

Title: Living with frozen shoulder. ‘Here are the risks. I want the injection’: An interpretative phenomenological analysis

Introduction

Frozen shoulder is a disabling condition characterised by persistent and severe pain and loss of shoulder movement (Kelley et al., 2013) with estimates it may affect up to five percent of the population. Onset appears to be most commonly in the fifth to seventh decades (Kelley et al., 2013). For people diagnosed with diabetes the incidence has been reported to be between 10 to 59% (de la Serna, Navarro-Ledesma, Alayón, López, & Pruiomboom, 2021; Le, Lee, Nazarian, & Rodriguez, 2017; Millar et al., 2022). The reason for this wide range could relate to different diagnostic criteria, challenges in deriving a clinical diagnosis, and no gold standard reference test. In the absence of known predisposing co-morbidities, trauma, or pathology, people are classified as having primary or idiopathic frozen shoulder. On average the duration of disability associated with frozen shoulder is approximately 30 months and return to pre-morbid pain free function is not guaranteed (Wong et al., 2017). Sleep disturbances are common, and activities related to occupation and daily living are substantially affected.

The etiology of frozen shoulder is not certain but may relate to lifestyle factors and systemic low-grade inflammation (de la Serna et al., 2021), but clinically, once diagnosed it appears to pass through two stages. The first stage has been described as a pain dominant phase and

the second clinical stage stiffness dominant phase (Lewis, 2015). There is also uncertainty regarding best management and poor understanding of the benefits and potential harms associated with the different treatment alternatives (Lewis, 2015; Minns Lowe, Barrett, McCreesh, de Búrca, & Lewis, 2019). This uncertainty has led to considerable variance in management. Management alternatives include physiotherapy (exercise, manual therapy, stretching, cryotherapy), surgery (manipulation under anaesthetic, capsular release), and myriad injection therapies, including corticosteroid injections to the glenohumeral joint, subacromial bursa, combinations of both, hydrodistension, suprascapular nerve blocks (Lewis, 2015; Rangan et al., 2020), and experimental procedures such as TNF- α (adalimumab) injections successfully used to treat inflammatory conditions such as rheumatoid and psoriatic arthritis (Hopewell et al., 2022). Corticosteroid injections are currently one of the most common interventions and aim to reduce pain in the pain dominant phase (Ahn et al., 2018; Sun, Liu, Chen, & Chen, 2018). These injections appear to be as effective as manipulation under anesthetic and capsular release (Rangan et al., 2020).

Qualitative research consistently describes severe, inexplicable and debilitating pain, inconvenience and disability, confusion and anxiety around delayed diagnosis, uncertainty about the future and concerns around treatment (Jones, Hanchard, Hamilton, & Rangan, 2013; King & Hebron, 2022; Lyne, Goldblatt, & Shanahan, 2022). When psychological and emotional aspects are further explored in people with frozen shoulder, struggles for normality are paramount (King & Hebron, 2022; Lyne et al., 2022), succinctly described as 'living in no man's land' (King & Hebron, 2022). For people with frozen shoulder, the practical aspects and challenges of healthcare systems are described whilst being in extreme pain (Jones et al., 2013; King & Hebron, 2022; Lyne et al., 2022). Previous studies have

described how gaining access to treatment is a priority for people with frozen shoulder (Jones et al., 2013) and that ‘*above all else*’ pain management was the patients’ priority (Lyne et al., 2022), however these studies have not described treatment. King and Hebron (2022) briefly touched on the dilemma faced by participants considering a corticosteroid injection and how this was a fearful proposition. This study aims to address this gap in the knowledge by exploring the lived experience of people with frozen shoulder who have undergone an injection and to highlight novel findings by using an interpretative phenomenological analysis (IPA) approach.

Methodology

Phenomenology is the study of human experience from the perspective of the individual (Smith, Flowers, & Larkin, 2022). Two main phenomenological approaches used in healthcare are descriptive and interpretative with both approaches using in-depth interviews. The descriptive approach aims to shed light on the conscious understanding of the lived experiences of a specific group of people by interviewing with an open mind while constantly assessing one’s own biases during the process (Lopez & Willis, 2004). This process creates features or themes, considered to be common to all who live through that experience resulting in a generalisable description (Lopez & Willis, 2004). Phenomenology developed with Heidegger (1889–1976) who was influenced by *hermeneutics*: the theory of interpretation.

The interpretative approach goes beyond the description of what people consciously know or understand about their experience and instead searches for the meanings lying beneath the

surface of that description (Lopez & Willis, 2004). These meanings are often not evident to the participant, but through a process of analysis, the researcher is able to uncover previously unrealised meanings (Lopez & Willis, 2004). Specifically for interpretative phenomenological analysis, there is what is termed the *double hermeneutic*, where the researcher is attempting to make sense of the participants attempting to make sense of their own experience. This is explained as “*what it means’ for the participants to have made these claims, and to have expressed these feelings and concerns in this particular situation*” (Larkin, 2006). Put simply, a descriptive approach pays attention to what is said and an interpretative approach on what is implied. Interpretative phenomenology is underpinned by ‘*ideography*’, which can provide a detailed and unique perspective of the individual through a single case analysis, before making cross-case comparisons. Generalisations can then be made, described in IPA as convergence. This methodological approach was chosen as it aligns with the authors stance on the individual bringing their own story to the subject and it is accepted these accounts can vary.

Participant selection and recruitment

A purposive sample of participants aged 18 years or older were identified following referral to a community musculoskeletal service, via a frozen shoulder pathway, between November 2020 and June 2021. Participants were considered for the study if frozen shoulder was confirmed by clinicians specialising in shoulder conditions. All participants were either nearing or at the end of their physiotherapy treatment ensuring thoughts and feelings of their experience would be relatively fresh in their minds. All participants had undergone a

corticosteroid injection for frozen shoulder. A small number of participants were recruited to ensure in-depth description of the data.

Potential participants were contacted by email or letter, and if they expressed an interest, were sent the study information pack. Preceding the interviews, written informed consent was obtained. Ethical approval was granted by South Central Oxford C Regional Ethics Committee, Ref. 20/SC/0278 and Health Research Authority approval.

Data collection

Participants were invited to participate in a single interview, which took place virtually via MSTeams™ due to Covid-19 restrictions. Data were collected through one-to-one semi-structured interviews by CBS (4 interviews) and KN (3 interviews). The interviews lasted between 33 and 65 minutes and took place between August and November 2021. Participants were encouraged to talk as openly and in-depth as possible about the different ways frozen shoulder had impacted their lives and started with the opening statement “I am interested to know about your experience of what it is like to live with frozen shoulder”. Prompts, when required, touched on topics related to diagnosis, social, emotional factors and treatment in terms of injection therapy. The interviews were recorded and transcribed via MSTeams™. The transcriptions were assessed for accuracy by the lead researcher and co-researcher and a handheld Dictaphone, used as backup, also served to clarify areas of transcription that were unclear. The participants were given the opportunity to amend their transcript if they felt relevant.

Data analysis

Audio recordings were listened to, and transcripts read to get an overall sense of the text. Data was analysed in accordance with interpretive phenomenological analysis methods. (Nizza, Farr, & Smith, 2021; Smith, Flowers, & Larkin, 2009). Analysis was completed by CBS and KN. Sections of text considered noteworthy, were highlighted and initial thoughts were made in a side column. Prior to the study the two lead researchers adopted a phenomenological attitude by producing personal statements to reflect on their own standpoint, held discussions to facilitate 'bracketing' and a reflexive diary was kept by the lead researcher throughout the process. Both lead researchers were involved in the analysis of all data sets operationalised by moving between the parts and whole of the text and the lead researcher continued this for the group data and had final say of the group experiential themes.

The next stage involved making exploratory notes, which precede any detailed analysis and facilitate in-depth thinking about the contents of the transcript (Nizza et al., 2021; Smith et al., 2009). This technique uses a combination of descriptive, linguistic, and conceptual techniques. An example of this is in Table 1.

Table 1. Illustrates styles of analysing the text using three different techniques

(Insert table 1)

Exploratory notes are the basis for formulating experiential statement, the next stage of analysis. Experiential statements, or phrases, summarise important sections of notes, whilst still being grounded in the original text. They should be 'open phrases' suggesting or implying psychological content, to help get to the meaning of the words as opposed to taking the text at face value (Nizza et al., 2021; Smith et al., 2009). Figure 1 is an example of developing an experiential statement.

Figure 1 Developing an experiential statement

(Insert figure 1)

Experiential statements were clustered together (convergence) by interpreting and synthesising conceptually similar data, which then formed *personal experiential themes*.

This is repeated for each participant and across participants. Following this, a process of cross-case analysis takes place, where the data for all cases is compared. This is an iterative process that uses a method known as the hermeneutic circle to highlight key factors in the experience that makes them similar and different and reveal new understandings for each participant and as a group. This involves working with the data, moving back and forwards, considering a range of different meanings, of 'the part' (e.g. a single word) and 'the whole' (e.g. the whole text) (Smith et al., 2009). The researchers moved back and forth between individual and group data, being open to new interpretations. Figure 2. Illustrates the stages in the development of group experiential themes.

Figure 2. The stages in the development of group experiential themes

(Insert figure 2)

Findings

Data was collected from seven participants, ranging from 45 to 68 years of age, four of which were females and all but one were employed. Duration of symptoms ranged from 8 to 21 months. (Table 2).

Table 2. Participant demographics

(Insert table 2)

Three group experiential themes were identified: *the dilemma surrounding injections; challenges of understanding the causes of frozen shoulder; impact on self and others.*

The dilemma surrounding injections

Corticosteroid injections help to manage the painful symptoms of frozen shoulder and all the participants in the study underwent corticosteroid injection at some stage of their treatment. Five participants described a strong desire to receive an injection, seemingly driven by the severity of pain. Three participants conveyed a single-minded pursuit in obtaining an injection, despite being aware of the associated risks. For one participant there seemed to be a belief in the injection as a 'miracle cure'.

"I had 100% faith in it. Or just probably in myself I want to believe that. And didn't question it". "I presumed, and I had too much faith in this injection. I thought it was going to be like the miracle cure....." "The fact that the benefits outweighed any risks, what I mean is the fact that I was hoping that I wouldn't have the pain outweighs any risk, so I didn't question it really. It's a pain that's so intense so I just wanted relief"
'BB'.

"He explained it all, but at the end of the day, I didn't really care about the risk, I just wanted it done and that was it. To be honest here" *'DF'.*

*"But in terms of the weigh-up the potential benefits was, uh was stronger than my concerns about risks. **Here are the risks. I want the injection** [laughs]"* *'JC'.*

"Uhm, my feeling was I will take absolutely anything you can give me to try to do something about this. So, I was kind of keeping everything crossed that I might get it"
'JC'.

Despite the eagerness for an injection, a level of scepticism appeared to be interwoven in the thoughts of participants with one participant even suggested the injection may have a subliminal component.

".... bearing in mind I wasn't really having any benefit from anything else..." *'JC'.*

"I would have been happy to have had the injection anyhow because the level of pain I was in and it just felt like just give her the injections right away like why, why mess around?" 'VA'.

"We're saying that the injection was just to take the pain away. It wasn't so much to, you know, miraculously make the arm better"....."Yeah, of course I'll do the same again, so I think it's definitely sped up my recovery even if it's psychological, you know" 'DF'.

Challenges of understanding the causes of frozen shoulder

In attempting to understand the cause of their symptoms participants frequently attributed their pain to age or ageing and injury. Concepts of ageing and injury may be readily understandable and could explain pain in easier-to-understand terms. Searching for meaningful explanations was important to participants which became clear in their speculations.

"At the time I used to play tennis and uh, because of the way I play sometimes I used to stretch my arm, my shoulder quite a lot in terms of muscle, so I first thought that I'd torn a muscle or something in my arm" 'DF'.

"Many, many years ago, I was in a car accident. This part of my arm, I hurt it, so every now and again I had to get aches in it. So, I thought it was something to do with that" 'BB'.

"Because years ago I used to run a post office and it had a serving hatch and they had to do this sort of movement (demonstrates pulling a hatch down) and both my arms used to absolutely kill me as a result of that, to the point of almost like, you know, twisting inside it was so, such a painful job to do that" 'DF'.

Ageing appeared to be closely associated with shoulder pain and there was an assumption for some that as the body ages, pain and altered body image seem an inevitable part of this process.

"This feels like an old age condition. This feels like a bit of you is seizing up. And you're just in that decline (pause) towards the grave, she said cheerfully [laughs]" 'JC'.

"It is what it is it yeah. I just take it as you, you know your your body's getting older and it's wearing out I suppose. It's put down to age and you just have to learn to live with it" 'DF'.

“ Thinking it's this is my life and in my old age. I felt, oh gosh well I have to live like that for the rest of my life now and at times I would think oh God, is it going to get worse as I'm getting older” ‘NS’.

“I don't feel like I'm old enough to be creaking around like this and not able to do stuff” ‘JC’.

“I look in the mirror and I just see I just see an old lady. I just see all this saggy arm, fat and cellulite my stomach's all bloated” ‘JC’.

Impact on self and others.

For one participant working in the hospitality industry, the onset of shoulder pain fundamentally altered her working life as she became more introverted and solitary in her occupation.

“But as far as far as I just prefer to do it in a solitary way just on my own rather than having to be up front and centre and “Hello, how are you” and pull out that smiley face when you're greeting people” ‘BB’.

“I used to be, as I said because I worked in pubs, be a very outgoing person. You have to be with you in that business and I've gone, I've swung around the whole opposite

way, and I don't want to be around crowds. I can't bear to be around people that I don't know. I'm comfortable with my small group of people” ‘BB’.

Participants described how frozen shoulder was felt to be a hidden disability and expressed frustration that others were not able to recognise this.

*“You can have this disability that it isn't, you know, **isn't visible to someone else**, but it feels like you're disabled and nobody getting that. And even the people that you feel like should be sensitive to that are very or don't get it that you can't, you know that you're not able to do to do things and you know it's a lot of pain and you can't, you can't move it” ‘VA’.*

*“Yeah, I mean work colleagues kind of get it to a degree because they're working in the arena. Uhm. Pain is a difficult one because if **you can't see it**, it's very difficult for anyone, whether they're a health professional or not. In fact, some health professionals are often the worst” ‘JC’.*

It was clear that living with a frozen shoulder had a significant impact on participants and the people they live or work with. Family members were called upon to provide support, leaving participants with a sense of guilt well described by ‘VA’ who depended upon her daughter.

“It had a massive impact on everyone around me. And so, if she'd gone out and I was getting ready for a meeting later on in the day, then I'd have to call her to come back,

and I just felt awful. I just felt so awful cause this poor kid's been locked away at home for like over a year and you know, in a teenage years and she's finally got freedom to go out and it's she's having to, you know, like she can't be 100% free'' 'VA'.

These accounts describe the impact living with frozen shoulder has on close relationships. Indeed, the effects extend beyond the home and permeate into the workplace, indicating the manifold ways that living with frozen shoulder have on people's lives.

Attending to divergence

A marker of high-quality interpretative phenomenological analysis is attendance to divergence (Nizza et al., 2021). This highlights areas where a participant's experience contrasts with others. Examples found include the positive experiences where they describe the close bonds and support developed with neighbours and family.

"We've always been there for each other, but two particular people, my next-door neighbour, and my neighbour at #1. And I think because we know each other so well the three of us we've always been there for each other. And they have been there for me so much. It's unbelievable'' 'BB'.

For another participant, having a frozen shoulder meant she was not required to carry out one aspect of her working duties she disliked.

“Uh, I'm not really driving much at the moment, but I don't really like driving anyway, so that's a good excuse not to do it” ‘JC’.

Discussion

Specifically, thought-provoking insights illuminated the desperation participants conveyed in seeking an injection for their shoulder pain regardless of the risks involved. Overall findings align with previous studies of people living with frozen shoulder that describe the challenges people face in attempting to understand the causes of their pain (Jones et al., 2013; King & Hebron, 2022; Lyne et al., 2022) and raises a novel concept that participants felt this was a part of the ageing process. Further insights highlighted the impact the condition had on self and others.

All participants in this study had received a corticosteroid injection for their frozen shoulder. Despite the myriad risks associated with injections, participants felt that having the injection was essential, conveying an almost unquestioning belief in it by using terms such as ‘miracle’, ‘cure’ and ‘faith’, elevating injection therapy, seemingly to the status of a ‘divine intervention’. Severe pain is one of the main characteristics of frozen shoulder and was arguably a strong motivating factor. What is illuminated here is the strong sense of desire for an injection whilst seemingly dismissing the risks. This contrasts with an earlier study where hesitancy surrounding injections for frozen shoulder was evident (King & Hebron, 2022).

The findings in this study also depart from those of other studies as concerns around the potential harmful effects of medications has been well documented (Pound et al., 2005) in surgical in-patients (Gan, Habib, Miller, White, & Apfelbaum, 2014), terminally ill patients (Weiss, Emanuel, Fairclough, & Emanuel, 2001), chronic pain (McCracken, Hoskins, & Eccleston, 2006) and rheumatoid arthritis (Treharne, Lyons, & Kitas, 2004). Perhaps due to the severity of pain, participants were willing to accept the 'trade-off' between the risks associated with the injection and benefits of a potential relief from their symptoms of pain. This could be viewed in terms of a 'risky-but-rewarding' behaviour (Larkin & Griffiths, 2004) and an indicator of the desperation experienced in trying to lessen the pain. Individuals are conscious, intentional and embodied beings (Larkin & Griffiths, 2004) and capable of making decisions that may either positively or negatively affect their health and possibly why the injection was so fervently sought.

Although some participants appeared to have a strong belief in the injection, there was some variation as it became apparent there was a level of scepticism interwoven in the thoughts of participants. Participant 'JC' had weighed up the risks and benefits and conveyed that as she did not benefit from other treatment an injection was worth trying. Another participant (VA) stated *"I would have been happy to have had the injection anyhow because the level of pain I was in....."*.

Overall, what became clear was how injections for pain were so fervently sought despite the risks and how the meanings differed between participants as some thought it a cure whilst others were more sceptical.

Participants sought to make sense of the pain as they speculated that previous injury (Jones et al., 2013) or repetitive movements may be the underlying cause. Participants searched for meaningful moments in their past, in the hope of making a connection between previous events and their current shoulder pain. Seeking plausible explanations from personal experiences could be viewed as a coping mechanism. This response is described in the '*Common Sense Model*' framework, which examines how, in an attempt to make sense of pain, one forms a '*representation*' of it through beliefs gained through personal experience, observing others with similar symptoms and the media for example but may not always be helpful and clinicians should seek opportunities to explore this as part of a management plan (Caneiro, Bunzli, & O'Sullivan, 2021).

For some participants in this study, age and ageing were inextricably associated with their shoulder pain. There was an assumption for some that as the body ages, pain is an inevitable part of this process. Phrases such as 'seizing up' and 'creaking around' were used and there was a stoic acceptance of having to live with it, possibly for the rest of one's life. This association with ageing seemed to permeate beyond just the shoulder pain and alter perceptions of body image as one participant, poignantly described seeing an 'old lady' when looking at herself in the mirror. The concept of '*embodiment*' described by the phenomenologist Merleau-Ponty (1962) refers to the lived experience of engagement of the body in the world. Individuals become aware of themselves as an entity, where their experiences of the world are inextricably linked with the body with many finding their bodies 'uncomfortable' to live in (Piran, 2017). Alterations in body image resonate with

studies of people living with long-term pain such as fibromyalgia (Sturge-Jacobs, 2002) and persistent pain (Sündermann, Rydberg, Linder, & Linton, 2018) and have shown individuals with chronic pain do not to regard their bodies as aesthetically pleasing (Markey, Dunaev, & August, 2020).

During periods of illness assumptions we make about our bodies functioning are challenged, which some may find difficult to cope with (Smith et al., 2009). One participant 'JC' refers to the lack of clarity around living with frozen shoulder as like being in '*the lap of the body gods*' alluding to a loss of self-agency and being a passive bystander in their own care. This loss of self-agency is mirrored in people living with chronic fatigue where the authors speculate this goes beyond 'learned helplessness' to being a loss of self, loss of identity and loss of embodiment (Dickson, Knussen, & Flowers, 2008).

It is recognised that high levels of pain are strongly associated with high levels of emotional distress, depression, anxiety, and pain catastrophising (Martinez-Calderon et al., 2018) affecting individuals in different ways. One participant 'BB' explained how she became more withdrawn particularly when at work. Societal norms influence coping beliefs which for BB meant concealing feelings by putting on a brave face described as "***pull out that smiley face***" reflecting previous research (Dickson et al., 2008; Osborn & Smith, 1998). Wanting to withdraw was not voiced by everyone and 'VA' described how it was like living with a hidden disability, consistent with other conditions like that of low back pain or chronic fatigue syndrome (Sturge-Jacobs, 2002). Perhaps driven by the scepticism of others in not taking the condition seriously (Dickson et al., 2008; Osborn & Smith, 1998), 'VA' explained how she bought larger size clothes and '*disabled products*'. These outward signs

of pain and disability have been described as a way of establishing the 'legitimacy' of their pain to others (Osborn & Smith, 1998).

For some participants there was a challenging impact on their social relationships as they came to rely heavily on family and others. A reliance on her daughter for simple tasks such as putting on her coat, led 'VA' to compare her daughter's situation to a form of imprisonment as she went from being 'locked away' during Covid-19 pandemic to still 'not being 100% free'. Illness changes the familiarity of our world, where it becomes strange and there is loss of certainty as usual life has altered. Heidegger (1962) used the word *uncanny* to describe a form of anxiety and fear from the realisation of one's solitary existence and mortality. As one notices the physical changes and the feeling of becoming ill, there is a feeling of *uncanniness*; a meaningful experience of fear or perplexity (Madeira, Leal, Filipe, Rodrigues, & Figueira, 2019). The concept of the *uncanny* is a universal experience and in terms of illness it can induce feelings that the body is alien and there is a strangeness and loss of the familiar world (Madeira et al., 2019). Participants in this study universally experienced the unfamiliar, becoming withdrawn, putting on a brave face, confronting a hidden disability and guilt around family dependence.

Given the natural history that frozen shoulder may last years and, in some cases, not fully resolve, it might be useful to consider frozen shoulder a long-term musculoskeletal condition similar to persistent low back pain. Adopting this approach and understanding how people can find illness unfamiliar and strange, will support clinicians in the management of people with frozen shoulder more effectively.

Strengths and limitations

One marker of high quality IPA (Nizza et al., 2021) is divergence with two participants highlighting the positive effects having frozen shoulder had on their lives.

The interviews were conducted by two researchers, thereby allowing different perspectives during the interview and analysis stages. The lead researcher does not see people with frozen shoulder as part of usual clinical practice, thereby distancing themselves from the subject matter and allowing greater objectivity.

The interviews were conducted virtually, which may have led to participants feeling less connected to the interviewer or interview process. Given that virtual meetings have now become a well-established part of social, occupational, and healthcare practice it was felt any negative impact would have been outweighed by people already being familiar with this process.

Conclusion

Participants conveyed a strong desire in seeking a corticosteroid injection whilst seemingly dismissing the risks, clearly driven by pain. A novel concept was illuminated as participants sought explanations for their shoulder pain and for some, frozen shoulder was inextricably

linked with the ageing process, which negatively impacted body-image. The impact on others is driven by a sense of the unfamiliar nature of some illness and it is incumbent on healthcare professionals to seek opportunities to explore the individual's beliefs.

Future research

Further research could explore the clinical, physiological and psychological outcomes of corticosteroid injections for frozen shoulder to inform shared decision making.

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