take yourself back to that moment and explain it in as much detail as possible?” Questions such as “can you explain that in more detail?” or “can you describe a further example of that?” were used to prompt and explore participants’ experiences in depth. Interviews lasted between 35-95 minutes and ended when the prompts were not bringing forth any further information and the participant gave a negative response when asked if they had anything more to add (Brinkman and Kvale, 2015). Interviews were recorded and transcribed verbatim. Notes were made in a research diary of non-verbal and verbal cues with potential relevance for interpretation in the data analysis. The interviewer’s thoughts on how the content resonated with them were also noted and revisited during the data analysis.

Data Analysis

Interview transcripts were analysed using the six steps of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009). The analysis process was completed by the lead researcher and then reviewed with the second author, who at each stage of the analysis process entered dialogic discussions with the first author and offered alternative interpretations.

In step one, the transcripts were read and re-read to immerse the first author in the data. Notes were taken on each passage and text that was striking or provoking was noted (Austgard, 2012).

In step two, each transcript was divided into whole passages of continuous speech and then further subdivided into sections of text holding a meaning, (meaning units). Then for each meaning unit, descriptive, linguistic and conceptual comments were added (See Table 2 below).

Table 2 An Excerpt of the Transcript Analysis for Participant ‘Ezra’

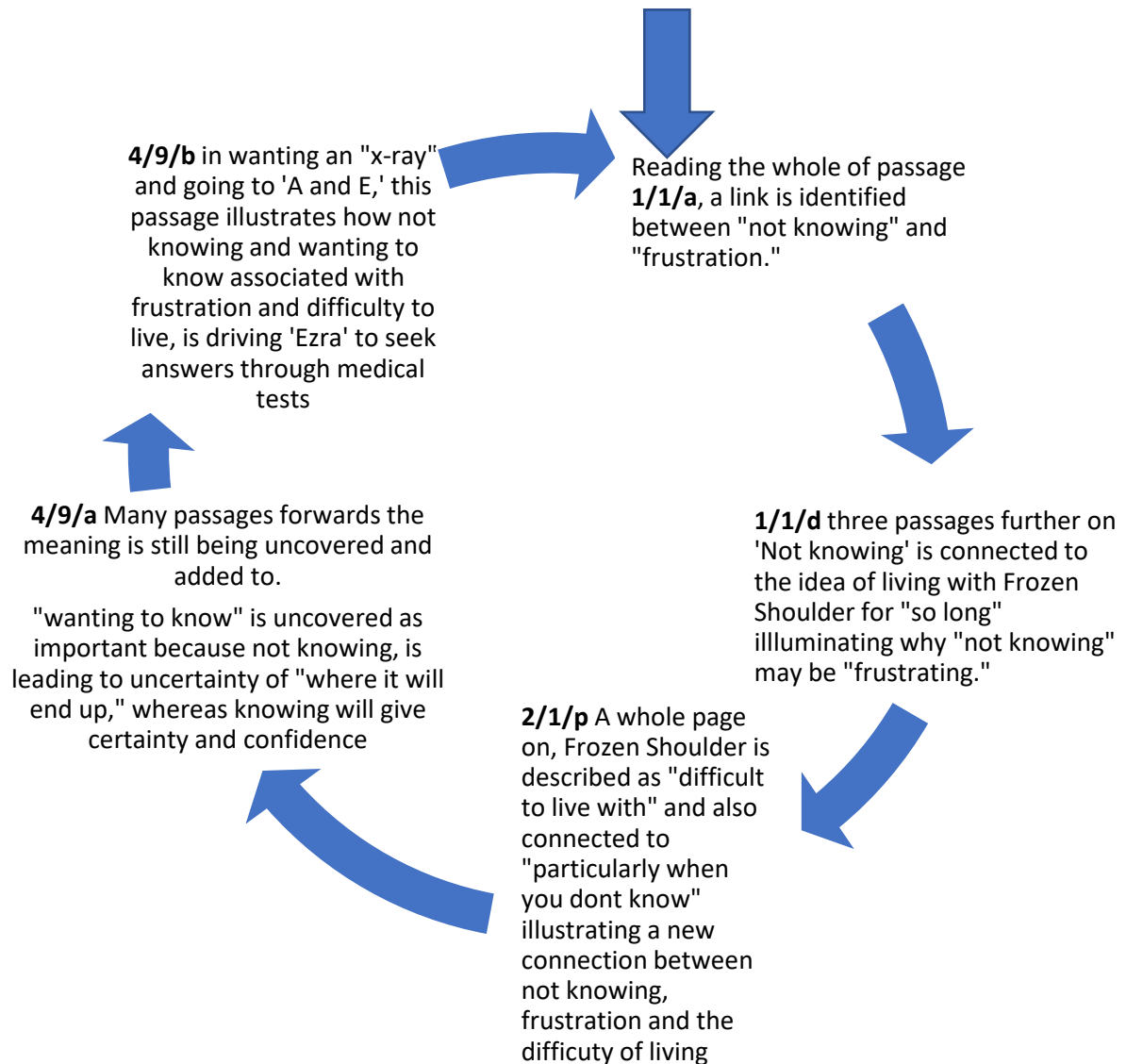
Key				
Page Para Graph and unit	Meaning Units of Raw unaltered transcript	Exploratory Comments	Possible Emergent Themes	Connections Column Showing:
		Normal Text = Descriptive Comments		<i>Hermeneutic circle connections</i>
		<i>Italic text = linguistic and interpretive comments</i>		<i>Reflexive awareness</i>
		<u>Underlined text = Conceptual comments</u>		<i>Possible Fusion of Horizons</i>
Excerpt				
2/1/p	And I mean in the morning right, you wanna like get a good stretch yawn, stretch and you just can't because its agony and my missus will like hear me screaming (laughs) because, because I'm trying to like stretch and straighten	<p><u>Descriptive Comments:</u></p> <p>In the morning you want to get a good yawn and stretch, and you can't because its agony. His Mrs will hear him screaming as he stretches and straightens. It's difficult to live with particularly when you don't know what it is.</p> <p><u>Linguistic Comments:</u></p> <p><i>'good stretch, yawn' in the 'morning' locates these physical actions in life and to a certain time of day.</i></p> <p><i>The 'want to get' a stretch in the morning suggests an important starting action to the day?</i></p> <p><i>'just' is used for emphasis and 'can't' as a statement of inability.</i></p> <p><i>Inability is because 'its agony' strong indication of the level of pain, possibly unsustainable pain or suffering with pain.</i></p>	<p>Screaming as you stretch</p> <p>Its agony</p> <p>Difficult to live with</p> <p>Not knowing</p>	<p>Possible Hermeneutic Connection points:</p> <p><i>This passage is a first reference to his 'Mrs,' which changes the life-world context of the experience, confirming it in the homelife and involving a shared experience in his relationship</i></p> <p>Hermeneutic Circle:</p> <p>This passage continues to confirm the severity of pain with the descriptive comments that he is 'screaming' in 'agony.'</p> <p>It also situates the severe pain experience with physical movement when stretching.</p> <p>There is a return and reiteration of the concepts that life is difficult to live with FS and not knowing is difficult, but these</p>

	<p>(pause) so it is quite difficult to sort of live with, but particularly when you don't know (pauses laughs and then stops talking).</p>	<p><i>Pain severity and potential suffering are further illustrated by him 'screaming' (a vocal action associated with fear, pain, shock).</i></p> <p><i>His 'Mrs' hears him screaming which appears to situate this part of the experience in the context of his life world at home.</i></p> <p><i>The effect of doing these actions is connected to making frozen shoulder 'quite difficult to live with' which is in turn connected to 'when you don't know' lacking knowledge about something, in this case why his arm is behaving this way?</i></p> <p><u>Conceptual Comments:</u></p> <p><u>screaming because its agony to stretch</u></p> <p><u>Difficult to live with</u></p> <p><u>When you don't know</u></p> <p><u>Possible interpretation:</u></p> <p><i>Pain severity in the morning is severe when stretching leading to a sense of suffering and vocalisation of the pain experience with simple everyday actions. There appears to be a connected reflection that living with frozen shoulder is difficult particularly when you don't have knowledge about it.</i></p>		<p>concepts now appear interconnected.</p> <p>Fusion of Horizons:</p> <p>This example confirms the clinical horizon for the researcher that frozen shoulder can be agony to experience when doing certain physical movements. New elements to the horizon are that it is bad enough to produce a vocal response and that this is connected to people in the homelife also being involved in the experience.</p> <p>Reflexive awareness:</p> <p>The is a reflexive awareness that the researcher has experienced many accounts in the clinical environment of how bad the pain from frozen shoulder can be but if anything, rather than biasing the interpretation of the pain experience this account helps to keep that awareness fresh and has added insights into how important not knowing about the condition is to those with it and how it can affect the homelife.</p>
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The first author dwelt on potential interpretations from the comments and used the hermeneutic circle throughout the analysis to move between the parts (meaning units) and the whole transcript to interpret and uncover deeper meanings (see Figure 1 below) (Peat, Rodriguez and Smith, 2019; Stenner, Mitchell and Palmer, 2016).

Figure 1. An Illustration of the working Hermeneutic Circle for Participant ‘Ezra’

Entering into the process of the Hermeneutic Circle through the identification of a possible key feature ‘not knowing.’ The bold labels locate the different parts within the whole transcript for example **1/1/a** refers to text on page **1/** paragraph **1/** in meaning unit **a**



Innovation is encouraged in IPA (Smith, Flowers and Larkin, 2009) and in this study, a fourth column of analysis was added to illustrate when the hermeneutic circle was in action and when reflexive thoughts were occurring ‘in the action’ (Finlay, 2012). This column of comments also highlighted potential areas where a fusion of horizons was occurring between the researcher and their interaction with the participants’ accounts (refer to the fourth column Table 2 above).

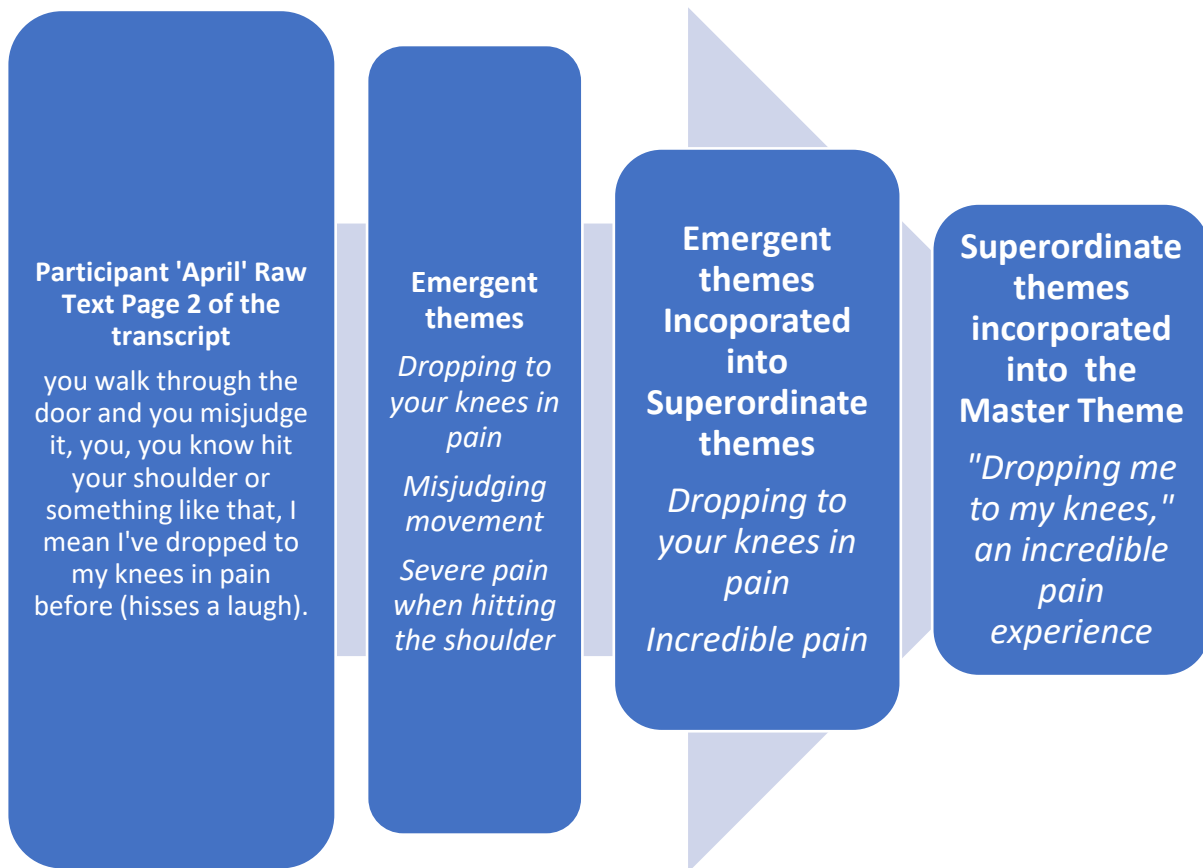
In step 3 of the analysis, the elements were reviewed again for any potential emergent themes and time was given to dwell and reflect on the data before a further drawing out of emergent themes (Finlay, 2014). The themes had a level of abstraction which is intellectually connected to the interpretation process and makes them different from simple categories.

In step 4, the emergent themes from one participant's text were formulated into a grid and an iterative process was used within each case along with continued abstraction to cluster similar emergent themes into superordinate themes for each case (Smith, Flowers and Larkin, 2009). In the process of clustering the binding meaning between emergent themes was sought through further dwelling on the data. This allowed a detraction from the raw text with more conceptual depth being given to the resultant superordinate themes (Finlay, 2014; Smith, Flowers and Larkin, 2009; Vaismoradi, Jones, Turunen and Snelgrove 2016).

In step 5, in its idiographic commitment to examining the detailed experience of each case in turn, the process for the first case was repeated across all cases through stages one to four until a full list of superordinate themes had been gathered.

In step 6, the superordinate themes were reflected upon, moving back and forth from the raw data and other stages of analysis where appropriate, to find connections across the sample of cases. From these interpretations the final master themes and sub-themes were generated. Throughout this process the focus was to uncover hidden meaning, whilst staying close to the participants' original text and experience (Finlay, 2014). To stay true to the participant's account and 'do it justice,' a transparent trace from the raw data to emergent and then superordinate themes was sought, which is an innovative part of this study's rigour (see figure 2 below).

Figure 2. The journey of analysis from a piece of ‘raw text’ through to a ‘master theme’



Strengths and Limitations of the research

Qualitative rigour has been described as elusive, but components of qualitative rigour have been utilised to enhance transferability, credibility and dependability in this study (Lincoln and Guba, 1985; Ryan-Nicholls and Will, 2009).

This study involved six participants. Although similarities and themes emerged between participants, the findings cannot claim to be generalisable to the wider population and are specific to these six persons with FS. However, using a small number of participants is appropriate for Interpretive Phenomenology as it enables the collection of rich data and a prolonged engagement with it. Furthermore, in qualitative rigour, generalisability can be

replaced with transferability (Noble and Smith, 2015). This refers to whether the study could be completed and attain similar findings in different contexts, or with different groups of people (Ryan-Nicholls and Will, 2009). A similar methodology and methods have been used to study closely related musculoskeletal conditions such as the lived experience of rotator cuff tear (Minns Lowe, Moser and Barker, 2014), which suggests this study may be transferable to other conditions and other groups. However, all the participants were white British, which may limit the transferability to peoples with a different ethnic origins and cultures.

The lead author acknowledges that this is their first use of Interpretive Phenomenology and the analysis and interpretation of findings is potentially subject to author bias. However, to enhance credibility and transparency the author assumed a phenomenological attitude prior to the study's commencement, gained in depth knowledge of the methodological approach and completed a fore-conception statement to display prior position, values and beliefs (Koch, 2006). In addition, the use of analysis checking with the second author enabled interpretations, meaning and themes to be robustly challenged and guarded against one researcher's influence on the findings (Baillie, 2015). This study did not seek data saturation, which is a method more in keeping with Grounded Theory methodology, but the lead author embraced a reflexive approach. This involved a continual inward reflective gaze in the analysis to enhance and demonstrate sensitivity to how the self and self-knowledge may influence interactions in the research process (Dodgson, 2019; Finefter-Rosenbluh, 2018). However, this study did not utilise participant validation of the analysis due to time and resource constraints of the research process. The clear steps followed in this study aid the study's auditability and these steps have been widely used by other authors (Smith, Flowers and Larkin, 2009).

Findings

Five master themes with several sub themes were generated from the data (see Table 3 below). Although master themes were distinct, they were intertwined through the experience as a whole, which appears to reflect the complexity of living with FS. The binding thread connecting themes was that the experience of FS was pervaded by uncertainty strikingly analogised as being in “no-man’s land.”

Table 3. Displaying the Sub-Master themes and Master themes

Overarching ‘binding’ theme	Master themes	Sub themes
Frozen Shoulder: Living with uncertainty and being in “no-man’s land.”	1) “Dropping me to my knees,” an incredible pain experience	
	2) The struggle for normality	The shock and surprise of a restricted less capable life
		Disturbed homelife and relationships
	3) An emotional change of self	Suffering and being miserable
		Disrupted sleep and it’s enduring effects
	4) The challenges of the healthcare journey	
5) Coping and adapting	Learning to adapt, changing life and doing things differently	
	Playing it down, putting on a brave face and coping	

Participants in this study conveyed the severity of their pain, illuminating how this meaningfully affected their lives and forming the first master theme *“Dropping me to my knees,” an incredible pain experience*. The pain experience reverberated through all participants’ lives such that their life-worlds became disrupted and life was described as “very difficult” to live. The uncontrollable pain provoked by sudden movement was connected to

several powerful descriptions of involuntary body responses striking language such as this within participant quotes has been additionally highlighted in bold.

*“If you walk through the door and you misjudge it, you, you know you hit your shoulder or something like that, I mean **I’ve dropped to my knees in pain before.**”*

‘April’

*“The motion just jarred my shoulder back and I dropped, **it doubled me over** where the pain shot through.”*

‘Rex’

However, it was not solely severe pain exacerbated by sudden movement that was meaningful to participants, other aspects of the pain experience were also conveyed as having significance. The invasiveness of the pain could be ever-present, all-encompassing and be described as affecting the mind as well as the body, with participants’ perception of life as a whole being changed.

*“It’s funny, it’s a nagging dull ache, you can’t, you can’t take your mind off it. It’s just a very difficult thing to live with, (long pause), I think what it is, is because its **ever present.**”*

‘Ezra’

The Struggle for normality

The effect of these incredible pain experiences on normal life, related to the second master theme ***The struggle for normality***, which was characterised by the sense of realisation and unwillingness to accept the apparent limitations FS brought. Physical restriction in the shoulder affected how the body felt and affected capability. Backing off activity could only be achieved so far and then participants faced a struggle to hold onto what was meaningful in their lives. The struggle for normality was further characterised by the surprise and shock of a

restricted less capable life which formed one of two sub master-themes ***The shock and surprise of a restricted less capable life.***

*“Even things like just getting out of bed, getting dressed, sleeping was awful erm working, driving, just all very difficult. **You** don’t realise how debilitating it is. It’s just silly things like if you walk through the door and you misjudge it. It’s just been **a bit of a shock** really.”*

‘April’

For some participants, the amount of curtailed ability made normal life untenable. This could lead to unwelcome life changes, where the struggle was being lost. For one participant this meant having to sell a fishing boat and for others “giving up” on work.

“I mean I’ve got a fishing boat, which I found it was becoming increasingly difficult to move round my boat because I have to hold onto the sides and I haven’t been able to put me arm above shoulder height (indicates left side) and my grab rails are up, up there (tries to point above shoulder), so my boat is now up for sale (sighs).”

‘Lance’

The shocking loss of ability and a sense of struggle to maintain a normal life appeared to invade participants’ homelives and relationships leading to a second sub-theme ***Disturbed homelife and relationships.***

Participants’ descriptions were characterised by loss of independence, feelings of disenfranchisement and of being a burden. This is illuminated in ‘Rex’s’ descriptions of his relationship with his son whilst experiencing FS.

*“We was on holiday in the pool with friends and I’m watching my friend play with his kids and my boy and sitting there thinking I can’t even like go and throw him in the air I can’t even chase him round the **pool**.”*

“I think I was playing football with the boy in the garden, larking around, he grabbed my arm and instantly the pain was searing to the point where I think I hit the deck and it made him scared because he thought I was really hurt, it made him cry because he thought he had done something really bad. I tried to explain to him afterwards that it’s my shoulder mate, it was an accident.”

‘Rex’

The consequences of this disruption could lead to feelings of low mood and reduced self-worth, which connected to the third master theme *An emotional change of self*.

FS was explicitly conveyed as an emotional experience by all participants and this is reflected in the master theme *An emotional change of self*. The experienced exhaustion and disability were meaningfully related to a change in participants’ sense of self, which was poignantly characterised by feelings of uselessness, hopelessness and depression.

*“You feel a bit **useless**; you know, I mean I am useless to all intensive purposes. I tell you what, **if you were an animal you would be put down because you’re miserable.**”*

‘Ezra’

*“Yeah I mean **it kind of spirals you down into depression and I couldn’t see any light at the end of the tunnel at all really.** It’s very hard, mmm (non-verbal, swallows and holds onto her breath, some tears follow) **I’m breaking up.**”*

‘April’

All participants also illuminated sleep disruption as exhausting and “physically draining.” This was meaningfully connected to an emotional change of self and formed the subtheme *Disrupted sleep and its enduring effects*.

“I probably get about one night’s sleep out of three. So, two nights no sleep then the third night so absolutely knackered that you sort of die.”

‘Ezra’

It also led to other changes such as having to sleep in a separate bed from a partner, creating not just physical distance in relationships but also a loss of intimacy. Several participants attributed loss of sleep to changes in mood and in turn effects on their relationships.

“Consequently, because my sleep was disrupted that made me feel ratty, then of course you’d not had that sleep, then this would not be working properly (points to left arm), then you’d get really aggravated.”

‘Leah’

Participants sought help for their pain and sleep disruption through healthcare, but this presented its own mixture of challenges leading to the fourth master theme, ***The challenges of healthcare.***

The healthcare experience was a variable journey for each individual, but all participants expressed the challenges they faced. Participants described seeking answers and assurance from healthcare professionals to address the uncertainty of not knowing what was wrong with them. Many participants conveyed the experienced significance of gaining a diagnosis and prognosis for the condition so they could “get on” in their lives. However, the delays in the health system and delay to diagnosis were voiced as meaningful features across cases that participants illustrated as not being taken seriously and halting progress.

“So, I went back to the Drs, but it’s very difficult to see a Dr, I don’t know how aware you are of that. I felt I was getting fobbed off.”

‘Tadgh’

As well as delayed diagnosis the delay to and uncertainty of effective treatment was also meaningful for many participants. Participants illustrated their apparent frustration at the time spent engaging with ineffective treatments that they perceived they had little choice over. Treatments were described as involving a process of back and forth, trial and error being issued inconsistently and of varying effectiveness. In addition, advice from General Practitioners to go onto stronger medications appeared to create a dilemma for several participants due to fears of addiction.

“So, she said, ‘well there’s Tramadol.’ I said, ‘well I’m not really keen on tramadol I had a mate who had a bad knee and he got hooked on it.’”

‘Ezra’

Conversely a corticosteroid injection was perceived and experienced as a life changing treatment across participants’ accounts. However, participants illuminated a sense of internal dilemma between wanting to gain pain relief and better quality of life set against the fear of having the injection.

*“Yep, it’s taken the pain away, not completely but **it’s given a new lease of life**. I’m no longer taking any tablets, I stopped those within two weeks after the injection. I really don’t like taking strong painkillers, so yeah **that injection has worked wonders for me.**”*

‘April’

*“**It was quite alarming when I saw the size of the needles** it looked like a quarter of a litre (laughs) and then they put one in the front. That one really, really, hurt, you know I could almost see me shoulder swelling. **It was a bit nerve wracking.**”*

‘Lance’

Physiotherapy was more negatively experienced. A mixture of delays and ineffective painful treatment led to a sense of frustration, incredulity and loss of confidence.

“I done eight weeks of physio and it never got easier, it got harder and I kept saying to the physios, ‘the manoeuvres you’re asking me to do, its worsening. You’re asking me to do these stretches and these exercises, I can’t do them.’ To have to wait a week to tell someone that and to let them actually witness you trying to do it and then tell you to try again next week and the following week and the following week.”

‘Rex’

For all participants, the communication with their health-carers was meaningful. Healthcare encounters where participants were not listened to, taken seriously and at times dismissed permeated across the experiences. This was vividly encapsulated by one participant’s description of his ultrasound scan examination and the way he was spoken to by the consultant and assisting nurse.

“You’re hoping to get some sort of answers and all he said was, ‘there’s no rupture you’ve got frozen shoulder, you better get good advice and good treatment otherwise it’s gonna be 2 years’ and then he walked off. Then the nurse says, ‘put your shirt back on off you go.’”

‘Ezra’

Through various similar descriptions, participants illuminated a convoluted healthcare journey that had to be pushed by them yet was not in their control. In some experiences, pushing and making a fuss was perceived to move things forwards, but there was a sense of this being an unnecessary part of the journey.

*“So, I kicked up a fuss and X said, ‘well you can see a doctor if you want,’ **I felt like I’d had to make a fuss to get referred.**”*

‘Tadgh’

Several participants contrasted their challenging encounters with seeing specialists who “knew” what was going on. The specialist encounter seemed to provide certainty and security where an efficient diagnosis was made, and effective treatment options were provided.

*“When I saw the specialist literally five mins done a few movements and he was like ‘it’s a frozen shoulder.’ **If there’s any way that the process can be sped up, to see that specialist first rather than have to go through the motions of seeing three different people before seeing that person who probably does know.**”*

‘Rex’

Despite these reflections and aspirations for a less challenging healthcare journey, most participants’ experienced healthcare as helpful whilst living with FS. This was strongly conveyed by one participant who returned to a previous analogy they had used of losing hope and reversed it having had a meaningful effect from a steroid injection.

*“**I do see light at the end of the tunnel now, as I say I think my movement field is definitely improving and the pain has definitely gone right back.**”*

‘April’

Receiving effective treatment was one part of trying to manage the experience of FS and there were other aspects of **Coping and adapting**, which formed the final master theme.

There was variation in how individuals managed their experience of FS. This variation formed two subthemes. The first subtheme **Playing it down, putting on a brave face and coping** illuminates the implicit meaning of participants ability to develop intrinsic coping

strategies. The ability to “press on” in the face of adversity and uncertainty seemed a meaningful characteristic for participants to help cope with FS.

“So, in a way I just sort of got on with it, you know get up and stomp, go around, have a glass of water and then go back to bed.”

‘Leah’

However, some participants conveyed a different sense of coping strategy, one of acceptance, even resignation at their situation.

“Oh! I just lie flat on my back and wait for the ache to go away, there’s not really much point in doing anything else.”

‘Lance’

The language participants used to describe their own experiences suggested that they sought an external reference point to anchor their own experience, often this was a comparison to what the experience could be like for someone else. For some participants’, this hypothetical projection was used to play down their own struggle.

“I’ve had it fairly easy compared to someone who had this at the age of 70 or you know, older. I think it would have just been awful I really do.”

‘April’

Most participants also expressed the experienced significance of learning to do things differently to cope with FS leading to the second subtheme ***Learning to adapt and change life, doing things differently to cope***. A sense of learning was conveyed as meaningful, whereby they learnt to work with the experience, reorganising their lives and doing things differently to achieve their goals.

“I’m always taking measurements right-handed and it is my right shoulder that is frozen. So, I’ve actually learnt to do it left-handed, so I’ve had to do that otherwise I wouldn’t be able to work.”

‘April’

“Well obviously you have to reorganise yourself around things like that, the main thing for me is that I have just worked around it.”

‘Tadgh’

However, for some participants the adaptation and ability to cope with FS was at times uncertain. Uncertainty pervaded the experience of living with FS and interconnected with all the master themes binding them together encapsulated by one participant’s description of life being in ‘no-man’s land.’

Frozen Shoulder, living with uncertainty and being in ‘no man’s land.’

The **struggle for normality** and its subthemes were linked with *the incredible pain experience, challenges of healthcare, emotional change of self* and *coping and adapting*. In turn these themes also appeared connected to “not knowing” and “uncertainty,” which formed the central tenets of the overarching theme. “Not knowing” was a feature that many participants described as meaningful to their experience of FS. However, there was variation as to what not knowing meant and how it was meaningful to different participants.’ For some it seemed to be the unpredictability of living with FS, whilst for others, the experience of uncertainty appeared more connected to knowledge and being unable to explain their experience. A state of not knowing seemed meaningfully connected to the idea of an uncertain future. Participants voiced their uncertainty over what would happen, how the condition would progress and what this would mean for their lives. These elements appeared to create an insecure footing for life or

conversely a sense of being stuck. These nuances were vividly encapsulated by the powerful image one participant created of feeling their life was in “*no man’s land.*”

“How am I going to work, how am I going to operate? you wanna know what is it? What’s causing it? Why it is happening and what are the repercussions going to be? Where is it going to end up? I feel in no man’s land.”

‘Ezra’

Discussion

Pain is commonly listed as a symptom of FS (Jones, Hanchard, Hamilton and Rangan, 2013). However, the findings of this study illustrate how a list of symptoms do not seem to reflect the lived through experience as it was illuminated by the graphic descriptions of participants in this study. Participants used powerful analogies to illustrate the impact of pain on the body and their lives for example by capturing how the nature of their pain literally subjugating them by bringing them to their knees. Participants also conveyed the sense of pain pervading their lives, which became severely restricted and controlled by pain. The concept of pain literally constraining, subduing, and controlling life for participants in this study is a stark reminder of how musculoskeletal conditions like FS can totally disrupt the world of the person experiencing it. The invading nature of participants’ pain experiences were akin to an ‘assault on the self,’ which echoes the lived experience of persons with back pain and illuminates the experienced loss of identity when living with pain (Smith and Osborn, 2007). The tortuous nature of pain in this study is also mirrored in the quote.

“It is easier to find men to die than it is to find men who will endure pain with patience” (Julius Caesar)

Indeed, pain has been used as a method of torture through the ages, as has sleep deprivation (Scarry, 1987). Sleep deprivation was meaningful for all participants in this study who conveyed it as related to low mood and emotional responses such as anger. These changes have also been connected to sleep deprivation during interrogations, which has been described as a form of mental torture (Lee, 2006; Porrás-Segovia et al, 2019; Saghir et al 2018). Furthermore, sleep deprivation held significance for participants by inducing miserableness, hopelessness and depression. This was graphically captured by ‘April’ with the analogy of a life with no light at the end of the tunnel. A life constrained by pain and sleep deprivation was conveyed by all participants to be unacceptable. They described the struggle to retain a normal life and within this their attempts to minimise the disruption to their homelife and relationships.

The consequences of FS on the homelife exposed an unrecognised facet of FS in the literature. Pain, restriction and sleep loss are well known features of FS (Jones, Hanchard, Hamilton and Rangan, 2013), but what has been less understood are the social ramifications for the experiencer and those around them. The negative effects of living with a health condition on others has been identified as a ‘spillover’ effect. (Lavelle, Wittenberg, Lamarand and Prosser, 2014). Spillover is an interdependent, intersubjective two-way flow of interaction where each person effects the other (Kershaw et al, 2015; Lavelle, Wittenberg, Lamarand and Prosser 2014). In this study ‘Rex’ poignantly illustrated this through describing the effect his pain experiences had on his son, which in turn reflected back negatively on his own mental health and changed his perceptions of himself as a father. Uncovering how experiencing FS reverberates through the lives of those affected, highlights the need for health professionals to have an in depth understanding of the life-world for each person receiving their care. Indeed, participants illustrated the challenges of healthcare when they perceived that their life-worlds were poorly understood by health professionals.

The experienced significance of healthcare encounters resonated through all participants accounts. Whilst participants described the importance of specific interventions (such as injections), participants also illustrated the significance of not being listened to, taken seriously, or trusted in their healthcare encounters. In effect they lost their ‘voice’ and these descriptions imply that they experienced their healthcare as paternalistic. Although this study did not explore clinicians’ perspectives or observe healthcare encounters, participants’ accounts echo research exploring physiotherapists experiences of managing low back pain, which highlighted a paternalistic approach to physiotherapy care (Cosgrove and Hebron, 2020; Sullivan, Hebron and Vuoskoski, 2019). Furthermore, this study exposes the limitations of healthcare models that health professionals are applying. Healthcare has evolved from taking a purely biomedical perspective (biomedical model) to a biopsychosocial one (BPS), (Wade and Halligan, 2017). This evolution theoretically incorporates not just tissue-based pathology but also a more holistic perspective with consideration of the whole person. However, how the BPS model is conceptualised and operationalised may vary and can be viewed in a reductionist manner (reducing life to three component parts) (Dalusio-King and Hebron, 2020). The challenges physiotherapists face in operationalising a more holistic model of care are highlighted in qualitative research (Singla, Jones, Edwards and Kumar, 2015). This seems to accord with the experiences of participants in this study, which added to the uncertainty they described.

Uncertainty was illuminated as meaningfully related to living with FS and is encapsulated by one participant’s vivid description of living in “no-man’s land.” No-man’s land has been defined as a barren tract of land, land that no-one controls and land unoccupied out of fear of uncertainty (Collins Dictionary 2021; Wikipedia, 2021). This definition seems to resonate with the uncertainty and difficulties that living with FS created for participants. The findings of this study illustrate how uncertainty is interconnected with the struggle for a normal life that participants experienced. Uncertainty is experienced by many persons in their healthcare

situations and can lead to fear, anxiety and a loss of self-confidence and control, (Hillen et al, 2017; Penrod, 2001). This may be discomforting to experience because it can change people's everyday way of being in their world (Penrod, 2007). Ongoing uncertainty, inducing anxiety, has been categorised as a form of stress and stress is well recognised as changing physiology and mental states in the body particularly if being endured for some time (Wu et al, 2020). Tolerance of uncertainty is a growing focus of research and is associated with health outcomes (Strout et al, 2018). The ability of participants to develop a resilience to the adversities they faced and learn how to adapt and cope with FS formed part of their struggle to maintain normal lives. Participants frequently cited their innate stoicism and "just getting on with it." The value of being stoical in the face of adversity echoes the feelings of people living through other long-term health conditions such as fibromyalgia and rheumatoid arthritis (Flurey et al, 2017; Wuytack and Miller, 2011). Learning to adapt, avoiding problems and doing things differently such as learning to use the non-affected arm, were also ways of coping that lessened participants' struggles with FS. It would seem that having an understanding of the uncertainty people may experience with health conditions, their tolerance to uncertainty and how individual's resilience, learning and adaptation interplay with these concepts may help physiotherapists to better assist those with FS and other conditions.

Conclusion

The evocative descriptions used by participants in this study, provide deeper insights to the meaning of the 'list of symptoms' recognised by clinicians as features of frozen shoulder and the struggle for normal life that lies beneath them. Symptoms were meaningfully related to a change in participants' life-worlds and their relationship with others. Healthcare encounters were meaningful for participants in this study and when participants felt that they were not

heard, this compounded the challenges of managing the uncertainty resulting from living with FS. Despite the challenges and pressure of working in a clinical setting, we hope that these findings will prompt readers to pause before and during clinical encounters, to take the time to listen and approach healthcare encounters from a holistic philosophy. Understanding the challenges of living with uncertainty for persons receiving healthcare and facilitating a tolerance to the uncertainty of living with FS and other health conditions is an important area for further physiotherapy research.

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Appendices

Document 1 A Fore-conception statement of the researcher's position prior to the study commencing.

Date written 01/10/2018.

- As an Advance Physiotherapy Practitioner APP in an upper limb musculoskeletal clinic, I hear stories everyday of people's experiences of shoulder conditions.
- Frozen Shoulder the topic of interest for my forthcoming clinical MRes research project, is one of these conditions and probably is the second most common presentation in my clinical caseload.
- After several years of doing this work I can't help but start to draw a picture of what it must be like to experience Frozen Shoulder from the myriad of experiences I have encountered second hand via patient interactions. Patterns and similarities are mentally drawn. The extremes of experience both good and bad are logged. The other subtle nuances such as patient's attitude, mental state and other physical wellbeing and how these traits influence outcomes are sub-consciously and consciously logged at one time or another.
- In addition, through the career I have built up a different kind of knowledge, of the anatomy, the research studies I am aware of in this field, of treating the condition in my physiotherapy role, radiology tests and so on.
- Having never experienced Frozen Shoulder myself I don't have that first-hand knowledge. So, my picture of experiencing Frozen Shoulder is not a lived one it is already an interpreted one.
- Nevertheless, I need to acknowledge that these types of knowledge and my second-hand picture of Frozen Shoulder has been formed.
- For me to believe I can fully bracket that is not possible in my opinion. However, I do believe that I can assume something of a phenomenological attitude and try and see where my opinions are meeting the data.

- I can write a list of what I expect to find and see if that matches the data and also the reader of the research can see where those expectations may have influenced the interpretation of results.

My current position

- I believe that experiences in healthcare where the researcher is inside the data are co-constructed but that the researcher can be aware of this and try and separate where a fusion of horizons is occurring and where the raw experiencer's account can remain unadulterated.
- I believe in interpreting the account of the experience but only so far as is reasonable to postulate. Some meanings can be confirmed from the use of tools such as the hermeneutic circle, but others remain possibilities and with the structure of the current research there will not be a chance to patient validate the findings. I'm not validation is without influence in any case as in taking ideas back to the participant it would be difficult not to influence their second interpretation of what they meant at the time of any interview.
- I think I have some critical realist views having seen the frustrations of people with the condition and the healthcare they have received I think this is a potential influence over my interpretations.
- I understand and value concrete description and the need for very stringent interview technique so that the researcher brings little to influence the account of the experiencer.

Main Expectations of findings

- I think people will have severe pain experiences and significant disruption to life.
- I think they will have significant restriction of the movement and function.
- I think those in the earlier phases of the condition will have significant sleep loss.
- I think there will be a mixture of healthcare experiences, but some will certainly be bad, probably around not getting a diagnosis and not getting intervention that helps them.

Tables

Table 1 Participant Demographics


Participant Pseudonym	Ethnicity	Gender Female/Male/Other	Age	Duration of symptoms	Arm affected	Dominant upper limb
April	White/British	Female	52	10 months	Right	Right
Ezra	White/British	Male	60	24 months	Right	Right
Rex	White/British	Male	35	12 months	Right	Right
Leah	White/British	Female	66	11 months	Left	Right
Lance	White/British	Male	56	18 months	Bilateral	Right
Tadgh 	White/British	Male	60	18 months	Bilateral	Right

Table 2 An Excerpt of the Transcript Analysis for Participant ‘Ezra’

Key				
Page Para Graph and unit	Meaning Units of Raw unaltered transcript	Exploratory Comments	Possible Emergent Themes	Connections Column Showing:
		Normal Text = Descriptive Comments <i>Italic text = linguistic and interpretive comments</i> <u>Underlined text = Conceptual comments</u>		<i>Hermeneutic circle connections</i> <i>Reflexive awareness</i> <i>Possible Fusion of Horizons</i>
Excerpt				
2/1/p	And I mean in the morning right, you wanna like get a good	<u>Descriptive Comments:</u> In the morning you want to get a good yawn and stretch, and you can't because its agony. His Mrs will hear him screaming as he stretches and straightens. It's	Screaming as you stretch Its agony	<i>Possible Hermeneutic Connection points:</i> <i>This passage is a first reference to his ‘Mrs,’ which changes the life-world context of the experience, confirming it in the homelife and involving</i>

<p>stretch yawn, stretch and you just can't because its agony and my missus will like hear me screaming (laughs) because, because I'm trying to like stretch and straighten (pause) so it is quite difficult to sort of live with, but particularly when you don't know (pauses laughs and then stops talking).</p>	<p>difficult to live with particularly when you don't know what it is.</p> <p>Linguistic Comments:</p> <p><i>'good stretch, yawn' in the 'morning' locates these physical actions in life and to a certain time of day.</i></p> <p><i>The 'want to get' a stretch in the morning suggests an important starting action to the day?</i></p> <p><i>'just' is used for emphasis and 'can't' as a statement of inability.</i></p> <p><i>Inability is because 'its agony' strong indication of the level of pain, possibly unsustainable pain or suffering with pain.</i></p> <p><i>Pain severity and potential suffering are further illustrated by him 'screaming' (a vocal action associated with fear, pain, shock).</i></p> <p><i>His 'Mrs' hears him screaming which appears to situate this part of the experience in the context of his life world at home.</i></p> <p><i>The effect of doing these actions is connected to making frozen shoulder 'quite difficult to live with' which is in turn connected to 'when you don't know' lacking knowledge about something, in this case why his arm is behaving this way?</i></p> <p>Conceptual Comments:</p> <p><u>screaming because its agony to stretch</u></p> <p><u>Difficult to live with</u></p>	<p>Difficult to live with</p> <p>Not knowing</p>	<p><i>a shared experience in his relationship</i></p> <p>Hermeneutic Circle:</p> <p>This passage continues to confirm the severity of pain with the descriptive comments that he is 'screaming' in 'agony.'</p> <p>It also situates the severe pain experience with physical movement when stretching.</p> <p>There is a return and reiteration of the concepts that life is difficult to live with FS and not knowing is difficult, but these concepts now appear interconnected.</p> <p>Fusion of Horizons:</p> <p>This example confirms the clinical horizon for the researcher that frozen shoulder can be agony to experience when doing certain physical movements. New elements to the horizon are that it is bad enough to produce a vocal response and that this is connected to people in the homelife also being involved in the experience.</p> <p>Reflexive awareness:</p> <p>The is a reflexive awareness that the researcher has experienced many accounts in the clinical environment of how bad the pain from frozen shoulder can be but if anything, rather than biasing the interpretation</p>
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		<p><u>When you don't know</u></p> <p><u>Possible interpretation:</u></p> <p><i>Pain severity in the morning is severe when stretching leading to a sense of suffering and vocalisation of the pain experience with simple everyday actions. There appears to be a connected reflection that living with frozen shoulder is difficult particularly when you don't have knowledge about it.</i></p>		<p>of the pain experience this account helps to keep that awareness fresh and has added insights into how important not knowing about the condition is to those with it and how it can affect the homelife.</p>
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Table 3. Displaying the Sub-Master themes and Master themes

Overarching 'binding' theme	Master themes	Sub themes
Frozen Shoulder, living with uncertainty and being in "no-man's land."	1) "Dropping me to my knees," an incredible pain experience	
	2) The struggle for normality	The shock and surprise of a restricted less capable life
		Disturbed homelife and relationships
	3) An emotional change of self	Suffering and being miserable
		Disrupted sleep and it's enduring effects
	4) The challenges of the healthcare journey	
5) Coping and adapting	Learning to adapt, changing life and doing things differently	
	Playing it down, putting on a brave face and coping	

Figures

Figure 1. An Illustration of the working Hermeneutic Circle for Participant 'Ezra'

Entering into the process of the Hermeneutic Circle through the identification of a possible key feature "not knowing." The bold labels locate the different parts within the whole transcript for example **1/1/a** refers to text on page **1/** paragraph **1/** in meaning unit **a**

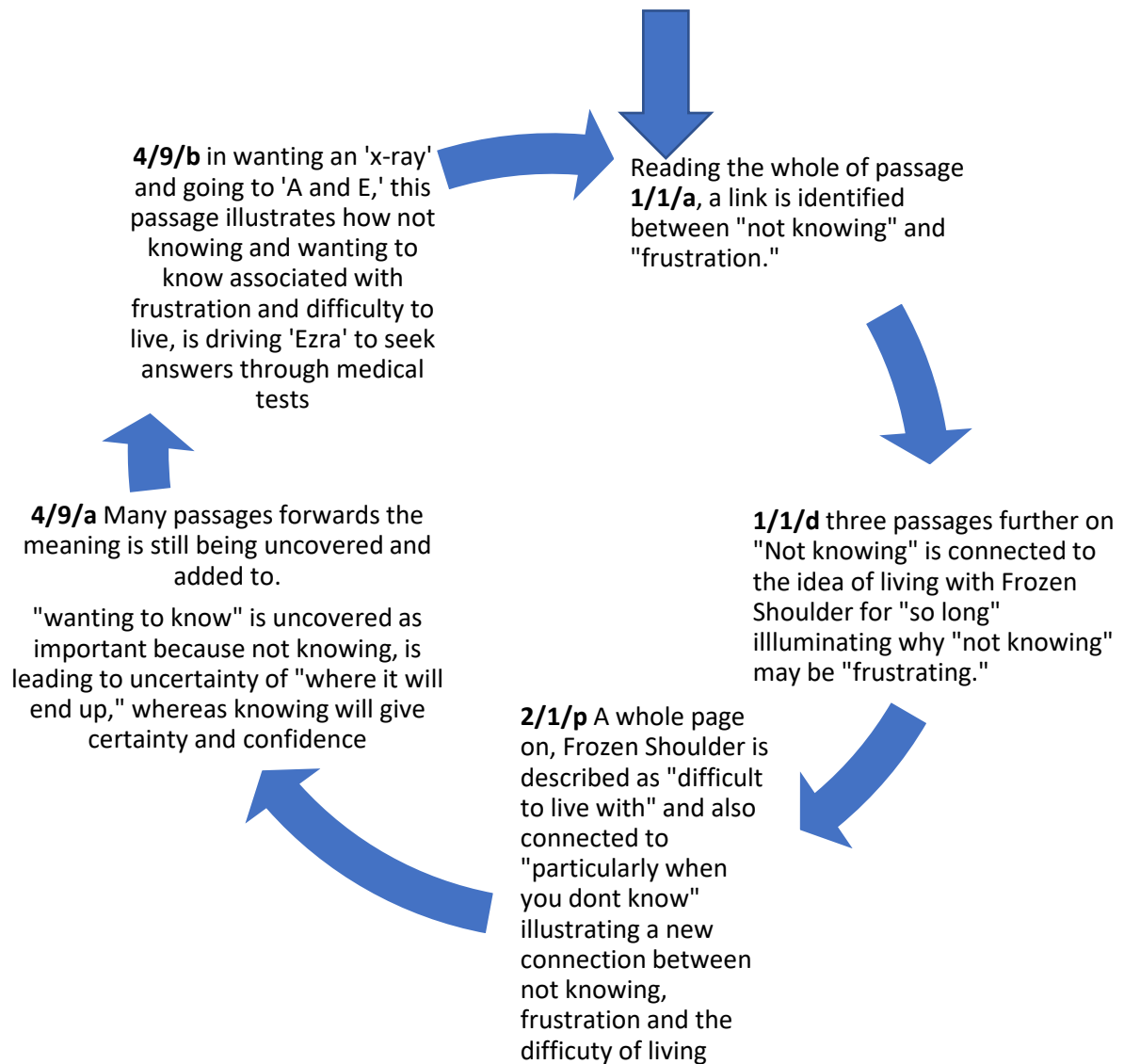


Figure 2. The journey of analysis from a piece of ‘raw text’ through to a ‘master theme’

