

“I just get on with it.”: A qualitative phenomenological study looking at the personal experience of chronic benign pain

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## ABSTRACT

### Objectives:

Chronic benign pain is a complex, distressing and prevalent problem in society. It is observed that pain impedes everyday activities (Andrew et al., 2013) and that it is a unique sensory and emotional experience (Bushnell, Čeko, and Low, 2013). Therefore, the objective of this study was to look at individuals' experiences of pain to help understand its complicated nature and their perception of the self.

### Design:

A qualitative phenomenology approach was used, with a small, profound sample of chronic pain sufferers.

### Methods:

Semi-structured interviews were conducted and diary entries collected from two women and one man, which were then transcribed for interpretative phenomenological analysis.

### Results:

Three major themes were found under the headings; the adversarial nature of pain, pain and the family role, and the physical entrapment of pain.

### Conclusions:

Participants found the journey of chronic pain distressing and mostly negative by accounts of what they had experienced. The participants found that social interaction could be both positive and negative. Support systems were positive in one regard, however it also showed individual what they lacked physically. Physically, pain trapped the participants, with pain depersonalised from the self.

KEY WORDS:	CHRONIC	PAIN	PHENOMENOLOGY	EXPERIENCE	HEALTH
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## Introduction

Chronic benign pain is a distressing, costly and prevalent problem in the general population (Leadley et al., 2012). DSM-IV criteria for chronic pain is defined as one or more sites that are in pain, which are not accounted for by mood, anxiety or a psychotic disorder, that lasts six months or longer (DSM-IV, 2006, as cited by Andrew et al., 2013). Andrew et al., (2013) found that 20% of people suffer from chronic pain, which impede daily activities, work and even quality of life. Supporting Andrew and colleagues, Pain UK report that 14 million people in the United Kingdom live with pain day to day, and suggest that more needs to be done to secure “general acceptance of pain as an issue in its own right” (Pain UK, 2002). Research into the epidemiology of chronic pain consistently criticises the way in which studies that collect data on prevalence rates collects its data (Reid et al., 2011; Raftery et al., 2011; Verhaak et al., 1998). Reid et al., (2011) suggest that prevalence estimates range from as low as 2% to as high as 50%. Verhaak et al., (1998) suggests that the methodology and definitions of chronic pain is varied across the literature, however, similar to Reid et al., they report that 2-40% of the population have at some point experienced chronic benign pain. The suggestion that pain effects such a large part of the population provides the most salient reason as to why more research needs to look at understanding the psychological phenomena that comes with chronic pain. Elliott et al., (1999) reported a prevalence rate of 62% in an older age group, in comparison to 31, 7% in a younger age group. This is an unsurprising finding due to the nature of age and illness; however, as the population is aging, we can only assume an ever-increasing number of people suffering with chronic pain. Other risk factors were also identified by Elliott et al., (1999) which included older age, housing tenure (living in rented council accommodation) and employment status (being retired or unable to work). Issues with this study include; the higher response rates from women and older people, which could explain the reported prevalence of older people with chronic pain, that being said other epidemiological studies have found age as a risk factor for chronic pain (Tunks, Crook and Weir, 2008; Sjøgren et al., 2009; Rustøen et al., 2004; Tsang et al., 2008a).

Smith et al., (2001) have described chronic pain as “multidimensional” in its aetiology and suggest that more research in the area of individual experience of chronic pain needs to be conducted to further our understanding of the impact of chronic pain in everyday life. Literature such as this, provides rationale for researching the individual experience of chronic pain, as it effects millions of people and understanding perceptions of pain can help professionals to develop systems of support and family members to appreciate and recognise when suffers need to access these support systems. Bushnell, Čeko, and Low (2013) who articulate, “Pain is a complex sensory and emotional experience that can vary widely between people depending on the context and meaning of the pain and the psychological state of the person”, reinforce this rationale. This shows that pain can affect individuals both physically and psychologically, therefore making it an important problem to comprehend and research, due to its complex and pervasive nature (Verhaak et al., 1998; Gatchel, 2004; Breivik et al., 2006). Smith and Osborn (2007) suggest that only a small number of studies look at the personal experiences of chronic pain, they highlighted that there is a great value in ‘exploring the subjective experiences of chronic benign pain beyond disease specific beliefs’. As the concept of pain is so varied between specific ailments, understanding the shared problematic psychological boundaries in those that suffer with chronic pain can only be important in working towards

managing and improving self-worth for those that have to cope with pain on a daily basis. Thus, investigating how pain is part of the self and daily activities can help the world of clinical health psychology to improve access to help for pain related distress for those that do not necessarily suffer from mental health issues, but suffer with distress due to the managing with pain for a long period. That being said, the co-morbidity of pain and depression is high, (Bair et al., 2003), so studying experiences that cause distress in those not in acute stages of depression and other mental illnesses can only contribute to helping professionals understand how pain effects an individuals' psychological state.

Andrasik, Turk and Flor (1999) explain the biopsychosocial model of pain. The model assumes that there is a complex interaction between psychological, social and biological factors in a person's response to pain. They theorise that there are behavioural aspects to pain and that habituation and associated learning can create pain responses, as well as cognitive aspects, which include attention, coping, expectations and memories. The model outlines a variety of reasons to how and why people do suffer from pain; however, it raises questions about how it influences sufferer's lives. Therefore, the model provides rationale for study in a more in-depth personal approach to experience of pain, which could help explain how people cope with their own pain, rather than generalise a model to all pain sufferers. The model is critical of how people experience pain and criticises the legitimacy of a person's pain by assuming that learnt processes and cognitive expectations are the reason for a person to experience it. This is an issue because pain is prevalent in the population, and taking the view that pain does not have a legitimate cause, could lead clinicians, families and health professionals to not respond sensitively to those that suffer with chronic pain. This issue provides further rationale to study personal experiences with pain, so that it can help healthcare professionals, clinicians and family members to understand pain that people experience and to be more empathetic in their approach to it.

To conclude, the literature in the area of experiencing chronic pain shows that pain is a common issue in the general population and the experience of chronic pain is something that is very complex, yet relatively understudied. The overall justification for conducting a study into the lived personal experience of chronic pain include giving clinicians, other healthcare professionals and those that live with people who suffer from chronic pain day to day a better understanding of what they have to experience. This study can have implications for further studying pain and help to modify interventions used to be more useful in helping patients to cope with the management of their pain and to support those that are new sufferers of chronic pain to adjust to managing it. By studying the area and learning about social issues of chronic pain, it could lead to further research into alleviating the stigmatism that has been found to occur in other studies. Werner, Isaksen and Maiterud (2004) who looked at women's shame stories, found that women have to attempt to cope with the scepticism and distrust relation to the credibility of their pain. Holloway et al (2007) found similar findings when studying time spent in pain clinics. Therefore, in an attempt to understand what people experience with chronic pain, it could aid other research like this, add to the understanding of pain, and give other studies reliability but replicating a similar study. The questions that this research intended to answer are as follows; how does pain affect an individual's perception of the self, how does physicality and psychology interact and how are emotions experienced in those with chronic pain?

## Methodology

The study design is a qualitative phenomenological study looking at the personal experiences of chronic benign pain, using a purposive sample of three participants with conditions such as Arthritis and Lupus, recruited through personal networks of the researcher. Data was gathered using semi-structured interviewing and diary entries, to gain detailed, idiographic data for Interpretative Phenomenological Analysis.

Using personal networks gave the researchers an advantage when studying the phenomena, as rapport between the interviewer and the participants was already built. This built a comfortable environment for the interviews to be conducted in, putting the participants at ease when discussing experiences of their conditions, which greatly influence their lives both physically and psychologically. Ethics was considered in great depth when proposing the sampling methods, it was acknowledged that the personal relationships that the interviewer has with the participants could potentially be distressing for the researcher, however, distress procedures and the use of supervision was thought to be appropriate for both the researcher and participants. The rapport and relationships were considered more of an advantage to the study's phenomenological nature than a hindrance in this sense. Ethics forms, invitations to participate, participant information sheets and debriefs were given to all of the participants involved as part of ethics procedures to which all the participants were made clearly aware of the right to withdraw and the right to not answer if they so wished, to which all participants consented to. Diary entry templates were given to the participants to complete for a period of seven days before interviews were conducted.

Six participants (n=6) were originally planned to be used for the study, a number chosen so that rich data could be gathered from the participants, as the phenomenological aspect of the study meant that personal experiences would be explained by each participant. However, three participants dropped out of the study due to personal reasons. This did not affect the study as it could have been conducted as a case study (n=1), as the methodology used is appropriate as 'it works in detail on an individual level' (Forrester et al 2010).

Semi-structured interviews were appropriate for the nature and aims of the study. They allowed for structure, and responses between participants to be more easily analysed (Landridge and Johnson 2009). It allows for flexibility in the response, so that the researcher can so with what has been mentioned rather than moving on to another question. It puts more attention on the answers of the individual and not the researcher, which is useful when studying personal experience (Landridge and Johnson 2009). Barriball and While (1994) suggest that using semi-structure interviewing is 'well suited' to explore issues that are sensitive to the participant, and allows for probing for more information and to clarify answers to completely understand the meaning.

Diaries allow for self-written thoughts that the participant feels are appropriate to note as a relevant lived experience in their own understanding of chronic pain. Wheeler and Reis (1991) explain that "self-recording is rich in detail permitting sophisticated analyses of variation across time and type of activity". They mention how researchers should not "interjudge reliability of the occurrence of an 'inner event'" which wholly provides justification of the diary method, as we are looking at

how the participant experiences pain and it does not require the reliability of an observer to validate how the participant feels.

Each interview was audio recorded for transcription by the research for the analysis process which permitted “further access to the nuances” and “helps validate accuracy” of information collected for analysis (Barriball and While, 1994). Data storage and protection issues were raised due to the interviews being audio recorded, and diary entries being kept by the researcher for analysis. However, audiotaping provided data for continued scrutiny when being analysed. To keep the participants’ identity anonymous, pseudonyms were used in the transcription process when names are mentioned, and in the write up of the research journal. Raw data collected, such as the audio file was stored on an encrypted drive, and hard copies of the diary entries were kept in a locked draw, until it was transcribed. All of the information shared is anonymous.

The study was not designed to create harm in any way; however, sensitive issues about mental health could have arose because of the high comorbidity of depression and chronic pain (Fishbain et al, 1998; Arnow et al, 2006, Tsang et al, 2008; Miller and Cano, 2009). As part of the consent forms, this was mentioned, and participants within an acute period of a mental illness were discounted from the study. A distress protocol was used when participants become upset about their experiences and the right to withdraw made aware of at this point, and participants were directed to mental health services and their GP if they needed support on any of the issues raised.

The analytical technique is interpretative phenomenological analysis (IPA). This allows researchers to understand the ‘conscious experience from the viewpoint of the person having the experience.’ (Howitt 2013). When conducting IPA, researchers attempt to make sense of personal experience at a particular point in the participants’ life, history, social, cultural, political, and economic contexts (Forrester et al 2014). This is appropriate as it makes the analysis process dynamic it gives the researcher a deep understanding of what the participant is experiencing and the impact that pain has on each of the participants’ lives. By looking at the participant individually in their own context, it allows for individual differences in the participants’ experience and does not exclude social, political, cultural and economic reasons for why people may experience pain and the effects of this differently. The idiographic nature of the method means that it is focused on the data at an individual level, rather than a collective.

The steps that were taken to conduct the analysis were based on, Smith, Flowers and Osborn (1997). Firstly, the researcher looked for themes in the first case. The transcript was read multiple times, in order to become familiar with the account. Notes of insights were made in the left hand margin. Themes were then noted in the right-hand margins. Secondly, the researcher connected the different themes found when analysing the first case, and clustered them together as ‘superordinate concepts’, a table of themes was then constructed. Thirdly, the analysis was continued with the rest of the cases, using the themes from the first case to orientate the analysis process. Finally, the analysis was written up into a narrative account and the themes expanded. The justification for using IPA is that it allows for ‘idiographic inquiry’ (Smith and Osborn 2015). It allows personal experience to be explained by the participant in his or her own terms and use biographical accounts to

make the researcher understand and empathise with the participant's life and issues that they experience.

## Analysis and Discussion

### *The adversarial nature of pain*

Susan's interview was by far the most poignant that was conducted. The way in which Susan poured out her emotions when answering the questions gave insight into how much that pain affects people both physically and psychologically, therefore this case was the starting point for the analysis process. The most salient theme throughout was emotions that were experienced in the journey of chronic pain. We start with Susan's account about how pain affects her psychologically due to her physical ailments. The following extract shows how anger and frustration builds in Susan as she explains the journey of her illness, age and ability to do everyday activities.

*'It's that what makes me angry. It's stopped me doing what I want to do. I get frustrated. Angry. The fact that it's my own body that is doing it, that is what gets to me, you're actually, you know, your own body is failing you and you're not able to do the things you once did. Erm, and obviously as I've got older and it's all got worse, the arthritis has got worse, and also [pause] this with my chest, I just can't do the things I wanna do, and I know I'm getting older but I still wanna to be able to do the things I should be doing at my age, if I was alright. And I can't do those things, and its stopped me. The pain.'*

There are many indicators in Susan's account which shows the anger and frustration felt as she was explaining how pain has taken away her agency. The way that she uses truncated sentences and takes pauses, draws attention to each point that she makes and shows the frustration present. Every pause created a lasting impression of what she was explaining and showed how emotionally distressing the experience is for Susan, she is battling with her emotions by getting frustrated in her lack of physical abilities. She becomes more emotional as the answer goes on, as though looking back on the time that she has dealt with the pain makes her increasingly frustrated. The end of the section is poetic, the statement 'the pain' leaves a lasting impression of the contemplation of how the pain affects her. When she then asked to move on, it showed that she was struggling to come to terms with how the pain made her feel outwardly. She does this in her diary entry.

*'I don't want to think about it today. Knee hurt like mad.'*

This sentence reveals the adversarial relationship that Susan has with chronic pain. It seems to show a dichotomy between acknowledging the pain as being within her, and not being present at all. By not paying attention to it, it shows a coping mechanism that Susan uses to make the pain less prominent, however, the mention of the pain in her knee, shows the intrusive nature of arthritis, as though she had to mention it because it was constantly being brought attention to in her mind. Susan consistently depersonalises the pain that she feels throughout her accounts, using 'it' and 'they' in relation to her aches and pains. She does not refer to pain that she encounters as belonging to her, instead she uses 'the' when referring pain.

The bipolarity of emotions in chronic pain is evident in Paul's interview.

*'I'm still lovely [laughs, long pause]. It affects me a lot really.'*

He first tries to cope with the distress that he feels by the nature of his illness by making a joke. The long pause he takes after this resonates, as it showed distress from the memories of his pain, from which he nearly died. We took a break from the interview because distress of the memories was so painful for Paul. After some recovery, we let Paul tell his story through a narrative account rather than asking him questions here because it was obvious that he felt uncomfortable about his feelings. When telling the story of his illness it gave him small relief as he looked back on this experience and told us his account light-heartedly.

Osborn and Smith (2006) explain the notion of 'living in a body separate from the self', whereby the body without pain was not noticeable to participants compared to what it is with pain, where it is "consciously excluded from the self". This is seen in the study in the participant's depersonalisation of pain. They suggest that pain gives the individual a steadily increasing negative view of the self, which is seen in the emotions displayed in Susan and Paul's narrative. In the first quotation, when Susan mentions that her 'own body is failing' her, she doesn't separate the pain from the self, but rather questions why her own body is punishing her with pain. This is also shown in Paul's diary account when he questions 'What's happening to me?' and explains that he is 'fed up and feeling depressed'. Here he longs for an answer, as he is unable to explain why he is dealing with his pain and therefore it causes psychological pain. Smith and Osborn (2015) comments on how participants are consistently "searching for an answer" in their experiences with chronic pain. By searching for the answer to what is happening, uncertainty is related to the distress that Paul feels (Härkäpää et al., 1996; Radley, 1994; cited by Smith and Osborn, 2015). Here, in relation to Toye et al., (2013) model of moving forward with pain, this finding doesn't fit in with how they suggest an individual can "redefine normal" or "integrate the body in pain" to manage the pain that they're in. The uncertainty suggested by Susan and Paul's accounts, questioning the pain that they are in, shows that these individuals cannot fit within the model, as they have not accepted the 'self with pain' or even integrated pain within the body. This insinuates that by putting individuals with pain into a bio-medical model of moving forward, cannot fit to everyone in the chronic pain category. Findings from Smith and Osborn (2015), which similarly find that individuals seek answers for why they endure suffering, which further alludes to this point. Following this, it shows an advantage of treating pain patients idiosyncratically, as imposing such models could hinder the sufferer's ability to cope with pain in the way that they need to. This has implications for treatment, as formulating what each patient needs could be timely and costly, however by treating patients as individuals, practitioners could provide more sensitive and effective care.

### Pain and the family role

Sociality is an important part of chronic pain, as it makes sufferers feel a range of emotions and can either help or hinder the individuals' ability to cope. Molly's explanation of how pain affects her shows that sociality is very important. She suggests that her family is a source of hope for the future which allows her to carry on through tough times.

*'I'm an older mother, so I've still got a young family... I've got to remain active for my younger children, well, all of them really, so that I can do things with them.'*



Molly talks about her family as a reason to carry on and help herself with the pain she has. The suggestion that she 'has to remain active' for her children spurs her on to cope with the aches and pains. The mantra of 'just getting on with it' is shown by her need to keep up with her children. As Molly is the youngest of the participants, the hope and support that she has is probably relevant to her early diagnosis, compared to both Susan and Paul, she has something to look forward to, and hasn't got the experience of the length of pain that the other two participants' have. Molly refers to her children again diary.

*'My mood is low again and had to get the kids to rub my arms and shoulders to try and help me feel better'*

She uses her children's support to help her feel better physically to alleviate numbness felt by the ache, however, it is pertinent to suggest that the tactility used by her children helps make her feel better emotionally, as the support element is felt physically. The emotional and physical support that Molly's children bring, show the importance of the family role within chronic pain. It allows Molly not to feel isolated, and the understanding of her children help her feel less distressed about what she is experiencing. Ojeda et al., (2014) suggest that chronic pain has a strong impact on the family, and that incorporating the family into therapeutic response can enhance quality of life for both the sufferer and their family. The importance of Molly's children suggest the strong impact of the family, and the relief that she feels from her children would agree with the statement that Ojeda et al., (2014) make.

However, something that comes to attention in Molly's narrative is the contrasting nature of how she describes her own position as a person in pain isolated from others.

*'I mean that person gets on with it, rides through the pain, does what they want to, but that's not enough, I can see what they have done is not enough for themselves, so the only person that can get through this is me.'*

She recognises that she is alone in the journey after learning from other family members experience with chronic pain. This suggests the relevance of sociality in the learning of how to cope with pain as a concept – something that cannot be felt or seen by others. This relates to the idea of 'I just get on with it' as a mantra that is repeated throughout the data. This sentence is repeated throughout the diary entries and interviews with all three of the participants, which shows an aspect of shared experience that the participants have had with chronic pain. By repeating this, it seems that the participants are using it as a coping mechanism for dealing with pain; it brings their attention from the pain to the activities that are effected and is motivation for pushing through the barrier that pain has on the life they lead. Öhman, Söderberg and Lundman (2003) propose that feelings of hope are a way of enduring pain and 'just getting on with it'. In this way, the participants show a hopefulness that they can endure through the pain that they are in, however hopelessness is displayed by the participants' accounts of distress throughout the interviews and in Molly's statement 'I can see what they have done is not enough' when relating how she sees pain in comparison to her family members. Öhman, Söderberg and Lundman (2003) explain this by suggesting that people in pain are 'hovering between enduring (hopeful) and suffering (hopelessness)', as hopelessness is a response to something that has changed the anticipated future.

In contrast to Molly, Paul's family seems to make him realise how pain prohibits him from doing day-to-day activities.

*'What upset me a lot was seeing our Phil doing jobs for me outside and I couldn't do them myself. He was someone I grew up with, my brother, I used to do things for him and we did a lot together. Worked together, messed about together. My life has changed.'*

In this example, Paul compares himself to his brother, which causes a certain amount of distress for him as he used to spend time and do things for his younger brother. He finds it hard to expect that he can no longer do the things he did as a person without pain, and seems to feel that he is a burden on those around him, compared to that of his past self. Here, by questioning his own ability, it suggests that Paul feels a loss of independence and control over his daily activity. He has lost his pain free existence and feels isolated from his 'normal self'. Öhman, Söderberg and Lundman (2003) comment on this phenomena, suggesting that a need for help from others infers dependence and this 'brings with it feelings that life has lost its value', naturally causing distress, due to 'inherent human nature to provide for most primary needs and desires'. This is shown in Paul's upset seeing his brother doing things for him, and his loss of autonomy. He realises that his life has changed, and that his family's presence in his everyday activity shows Paul what his illness has forced him to lose, therefore he is not suffering with physical pain alone, but also emotional pain. This has implications for treatment, as the psychological impact of chronic pain needs to be addressed when patients start treatment for their pain. Support in this area could help patients like Paul come to terms with loss. Franklin, Smith and Fowler (2016) highlight that better communication and frequent access to care services may lead to efficient management of the psychological impact of pain.

### The physical entrapment of pain

There is a certain complexity in the nature of physicality of chronic pain and this is shown by all three of the participants account of how pain limits the individuals' ability to live the life of 'the normal self', opposed to 'the self in pain'. Susan's account of her arthritis introduces us to the idea that pain physically traps her in terms of what she can and cannot do.

*'When you have arthritis you learn to cope with the pain each day, each year you have to get on with your life as it becomes part of you.'*

She looks at pain as a separate entity, which eventually becomes part of her 'self', almost trapping her by making itself part of Susan's own identity, which she cannot escape. Again, this shows the mantra of 'just getting on with it', and in this example, in particular you get a sense of Susan's intolerance to the pain that she is experiencing as she explores the timeline of her arthritis. The idea that pain is a separate entity to the 'normal self' is also shown in Kirkham, Smith and Franklin, (2015). Participants in the study show pain objectified, much like Susan does here. They describe pain as 'punitive and sinister' which is portrayed in images painted by participants in the study. The representations shown in the study by Kirkham, Smith and Franklin (2015) show an expression of pain unlike any other, which we could not grasp in this study and this method of gaining data is insightful and one which we would be encouraged to use in the future. However, through the diary entries

collected in our study, it allowed the participants to describe their own sense of pain without a researcher being present. This is a particular advantage of our study as the influence of the pain could be described in writing, without the need for a researcher's immediate validation.

The way in which Molly treats her illness also suggests that she is trapped by the condition, which she suffers with.

*'It has made me very aware of my age, which is strange at 46, but I know I've only got a certain amount of time left to get myself into a better position in because of getting older with the condition.'*

Quite like Susan, Molly brings attention to the temporality of her condition. In one sense, this could be interpreted that Molly accepts that pain is a part of her 'self', the way that she speaks about 'getting in a better position' suggests that she has control over her future. On the other hand, she insinuates that time is running out and that the physical pain can trap her and leave her helpless if she does not battle against it. This shows the adversarial relationship between pain and the 'self without pain' that was fore mentioned in Susan's dichotomous statement in her diary entry. Nanton et al., (2015) make reference to time and uncertainty in illness, which is pertinent to Molly and Susan's experiences. They suggest that changes in position and decision making about illness can result in loss of control and uncertainty about the future, which is evident in Molly's sudden awareness of her age, she realises that she needs to change her position and make decisions to improve her quality of life, however, this leaves uncertainty for the future as she realises that she will progressively endure more pain. Here as Nanton et al., (2015) suggest, acknowledging the capacity for individuals to recognise that they need to negotiate their lives in pain, to maintain their sense of self should be encouraged by health care professionals to help individuals develop a sense of certainty for the future.

In Paul's diary, he displays hopelessness that he does not engage in physical activity, again suggesting that he is trapped by the pain that he is in.

*'Rested today, couldn't be bothered.'*

By resting, it allows Paul to ruminate about what he is experiencing, which is suggested by the statement 'bad day' in contrast to his pain rating that day which was '4', this suggests that he underrated his pain, considering the comments that were made about having to rest and it not being a good day. This behaviour could be explained by fear avoidance as mentioned by Turk and Okifuji (2002), as resting, could be an effort to avoid causing anymore pain than he is already experiencing. The entrapment felt by Paul is also implied by the way, in which he describes the barriers that pain has caused him.

The idea of entrapment is evoked by Paul's anxiety about back pain alluding to potential death.

*'I remember getting to hospital, that's all I remember. And yet they were not gonna take me in... thought it was 'back pain'. It all started from back pain... it's all gone full circle though, I'm worried now... because the pains starting up. I'm worried about myself.'*

Paul's narrative account of his near-death experience, coupled with his fear of facing this for the second time, shows how pain can be intrusive in both mind and body.

Paul is trapped with the memories of the feeling of nearly dying, which drives his anxiety around his pain, and therefore he cannot leave the cycle of feeling of pain, not just physically, but also mentally. Paul's anecdotes about his experience of nearly dying suggest that he tries to come to terms with the situation, which allows himself some sort of escapism from what he feels. Paul's apparent fear of what is to come when feeling back pain could also relate to the findings made by Crombez et al., (1999). They found that in some cases, fear of pain was in some ways more disabling than the pain itself. This is apparent to some extent in Paul's account, as the fear of going into hospital leaves him distressed and reinforces his anxious thoughts about pain, therefore creating the cycle previously mentioned.

### Concluding remarks

In this study, the adversarial relationship between 'the self' and 'the self in pain' was important in the experience of chronic pain. This relationship was shown to have an impact psychologically, in the family and physically. The participants' depersonalisation of pain was important in coping with the distress felt, however, what was more salient was the 'just getting on with it' approach to pain that each participant used to endure the physical pain and loss experienced. The accounts showed the importance of looking forward to live life tolerating pain, so that life can be experienced in spite of pain and the implication having support with the diagnosis of chronicity.

### Reflexive Analysis

As researchers we can only plan what we think would be the most appropriate methods to use in qualitative analysis. Due to human nature, we cannot second-guess how individuals may react when speaking of their own experiences. Ethical considerations were carefully considered going into this study and for the most part what we planned for worked, however we could not plan for the unexpected. During the interviews two of the participants Paul and Susan, show distress about their experiences. For Paul, the questions asked brought back painful memories, which he did not expect. For Susan, she was nervous about telling us about the pain that she endured from the start of the interview, she revealed that she had never spoken about how the chronic pain that she suffers with affected her psychologically, and she soon got emotional when coming to terms with the acknowledgment of how the pain made her feel and behave. We saw that through Paul's interview that the semi-structured interview had to be stopped and continue unstructured, which worked for Paul as he had the opportunity to talk about what he wanted on his own terms. In this respect, using narrative analysis may have worked well, as each participant could tell their journey of pain. Considering these issues, using narrative analysis may have been better suited, as narrating lets people make sense of their experiences and seek explanations for events whilst telling them (Holloway and Wheeler, 2009) and in this way it may not have been as emotionally distressing for the participants.

From the point of view as a researcher, I learnt a lot from conducting this research. The turmoil of each participant was very distressing and through their account, they showed emotions that I did not realise would make as much impact on me as they did. However, this made me more aware of how a participant's account can affect a researcher and allowed me to consider my own experience as an important part of the data collection and analysis processes. In hindsight, using personal networks to

recruit participants was risky. Seeing suffering first hand was always going to be problematic from an ethics point of view, therefore seeing this extent of suffering in loved ones was going to be more challenging from the start. Rager (2005) suggests that “compassion stress” is an issue that qualitative researchers experience during data collection, which I whole-heartedly agree is an issue when interviewing about sensitive topics, such as chronic pain, and I realise that I was exposed to this during the research. Saying that, I would not change the participants that I recruited for the study, as I still believe that having already established rapport was important for the individuals telling me their story. It allowed me to comfort the participants easier because I knew them personally, and I did not feel uneasy approaching them in this way. It allowed me to expand my knowledge of chronic pain and establish empathy that was useful for me both as a researcher and as family member of those that suffer with these issues. Dickson-swift et al., (2008) commented on the risk to researchers when confronting emotional risks during research, they suggest that researchers need to consider training, preparation and supervision to minimise risk to the researcher. We followed this advice with regular supervision and preparation before the interviews, which I believe worked effectively to reduce the distress for me when looking back at what each participant had experienced.

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