

THE UNIVERSITY OF HULL

The Effect of Pain Site on the Experience of Pain

A research portfolio submitted in partial fulfilment of the requirements for the degree of

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By

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Overview

This portfolio is made up of three parts. Part one is a systematic literature review in which the theoretical, conceptual and empirical literature relating to male and female experiences of chronic pain is reviewed. Part two is an empirical paper which uses IPA methodology to explore the influence of pain site on the female experience of chronic pain. Part three comprises the appendices.

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Part One

The Male and Female Experience of Pain: A Systematic Literature Review of Gender

Gender and the Experience of Chronic Pain

REVIEW ARTICLE

**A SYSTEMATIC LITERATURE REVIEW OF GENDER AND THE EXPERIENCE OF
CHRONIC PAIN.**

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This paper is written in the format ready for submission to Psychology and Health.

Please see Appendix 3 for the Guidelines for Authors.

Abstract

A systematic literature review was undertaken to explore gender issues in the experience of chronic pain. Specific inclusion and exclusion criteria were applied to retrieve relevant papers. Electronic databases were searched and references scanned for further relevant publications. Twelve studies were identified that met inclusion and exclusion criteria. These studies were assessed for quality; overall quality being moderate specifically with regards to reliability. Men and women shared many common experiences of living with chronic pain. There were, however, some experiences that were only described in one gender. This was especially the case for women with chronic gynaecological pain. There was little literature on the male experience of chronic pain; therefore, it was difficult to establish the full male experience.

Findings of this literature review, suggest further research needs to be conducted on the male experience of chronic pain and the also, effect of pain site on the experience of chronic pain.

Keywords: Chronic pain, Gender, Experiences of pain

Chronic pain is a phenomenon that although widely studied is not fully understood. It has been shown to cause distress and to “impact on daily life, well being and work” (Phillips, Main, Buck, Aylward, Wynne - Jones, & Farr, 2008, p. 167). Chronic pain is a major concern as it impacts on productivity of labour markets and is one of the main reasons that people stop working prematurely with major consequences to employers and also to benefit agencies (Phillips, Main, Buck, Aylward, Wynne - Jones, & Farr, 2008).

In 1999, Walker, Holloway and Sofaer reported that they had found there was little qualitative research exploring the lived experiences of chronic pain. It was also reported, by Neville – Jan in 2003 and Keponen & Kielhofner in 2006, that they had found the literature on chronic pain was dominated by biomedical and rehabilitation research. Since Grace (2003) proposed that pain is an experience that can only truly be understood by addressing the psychological, mental, emotional, behavioural and social factors involved as well as medical and physical aspects, it can be inferred that additional qualitative research exploring the lived experience of chronic pain is required to fully understand the development, management and potentially treatment of chronic pain.

Studies have shown that many different factors affect the effects and perceptions of chronic pain (Turk & Monarch, 2001). Gender differences in pain perception and management have been widely researched (Dao & LeReche, 2000; Edwards, Haythornthwaite, Sullivan, & Fillingham, 2004; Raak & Wahren, 2001). From a physical perspective, studies looking at gender differences in fibromyalgia have shown men to have fewer symptoms, tender spots and report less pain and fatigue than women (Yunus, Inanici, Aldag, & Mangold, 2000). Further studies have found gender to directly affect the experience of pain. Cepeda and Carr (2003) found that after an operation, women reported higher intensities of pain than men. Unruh (1996) also found women to report higher intensities, frequencies and endurance of pain. This gender difference could be due to a number of factors including hormonal differences (Cepeda & Carr, 2003) or the socialization of women and their greater willingness to discuss their distress which in turn influences the body experience (Barskey, Peekna, & Borus, 2001).

Raak & Wahren (2001), however, suggested that further research was required on the different ways men and women experience living with chronic pain from other perspectives than medically and physiologically. There appears to be a clear need to determine what the evidence, since this report and Walker, Holloway, & Sofaer's (1999) report, suggests about the influence of gender on the male and female experiences of pain. This systematic literature review aims to start this process.

Why is it thought there may be a difference in the way men and women experience pain? Haug (1992) highlighted the difference required in behaviour between men and women in order to be accepted as moral beings. Haug's study suggested that behaviour is interpreted differently depending on the gender of the person who is doing it, due to societal gender roles (Haug, 1992). In the Western society, gender roles specify that "...stereotypically, men are aggressive, competitive and instrumentally oriented while women are passive, cooperative and expressive." (Stets & Burke, 2000, p. 999). Ashmore, Arthur, & Del Boca (1986) described the stereotypical manner of men to be dominant, competitive, and autonomous whereas that of women to be expressive, warm, and submissive. Haug's study (1992), reported that men and women have different central elements, men's being property and women's being their relation to their body. It is, however, widely accepted that definitions of femininity and masculinity are rooted in social rather than biological understandings (Stets & Burke, 2000). Fibromyalgia¹, Chronic Fatigue and other medically unexplained disorders, however, have been associated more with women (Anderberg, 1999). Paulson, Danielson, & Norberg (1999) found that not only did this reduce the likelihood of men presenting to services with similar symptomology but also negatively influenced the prevalence of diagnoses given by doctors.

It is important to review the relationship between gender and chronic pain as there is the possibility that men and women will present to services, be diagnosed and respond to interventions in different ways (Paulson, Danielson, & Norberg, 1999). It could also be hypothesised that men and women are likely to have different beliefs about and attribute different meanings to their pain; hence, their lives are likely to be affected by pain in different ways.

¹ A chronic condition that causes pain all over the body affecting muscles, tendons and ligaments.

Bendelow (2000) postulated that social divisions of gender and the experience of pain are linked. If this is true, this link would be evident from discourses and beliefs men and women have about chronic pain and how these beliefs correlate with their expressions and experiences of it. This illustrates the importance of studies that analyse the discourses and beliefs of the participants, when investigating the lived experience of men and women living with chronic pain, in order to determine a link between gender and the experience of pain.

Objectives

To explore and assimilate findings from current literature on how men and women experience chronic pain. Additionally, quality of current research was assessed to help guide formulation and understanding of this complex area.

For the purpose of this review, any factors relating to mental activity, for example, emotions, motivation, attitudes, beliefs and cognitions were classified as “Psychological Factors”.

Method

Identification of studies

The following databases; PsychInfo, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Medline, AMED (Allied and Complementary Medicine), BNI (British Nursing Index) and ASSIA (Applied Social Sciences Index and Abstracts) were searched using the following search terms; “Chronic Pain” AND (Gender OR Sexes) AND (Experience OR Coping OR “living with” OR issues OR “factors affecting” OR differenc*). These databases were selected for review as they cover a wide range of disciplines that are likely to archive research on chronic pain.

The full body of text for all articles in each database were searched to capture the breadth of research on gender and chronic pain.

Limits were then put on each database search as an initial filter in accordance with inclusion/exclusion criteria (Fig.1). These limits were: search terms in title or abstract for relevance, human subjects only, adult participants aged 18 and over (previous research has indicated that there is a difference in how adults and children experience pain; (Elliott, Smith, Penny, Smith, & Chambers,

1999; Parsons, et al., 2007), written in English (translation of qualitative data may be misleading), and published between 1999 and 2009 (to establish the research carried out following Walker, Holloway, & Sofaer's (1999) report that little qualitative research has been carried out exploring the experience of chronic pain up to 1999 and Raak and Wahren's (2001) claim that further research was required on the ways men and women experience pain).

Selection of studies

Inclusion and exclusion criteria (Appendix 4) were developed following a scoping search carried out before the commencement of the systematic literature review process. The scoping search tested the search strategy and the search terms. Selections of abstracts from identified studies were read and this helped to illustrate important areas to consider in development of inclusion and exclusion criteria.

To be included in the review, articles had to meet all inclusion criteria, none of the exclusion criteria (Appendix 4) and achieve a quality rating of ++ or +. The procedure for the selection of studies is shown in Appendix 5. Twelve studies were ultimately selected and included in the review. Details of these studies are presented in Table 1.1 and extended details are in Table 3.1 (Appendix 6).

Quality assessment

All included studies were assessed for quality using the National Institute for Health and Clinical Excellence methodological checklists and guidance for qualitative studies (NICE, 2006) which awarded each study a rating of ++ (all or most of the criteria having been fulfilled), + (Some of the criteria having been fulfilled) or – (few or no criteria having been fulfilled). (For further details of the National Institute for Health Clinical Excellence methodological checklists and guidance for qualitative studies see Appendix 7.) The quality assessment was carried out to inform judgements on how far inferences could be made from studies. If there was insufficient detail to carry out a quality assessment or data extraction, the study was excluded. The quality assessment of included studies is presented in Tables 3.2, Appendix 8. No studies were omitted due to lack of details from which to assess quality. The highest quality studies achieved ratings of ++. Two studies received a quality

rating of + and no studies were allocated a rating of -. The most common limitations were the lack of triangulation, the use of only one method of data collection, although this was appropriate in some cases, and the lack of clarity about researcher roles and the number of researchers involved in the analysis. Studies had high validity.

Analysis Methodology

Results from reviewed studies are summarised in Table 3.1 (Appendix 6) and the themes produced using thematic synthesis are discussed below. Thematic synthesis was used because it has been described by Boyatzis (1998) as a process which is able to draw conclusions from heterogeneous studies with different methodologies and research questions and also, a process that can be used with most qualitative methodologies rather than another qualitative method in itself (Lucas, Baird, Arai, Law, & Roberts, 2007). Thematic synthesis is also reported to make the findings more accessible for the reader, however, it is important to note that the grouping of information is for the ease of reading and does not imply a comparison of information. It has, however, been noted that collating findings using thematic synthesis heightens the risk of limitations of individual studies being masked also, the synthesis process could possibly obscure individual study characteristics and qualities in the final conclusions (Lucas, Baird, Arai, Law, & Roberts, 2007). With this in mind, full study descriptions and quality appraisal details have been included (Appendix 6 and 8). In this review, information has been collated around the shared experiences of the men and women in the reviewed studies, the experiences that were exclusive to the men in the studies and the experiences that were exclusive to the women in the studies.

Themes derived focus on the participants in these studies not the general population.

The analysis of the review papers was based on the procedure as laid out by Lucas, Baird, Arai, Law, & Roberts (2007) and was as follows:

Step 1: Data collated under question derived from study aims.

Step 2: Themes produced and consolidated.

Step 3: Clustering of themes under each review question around common dimensions.

Results

Initial reaction

It is important to note that the results of the studies are not generalisable and therefore, any conclusions drawn can be attributed to the men and women who participated in the studies only. Themes produced, however, have transferability and therefore, can be applied to similar situations to aid understanding.

In these studies, both men and women reported struggling to live with chronic pain. Some experiences of chronic pain were exclusive to either men or women, and others were shared by both men and women but occurred for different reasons or in different manifestations. Both men and women in these studies struggled with living with the “invisibility” of their chronic pain and finding it difficult to explain their pain to others. There was a sense of needing to cope and live as independently as possible in order to maintain self esteem and feel valued.

Studies investigating the experiences of women with chronic pain reported a belief that being in pain was “part of being a woman” and gynaecological pain in particular was not easily distinguished from menstrual pain or the expected consequences of childbirth. The studies investigating the experiences of men with chronic pain reported they found the challenges to their ability to work difficult. The study comparing men and women living with chronic pain reported that men had a comparably more simple and structured view of their pain than women (Raak & Wahren, 2006).

Common experiences

General impact

Men and women alike found that the presence of the pain prevented them from doing the things that they wanted to do such as; physical training, education, looking after children, reading and progressing up the corporate ladder (Huntington & Gilmour, 2005; Paulson, Danielson, Larsson, & Norberg, 2001; Raheim & Haland, 2006; Soderberg, Lundman, & Norberg, 1999; Soderberg & Lundman, 2001; Werner, Isaksen, & Malterud, 2004). Huntington & Gilmour (2005) found that some

of the women in their study were restricted in the types of jobs they could get because they required part time flexible hours and their employers needed to be able to accommodate prolonged periods of sickness. This was similar to the men in Paulson, Danielson, & Soderberg's (2002) study who reported difficulties finding or sustaining work making them feel guilty for being unable to provide for their families.

For both men and women, relationships suffered due to stress (Huntington & Gilmour, 2005), participants attributed this to partners not being able to fully understanding the nature of the pain and sufferers unable to articulate it clearly (Paulson, Danielson, Larsson, & Norberg, 2001; Paulson, Danielson, & Soderberg, 2002). Life was described as a "heavy burden" when living with pain regardless of gender. It was a constant struggle to simply manage daily life with rituals having to be put in place just to get out of bed, resulting in loneliness and over dependence on others (Paulson, Danielson, & Soderberg, 2002; Soderberg, Lundman, & Norberg, 1999).

Men and women struggled with the invisibility of their condition. Their friends and family could not see that there was anything wrong and would comment that they looked fine leaving the men and women suffering with the pain wondering what people really thought about them and worrying that they were being perceived as lazy (Hallberg & Carlsson, 2000; Paulson, Danielson, Larsson, & Norberg, 2001; Raheim & Haland, 2006; Soderberg, Lundman, & Norberg, 1999; Soderberg & Lundman, 2001).

Psychological involvement

The majority of men and women who participated in these studies did not appreciate the concept that the pain they were experiencing may have a psychological component and/or origin (Grace & MacBride-Stewart, 2007; Hallberg & Carlsson, 2000; Paulson, Danielson, Larsson, & Norberg, 2001). Although a majority were able to acknowledge that when they were under psychological stress their pain increased, this did not impact on their opinions of the origins of their pain (Hallberg & Carlsson, 2000). Perceived causes or origins of chronic pain are discussed later.

Denial

Women struggled with accepting that they had fibromyalgia (Soderberg, Lundman, & Norberg, 1999) and men struggled even more rejecting the idea of having what has been described as a woman's disorder (Paulson, Danielson, & Norberg, 1999; Paulson, Danielson, & Soderberg, 2002) Gullacksen & Lidbeck (2004) found initially that there was little or no change in the participant's lives or in their plans for the future. Gullacksen & Lidbeck, (2004) attributed this to the belief that the pain was temporary and would eventually disappear. The perceived temporary nature of the pain encouraged participants to take extended sick leave rather than leave their job and it also permitted participants to accept help or support from others (Gullacksen & Lidbeck, 2004).

During the first stage in the life adjustment process in chronic pain (Gullacksen & Lidbeck, 2004) women reported a desperation to use denial as a solution to their pain. They would return to work regardless of improvement, avoid taking sick leave and explain the symptoms away to anyone who they were unable to hide them from. It was proposed that denial was necessary to maintain a social life and the hope that life in general may return to the way it used to be.

Powerlessness

Raheim & Haland (2006) found that the women in their study carried with them a sense of powerlessness and belief they were unable to do anything to change their situation. Previous feelings of control became feelings of powerlessness and exhaustion. This was in line with the women in Keponen & Kielhofner's (2006) study who used the metaphor of "standing still" in their narrative and who expressed their feelings of powerlessness by describing feeling like victims, blaming others or wanting to be rescued by others. They were socially isolated and withdrawn, generally had stopped any occupational activity and provided conditions, such as the pain subsiding, before they would consider participating in any activities.

Hallberg & Carlsson (2000) also encountered a sense of powerlessness in the women who participated in their study, who reported a sense that chronic pain had taken over their lives and who were, "preoccupied with the pain" (Hallberg & Carlsson, 2000, p. 31).

This was in agreement with Soderberg & Lundman who found that the women in their study experienced, "fibromyalgia as the choreographer of activity and relationships." (Soderberg & Lundman, 2001, p. 626). The women in Soderberg, Lundman, & Norberg's study (1999) whose narratives stated that, "living with fibromyalgia means having a life greatly influenced by illness." (Soderberg, Lundman, & Norberg, 1999) expressed a sense of powerlessness when they described having no inclination of what their health status would be from day to day and having to live for each day with their pain as their guide with no plans for the future (Keponen & Kielhofner, 2006; Soderberg, Lundman, & Norberg, 1999; Soderberg & Lundman, 2001). Men also reported an impossibility in trying to make plans and thus having to resort to living one day sometimes even one minute at a time (Paulson, Danielson, & Soderberg, 2002).

According to Hallberg & Carlsson (2000); Paulson, Danielson, & Soderberg, (2002) and Soderberg & Lundman, (2001), chronic pain also controlled when men and women felt they were able to see their friends. When the pain was severely intense, men and women both reported avoiding taking telephone calls and not answering the telephone to prevent having to explain that they were unable to attend a social gathering. Similarly both men and women in Raak & Wahren's (2006) study reported being controlled by the pain at work and expressed the need for freedom and to be in control of their workload to help them to better manage their symptoms and regain some control over their lives.

Coping

One role that was generally rejected by both men and women, was the sick role. Leaning on the aid or support of other people often led to feelings of guilt and fear of being perceived as a burden.

Women who did not want their families and friends to know about the level of their pain worked to hold it within themselves and suppress any pain behaviours such as wincing. The feeling of

having to cope was not exclusive to women, men reported feeling this as well. They did not want to ask for help and would continue doing what needed to be done regardless of the pain they were experiencing (Paulson, Danielson, Larsson, & Norberg, 2001; Paulson, Danielson, & Soderberg, 2002). Men described wanting to be alone when the pain was very bad because it helped to distance them from the pain (Paulson, Danielson, & Soderberg, 2002). Men were found to be unwilling to speak about feeling weak and fatigued. They preferred to soldier on and try and live as “normal” a life as possible. There was a clear resistance to becoming isolated or dependant on others, however, because of the continuous pain, these men became easily irritated (Paulson, Danielson, & Soderberg, 2002).

Changed sense of self

The women in Werner, Isaksen, & Malterud’s study (2004) described themselves before the onset of the pain and after . They described themselves as “strong then” and “weak now”. Men also described themselves as no longer being “the man they were before”. There was the sense that because they could no longer do things they used to be able to they were not a whole person (Paulson, Danielson, & Soderberg, 2002). However, a time came when these men were able to accept the new self and understand that all demands cannot be met all the time (Paulson, Danielson, & Soderberg, 2002).

Women spoke of missing the life they had before they became ill. They missed their social life, being able to plan ahead, having energy to interact with their children, being spontaneous and being able to concentrate and not forget details – all aspects of their lives they felt had been taken away by chronic pain (Soderberg, Lundman, & Norberg, 1999). Despite this, women were expected not only to cope with the pain but also to maintain their role at home and were left with feelings of guilt when they were unable to achieve this role which ranged from looking after children, being sexually intimate with their husbands or tending to elderly parents (Raheim & Haland, 2006; Soderberg, Lundman, & Norberg, 1999; Soderberg & Lundman, 2001; Werner, Isaksen, & Malterud, 2004). Men reported feelings of guilt for not being able to take care of their family financially in the

same way they had before (Paulson, Danielson, & Soderberg, 2002) (Paulson, Danielson, & Soderberg, 2002) (Paulson, Danielson, & Soderberg, 2002).

Gullacksen & Lidbeck, (2004) described stage two in the life adjustment process in chronic pain which was characterised by loss: the loss of self, loss of jobs, loss of relationships, loss of sense of value and the loss of experience of the world in the way women were accustomed to (Gullacksen & Lidbeck, 2004; Soderberg & Lundman, 2001). Self esteem and self confidence were negatively affected by the lack of certainty about what their new body was capable of (Gullacksen & Lidbeck, 2004).

Keponen & Kielhofner (2006) reported that some of the women in their study felt frustrated at the change in their abilities and their increased need for help. Therefore, a large proportion of energy was put into focusing on the here and now, developing routines and identifying replacement occupations allowing the women to take pleasure in small accomplishments and gain some level of independence. The frustration that came from not being able to do what they used to do was therefore prevented and their need for help reduced. Women who used this metaphor were found to be acutely aware of other people's perceptions of them hence needing to know they were not burdensome and were contributing in some manner. Unfortunately, this was not always understood by the people close to the women who wanted to offer practical support when the women themselves would have preferred "...empathic understanding, such as emotional support with a confirming function." (Gullacksen & Lidbeck, 2004, p. 149). Some men reported that if they were not under pressure, they would be better able to manage their new situation (Paulson, Danielson, Larsson, & Norberg, 2001), suggesting that men feel there is pressure to perform the duties they used to be able to perform before the pain and would constantly push themselves to the limit before they stopped. Pressures included financial commitments and expectations on how a man should behave.

Acceptance

During the final stage of the life adjustment process in chronic pain, (Gullacksen & Lidbeck, 2004) women reintegrated with the body they had alienated or distanced themselves from and used

their new self image to adapt to their roles as wife, mother and in some cases employee (Raheim & Haland, 2006; Soderberg & Lundman, 2001).

Making major life changes, the realisation of what the body is and is not capable of and establishing routines was something that women seemed to do once they needed to regain some of the agency and control back from the pain that had taken over every aspect of their lives (Huntington & Gilmour, 2005; Raheim & Haland, 2006). This increased their self esteem and self confidence by allowing them to achieve a level of independence and a sense of winning a battle (Gullacksen & Lidbeck, 2004; Huntington & Gilmour, 2005; Werner, Isaksen, & Malterud, 2004).

Initially, there was a battle between what the body could not do and what the mind wanted it to do (Soderberg & Lundman, 2001). Eventually, however, these women were reported to find it easier to accept their realistic needs and abilities, to communicate them to other people rather than just “soldiering on” and to create a mutuality and understanding thus reducing the distance between them and those around them.

In the Maintenance Stage of the life adjustment process in chronic pain (Gullacksen & Lidbeck, 2004) the women were aware of the importance of balancing what the body is actually capable of doing and what the mind wants it to do. They also had to learn to prioritise the needs of their body to prevent worsening of their condition. This was similar for some women in the Keponen & Kielhofner study (2006), who also learned to allow themselves to do things for themselves that they enjoyed even though initially they felt guilty that maybe they should be doing something for the family or the home or knew that they would suffer with immense pain for days afterwards (Keponen & Kielhofner, 2006; Soderberg & Lundman, 2001; Werner, Isaksen, & Malterud, 2004). Women who were able to say no without feeling guilty regarded themselves as strong (Werner, Isaksen, & Malterud, 2004) There was, however, discrepancy in the reported emotional strength of the women. They described themselves as emotionally strong but admitted their friends and families may not agree and in one case, a woman who described herself as emotionally stonger than her husband also described a situation where her husband had to call the Social Security Office because she had been reduced to tears the last time she had called (Werner, Isaksen, & Malterud, 2004).

Keponen & Kielhofner (2006) proposed that women who use the metaphor of “moving forward” in their narrative are the ones who relearn skills they had previously mastered in order to continue functioning with chronic pain. These women were the ones considered to see their chronic pain as a challenge requiring, “... patience, flexibility and ingenuity.” (Keponen & Kielhofner, 2006, p. 214).

Making major life changes was something that women seemed to do once they had regained some of the agency and control back from the pain that had taken over every aspect of their lives (Huntington & Gilmour, 2005). This increased their self esteem and self confidence by allowing them to achieve a level of independence and a sense of winning a battle (Haug, 1992) (Gullacksen & Lidbeck, 2004; Huntington & Gilmour, 2005; Raheim & Haland, 2006; Soderberg & Lundman, 2001; Werner, Isaksen, & Malterud, 2004).

Hope and appreciation was reported by most of the men in Paulson, Danielson, & Soderberg's (2002) study who felt that the situation could have been worse and drew strength from this. Those who were still employed appreciated that they still had meaningful tasks to achieve, those who were no longer employed appreciated the reduced pressure and increased freedom and those who were granted disability pensions interpreted this as a confirmation that their invisible symptoms were real. This did not mean that these men felt the pain would ever leave, but it allowed the retention of certain life goals (Paulson, Danielson, & Soderberg, 2002).

Metaphors

In order to fully communicate severity, men resorted to using metaphors to help with the translation of their experience into language. Men described their pain as “devillish, hellish or damned” (Paulson, Danielson, Larsson, & Norberg, 2001). The character of the pain was described with words like, “ache”, “pain” and “hurt” (Paulson, Danielson, Larsson, & Norberg, 2001). In many cases the pain was difficult to describe which led to feelings of anger and irritation (Soderberg, Lundman, & Norberg, 1999). Many women, like men, used metaphors to describe their pain such as, “it feels as if I have heavy weights in my arms.” (Hallberg & Carlsson, 2000, p. 32) and “My feet are burning, it is actually as if I had put them in boiling water.” (Hallberg & Carlsson, 2000, p. 32).

Women described their pain as a “gnawing”, “crippling” pain and equated it to “sitting on a knitting needle” (Huntington & Gilmour, 2005). Hallberg and Carlsson, (2000) reported that the majority of the metaphors used by women were dramatic, possibly reflecting women’s appraisals of pain being that it is threatening and stressful.

Although both men and women used metaphors to describe their pain, women described their pain in a more diffuse manner than the men and some used behavioural expressions, knowingly and unknowingly, to describe their pain, these included crying, rubbing the affected areas and facial expressions (Hallberg & Carlsson, 2000). Their descriptions implied a sense of exhaustion and helplessness although they also described an overall pain (Raak & Wahren, 2006).

Male experience of pain

Descriptions of pain—structured and simple

The men in the Paulson, Danielson, Larsson, & Norberg study (2001) reported how the pain had progressed from being a localised pain that would come and go, to being spread out over the body to finally settling in particular parts of the body as a continuous pain. Men in Raak & Wahren’s (2006) study reported that their pain had not changed over time (Raak & Wahren, 2006; Paulson, Danielson, Larsson, & Norberg, 2001). They would describe it in exact medical terms referring only to the pain (Raak & Wahren, 2006). Although sleep was mentioned, it was described positively in terms of the general pattern and number of hours slept (Raak & Wahren, 2006).

A distinction was made between “worrying” and “non-worrying” pain. This distinction was not so much about the type of pain but more about the consequences of the pain suggesting that the alteration to men’s ability to perform is more of a worry than the actual perception of the pain (Paulson, Danielson, Larsson, & Norberg, 2001).

Pain was described as fluctuating between calm phases resulting in the men’s daily life being fairly relaxed to difficult phases whereby the pain was even described as frightening. These difficult phases were said to be generally constant but some of the participants expressed that they varied in severity (Paulson, Danielson, Larsson, & Norberg, 2001).

Cause

Perceived cause of pain was not an issue reported by men in the studies included in this review, however, all the men in the Raak and Wahren study (2006), except one who was diagnosed with polymyalgia rheumatica², believed that the main reason for their pain was something that had occurred during or as a consequence of their earlier work situation (Raak & Wahren, 2006).

Nobody understands

Even though they felt they had become experts in their pain, men reported a sense of frustration at being unable to communicate their pain to others around them. (Paulson, Danielson, Larsson, & Norberg, 2001). There was a feeling that even when their friends and family did believe they were in pain, they were not able to truly understand what that meant and how it affected them (Paulson, Danielson, & Soderberg, 2002). Although women experienced similar feelings, they explained it as people not believing them more than people not understanding.

Female experience of pain*Descriptions – diffuse and complicated*

When women were describing their pain, it was in a more diffuse manner than the men (Raak & Wahren, 2006). Their descriptions implied a sense of exhaustion and helplessness although they also described an overall pain (Raak & Wahren, 2006). Chronic pain never seemed to exist on its own. In the case of fibromyalgia, accompanying symptoms were; fatigue, anxiety, headaches, irritable bowel syndrome, subjective swelling and numbness (Hallberg & Carlsson, 2000). Women living with endometriosis had to contend with abdominal pain and bloating, bowel problems, painful urination, malaise, fatigue and depression as well as chronic pain (Huntington & Gilmour, 2005). Unlike men, women did not describe their pain as constant but rather it was described as wavelike, fluctuating according to various factors such as treatment and the menstrual cycle progressively becoming worse.

² A condition that causes inflammation to large muscles resulting in pain.

All the women in Raak and Wahren's study (2006) were reported to have described their sleep pattern negatively and to also express clearly the negative consequences of their sleeping patterns.

Its normal for a woman.

Grace & MacBride-Stewart (2007) found that many of the women in their study were unable to differentiate between chronic pelvic pain, pain that is not easily identified as non-cyclic and pain associated with menstruation. This meant that the meaning attributed to the two former types of pain were similar to that of the latter. The women understood their pain as something that was part of being a woman and that they had to deal with it (Grace & MacBride-Stewart, 2007). Some women were even told this by their health practitioner, (Huntington & Gilmour, 2005).

Similarly, the association of gynaecological pain and childbirth affirmed that pelvic pain was just something that came with being a woman. Pregnancy was believed to cause internal damage by inflicting unnatural pressures on the body, however, giving birth was described as a very natural thing to do, suggesting an acceptance that it is normal for the body to be subjected to pain.

Cause –Importance of a diagnosis

Many women reported feeling dismissed and not being taken seriously by friends or family. This disbelief was experienced not only from friends and family but also from health professionals/ leading to mistrust and feelings of frustration and desperation (Gullacksen & Lidbeck, 2004; Hallberg & Carlsson, 2000; Soderberg, Lundman, & Norberg, 1999; Werner, Isaksen, & Malterud, 2004). Women also experienced similar treatment at work when they became affected by fibromyalgia symptoms (Soderberg & Lundman, 2001). These women reported feeling that their integrity had been threatened and also feeling disrespected as human beings (Huntington & Gilmour, 2005; Hallberg & Carlsson, 2000; Soderberg, Lundman, & Norberg, 1999). It was said to not only be an insult but a threat to the woman's reason and a further drain on the little strength that was available (Gullacksen & Lidbeck, 2004).

Many of the studies described the importance of a diagnosis. Besides alleviating anxieties that there was something fatally wrong, issues about control and validation were also touched on. A diagnosis empowered individuals to defend themselves and offered friends and family a better understanding of what was happening for that person (Soderberg, Lundman, & Norberg, 1999) however, women in the Raak & Wahren (2006) study were less sure than the men of the cause of their pain and tended not to give a definite explanation. The mystery around the unnamed condition led to lack of knowledge for all involved, professionals, friends, family and even the person suffering with chronic pain (Soderberg, Lundman, & Norberg, 1999)..

Gullacksen & Lidbeck (2004), reported that in an effort to obtain a diagnosis, women admitted to overt displays of discomfort and purposeful self neglect in an attempt to persuade people that their pain was real and not a sign of mental or social problems as was often the explanation provided by professionals (Gullacksen & Lidbeck, 2004; Hallberg & Carlsson, 2000). This often led to them being perceived as “being too obsessed by their troubles” (Gullacksen & Lidbeck, 2004, p. 148).

Grace & MacBride-Stewart, (2007) reported that only 5 out of 40 women were given a clear diagnosis. Huntington & Gilmour (Huntington & Gilmour, 2005) reported that the time period between seeking help and receiving a diagnosis of endometriosis was between five and ten years. Other women who had been given a diagnosis were not sure about the accuracy of the diagnosis and this seemed to have the same psychological and emotional effect as not being given a diagnosis at all.

Gullacksen & Lidbeck (2004) reported that a clear diagnosis was important to facilitate the transition process that would enable women to adjust to their new level of ability and new roles and identity. Grace & MacBride-Stewart (2007) stated that in the absence of a clear diagnosis, women were found to self diagnose attempting to use medical discourses even when they did not have a full understanding. Creating a diagnosis was seemingly better than not having one at all. Women felt a greater sense of control from knowing and from the certainty and concrete nature of a diagnosis.

Having a diagnosis was also important because it facilitated the visualisation of the pain. Grace & MacBride-Stewart (2007) found that transforming the invisible pain into a visible disorder

through tests, scans and diagnosis was important to the women in their study. As reported above, women felt that their pain was not taken seriously; having a diagnosis meant that the pain was not “in their head” and could potentially persuade others, in particular health professionals, to consider their situation to be a serious one (Gullacksen & Lidbeck, 2004).

The women with no diagnosis were left with a sense of uncertainty (Grace & MacBride-Stewart, 2007), uncertainty that there maybe something seriously medically wrong. No diagnosis led to feelings of isolation, worry and inadequacy experienced by having no confirmation or framework from which to explain the nature of the chronic pain to others (Gullacksen & Lidbeck, 2004).

Once the illness was named, it meant that it really existed (Soderberg, Lundman, & Norberg, 1999). It helped the women to live a life of dignity and be more accepting of their condition (Soderberg, Lundman, & Norberg, 1999). Furthermore, being examined or asked to take part in research meant the situation was being taken seriously and women found this validating and even expressed feeling lucky to be believed (Soderberg, Lundman, & Norberg, 1999).

Make it go away!

Huntington & Gilmour (2005) found that women would try many combinations of treatments and interventions in their attempts to ease the pain regardless of how disruptive they were to normal functioning. Often the desired effect, to be cured of chronic pain, was not achieved. Again this was characteristic of the women in Keponen & Kielhofner’s study (2006) who expected solutions to their problems to come from outside.

Hallberg & Carlsson (2000) found that women attempted to alleviate their pain in many different ways. They categorised these into: self initiated activity such as walking or cycling; professional treatments such as, “physiotherapy, acupuncture, massage, fasting, homeotherapy, laser therapy and ultrasound therapy” (Hallberg & Carlsson, 2000, p. 33), passivity such as bed resting and avoiding interactions with others; escape behaviours such as drinking alcohol and resignation characterised by accepting there is nothing that can be done and believing the pain will subside when it is ready.

As energy diminished, so did the hope of life returning to the way it used to be. A new lease of energy was directed away from searching for a miracle cure to trusting personal resources and developing new possibilities (Gullacksen & Lidbeck, 2004).

Understanding others in relationship to the new self

Women described having increased empathy for others who are ill once they had experienced chronic pain (Soderberg & Lundman, 2001).

Others described their negative attitudes towards other women in chronic pain which even prevented some attending treatment groups (Werner, Isaksen, & Malterud, 2004).

Discussion

Women in these studies reported not being believed by friends and family (Gullacksen & Lidbeck, 2004; Hallberg & Carlsson, 2000; Soderberg, Lundman, & Norberg, 1999; Werner, Isaksen, & Malterud, 2004) whereas men in these studies reported not being understood (Paulson, Danielson, & Soderberg, 2002). The tension between social roles assigned to each gender and individual personalities may have impacted on this experience.

Johannisson's (2001) paper described an expectation of women to be weak and delicate. This expectation seems to have influenced the reaction of others to women who are in pain. Werner, Isaksen, & Malterud (2004) describe the experience of the women in their study and their struggle to be believed and prevent "their (woman) body from being used against them" (Werner, Isaksen, & Malterud, 2004, p. 1037). They described the expectation of women to behave a certain way resulting in an expectation that women will exaggerate their symptoms which in turn influences the outcome of medical encounters (Werner, Isaksen, & Malterud, 2004). The expectation of women to be co-operative can also lead to uncomfortable feelings both within the woman who is living with pain and believes she cannot complain but must instead cope and also with those around her when she continues to complain that there is something wrong even after she has been told there is not. Similarly, men may have experienced not being understood by those around them due to the need to avoid being seen as feminine and therefore not expressing fully the emotional impact of the chronic

pain but rather focusing on the physical impact. It may also be that people around a man in pain feel uncomfortable broaching issues of emotional impact for fear of offending him.

In 1987, Eisler and Skidmore developed the idea of “masculine stress”. Masculine stress is a concept which describes the emotional stress exhibited by men when they feel unable to meet society’s expectation for masculinity such as physical inadequacy, emotional inexpressiveness, subordination to women, intellectual inferiority, and performance failures involving work and sex (Eisler & Skidmore, 1987; McCreary, Wong, Wiener, Carpenter, Engle, & Nelson, 1996). This idea was supported by a study investigating masculinity and spinal cord injuries. It was found that decreased physical and sexual prowess, feelings of guilt and overall loss of control which, occurred as a result of the spinal cord injury, contributed to a loss of male identity (Hutchinson, 2000). It could, therefore, be inferred that the beliefs about masculinity may discourage men from expressing their experience of pain for fear that doing so would reveal their inability to meet society’s expectations for masculinity.

In the medical field and in common understanding, it appears the male body seems to be taken as the norm and anything that deviates from this norm is abnormal, including the female body, thus accounting for the understanding that during pregnancy and childbirth the body is subjected to abnormal stresses and strains (that women cope with) rather than an understanding that perhaps it is normal for the female body to experience pregnancy and childbirth and that the female body is equipped to allow for the changes that occur. It has been accepted that not all pain signals damage but it is generally agreed that it signals some form of pathology so to now argue that pain can be normal and in some cases does not indicate pathology may seem inaccurate. In fact, this is precisely the case. Menstruation and childbirth both can involve pain that may not indicate damage or pathology. Bendelow (2000) put forward that women are expected to be able to tolerate pain because they have been naturally equipped to do so. Only women experience the pain of ovulation, menstruation, pregnancy and childbirth and it would make sense that if these are natural processes for women that women would be equipped to cope with any pain associated with them. This, therefore, can offer an explanation as to why women are seen as complaining and needy when help seeking in reference to

pain. If women are believed to be equipped to tolerate pain then they will be expected to do just that and when they do not they are considered to have a more fundamental problem labelled as hysteria thus, categorising the woman as unstable instead of dealing with the ambiguity or the normal pathology that is chronic pain (Grace & MacBride-Stewart, 2007; Gullacksen & Lidbeck, 2004). Changes in women's mood and behaviour are attributed to hormones based around the monthly menstrual cycle and dismissed as Pre-Menstrual-Tension (Ripper, 1994). Interestingly, changes in men's mood and behaviour are not generally described using hormones. Additionally, the belief that all women experience pain during menstruation and childbirth coupled with the physical changes that occur during pregnancy has influenced the belief that women have a "natural ability to endure pain" (Grace & MacBride-Stewart, 2007, p.49). Men, however, are not believed to experience pain as part of a monthly cycle nor does the male body undergo changes such as those evident in pregnancy and therefore, men are not generally believed to have a natural ability to endure pain (Grace & MacBride-Stewart, 2007). The understanding that women have a natural ability to endure pain and men do not may impact on the beliefs about how a man or woman should cope with their pain.

Women reported feeling rejected and stigmatized by the health care professionals and people close to them, exiled into the borderland of "hysteria" (Grace & MacBride-Stewart, 2007, p. 62), however, this was not something reported by the men in the studies reviewed.

Women dismissed the involvement of psychological factors feeling they were being called mad (Grace & MacBride-Stewart, 2007) and men dismissed this idea believing they were being called weak (Paulson, Danielson, & Soderberg, 2002). Although both men and women dismissed the idea of psychological involvement, they did so for different reasons having attributed different meanings to the suggestion; if it is necessary to challenge this response, it would need to be done in different ways.

It was noted by Gullacksen & Lidbeck (2004) that a clear diagnosis was important in the experience of chronic pain and without it, the experience was more difficult and yet health professionals are perceived as either disbelieving or unable to understand. The diagnosis was possibly so important to women because it signified that the health professional believed them and had not dismissed them as hysterical or hormonal. This however, has been extrapolated further. It was

proposed that if the diagnosis is translated directly from a medical narrative, it will be received as “strange, depersonalised, un-lived and unliveable (Hunter, 1991, p. 13). This was reflected in the experiences of the women who participated in Grace and MacBride-Stewart’s (2007) study in that for the few women who did receive a diagnosis this was not sufficient and a more detailed explanation was required. Men did not put as much emphasis on a diagnosis, this may be because men were more focused with their description than women describing them as either “worrying” or “not worrying” which, is easier to cope with than the diffuse explanation and the wide range of accompanying symptoms such as fatigue reported to be described by women. (Raak & Wahren, 2006). It could be that because men are expected to be strong and robust they have to develop methods to be able to cope with pain and continue to be strong and robust. Simplification of an otherwise complex situation such as the classification of their pain into “worrying” and “non-worrying” may be an example of this. Women, however, continue to present to their health professionals even though they perceive that there will be high chance that they will be dismissed or not helped for other reasons. It could be that women continue to present to their health professionals because of the expectation that they are weak and require an external person to help (Johannisson, 2001).

Many of the men and women in these studies described a loss of integrity and respect caused secondarily by the illness but primarily from the way those around them responded to them because of the chronic pain. The loss of role and importance resulted in the participants of these studies feeling less valuable. Nietzsche proposed that, “He who has a why to live can bear almost anyhow” (Frankl, 1993). It can, therefore, be inferred that he who does not have a why to live cannot bear it. The men and women in these studies had a drive to maintain their independence and a sense of worth potentially to maintain a why to live to be able to bear their chronic pain.

The Focus of Future Findings

These findings show that further research is required into the male experience of pain as there has been very little research over the past ten years conducted specifically on this area. Further research could also be carried out on women’s experience of pain in regards to pain sites exploring whether women with musculoskeletal pain have a similar experience to women with gynaecological

pain. Is there still a sense that pain is something women are meant to know how to cope with? Do women cope less well with musculoskeletal pain than gynaecological pain because it is more easily distinguished from menstrual pain and the pain of childbirth? Additionally, it was reported that different pain sites generated different experiences to different men - further research could be carried out in order to establish if this is the case with women and to understand this phenomenon further.

Conclusions and Implications

There are many issues that are common to both men and women who are experiencing chronic pain. There are also issues that are only described in one gender. Some of these are due to the social roles which influence the meaning attributed to certain events and some are due to the different physiology of the genders. For example, it is commonly believed that women generally experience pain as norm during their menstrual cycle although not all women do, however, men are not widely believed to routinely experience pain as a norm. It is likely that there are more issues that are shared between men and women because the social roles are becoming increasingly blurred with more women being more independent and staying single longer and more men moving further away from the stereotyped view of how a man should behave and paying more attention to physical health and appearance, thus being more comfortable in approaching their doctors about physical and mental health worries.

It is hard to say if the male experience of pain is accurate as there were only three papers that described it. If more studies were conducted it may uncover further experiences. In addition, if studies were to be conducted with men who are living with chronic testicular pain further information may be gained about which factors influence the experience of pain and for whom because this pain is exclusive to men, as gynaecological pain is exclusive to women, however, both have similar functions in terms of physically defining the sex of a person and also in reproduction. Additionally, a criticism of these studies is that it is not possible to separate whether depressive feelings and feelings of powerlessness were a result of the chronic pain or the chronic pain a result of the depressive powerless feelings.

Further studies could also be carried out looking at the experience of pain in regard to the meaning attributed to the consequence of having pain in that area of the body. Would women with

gynaecological pain experience pain differently from women with pain elsewhere in the body because they feel that it is something that is part of being a woman? With the merging of gender roles and the majority of issues experienced being common to both men and women could it be that pain site and the loss associated with pain in that area is more significant than whether it is a man or a woman experiencing the pain?

This systematic literature review has shown there is a shortage of literature on the male experience of pain. It has highlighted the importance of validation within the clinical – patient relationship. Many issues arose and were handled differently dependent on if the patient felt believed or not. Flippant comments to patients such as informing them that “there is little or no pain but [instead] exaggerated pain behaviour to obtain secondary gains” and “inappropriate pain behaviour is part of a maladaptive and irreversible sick-role” (Gullacksen & Lidbeck, 2004, p. 151) should be avoided as this has been found to alienate the patient. It has also suggested further areas that can be explored to further the understanding of the chronic pain experience.

Table 1.1 Study Details

| Author and Study Title | Factors Investigated | Gender of Participants | Characteristics of Pain | Quality Score |
|---|--|------------------------|---|---------------|
| Grave,VM., MacBride-Stewart,S. (2007). "Women get this": gendered meanings of chronic pelvic pain. | Meanings women engage to understand why they have chronic pelvic pain | Female | Chronic Pelvic pain unrelated to dysmenorrhoea or dyspareunia | + |
| Gullackasen,A.C. &Lidbeck,J. (2004). The life adjustment process in chronic pain: Psychosocial adjustment and clinical implications | Significant aspects and themes in the course of life that change because of chronic pain | Female | 1- 9 years Fibromyalgia (FM) and Myofascial (MF) Pain syndrome as described by the International Association for the study of pain | + |
| <u>Hallberg LR</u> , <u>Carlsson SG</u> . (2000). Coping with fibromyalgia. A qualitative study | What it means to the patient to suffer from fibromyalgia and how they manage the situation | Female | Chronic pain associated with endometriosis. | ++ |
| Huntington, A., Gilmour,J.A.(2005). A life shaped by pain: women and endometriosis | Women's perceptions of living with endometriosis, its effects on their lives and the strategies used to manage their disease | Female | Fibromyalgia - characterised by pain in all four quadrants of the body and tender points lasting for more than three months in the absence of secondary causes. Symptoms are modulated by physical activity and/or weather; symptoms are aggravated by stress, fatigue, anxiety, irritable bowel syndrome and subjective swelling and numbness. | ++ |
| Kopenen, R., Kielhofner,G.(2006). Occupation and meaning in the lives of women with chronic pains | How women with chronic pain experience and organise occupations in their everyday lives. | Female | Fibromyalgia, Cancer, headaches, Various Musculoskeletal pain and Thoracic outlet syndrome. | ++ |

| Author and Study Title | Factors Investigated | Gender of Participants | Characteristics of Pain | Quality Score |
|---|---|------------------------|--|---------------|
| Paulson, M., Danielson, E., Larsson, K., & Norberg, A. (2001). Men's descriptions of their experience of non-malignant pain of fibromyalgia type | Descriptions of men's experience of non malignant pain of fibromyalgia type | Male | Fibromyalgia: Widespread pain in four quadrants of the body lasting for at least three months and eliciting of pain on digital palpations (approximate force of 4kg) of at least 11 out of 18 specified bilateral tender points. | ++ |
| Paulson, M., Danielson, E., Soderberg, S.(2002) Struggling for a tolerable existence: The meaning of men's lived experiences of living with pain of fibromyalgia type | The meaning of men's lived experiences of living with pain of fibromyalgia type. | Male | Fibromyalgia: Widespread pain in four quadrants of the body lasting for at least three months and eliciting of pain on digital palpations (approximate force of 4kg) of at least 11 out of 18 specified bilateral tender points Length of time had pain: 4 – 25years | ++ |
| Raak,R., & Wahren,L.K.(2006). Health experiences and employment status in subjects with chronic back pain: A long term perspective | Health experiences, focussed on gender and return to work in subjects with chronic low back pain in a long term perspective | Female & Male | Non-malignant chronic low back pain. Duration: 5 years except one who had it for 13 months | ++ |
| Rahiem,M., Haland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life | The existential dimensions of women's lived experience of chronic pain and fibromyalgia | Female | Fibromyalgia Length of time had pain: 4 -20 yrs. | ++ |
| Soderberg, S. & Lundman, B. (2001)Transitions experienced by women with fibromyalgia | Transitions experienced by women with fibromyalgia | Female | Fibromyalgia Length of time had pain: 4 -25 yrs | ++ |
| Soderberg, S.Lundman, BNorberg, A. (1999). Struggling for dignity: the meaning of women's experiences of living with fibromyalgia | Meaning of women's experiences of living with fibromyalgia | Female | Fibromyalgia. Length of time had pain: 1 -25 yrs Time since diagnosis: 0.5 – 6 years | ++ |
| Werner, A., Isaksen, Malterud,K.,(2004).“I am not the kind of woman who complains of everything”: Illness stories on self and shame in women in chronic pain | Self and shame in illness accounts from women with chronic pain | Female | Chronic muscular pain – fibromyalgia and unexplained. Symptoms duration: 1 – 20 yrs; Average: 9yrs | ++ |

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Part Two

The Effect of Pain Site on the Experience of Pain

Pain Site and Chronic Pain

The EFFECT of PAIN SITE on the EXPERIENCE of CHRONIC PAIN

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Please see Appendix 9 for the Guidelines for Authors.

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Abstract

This study aimed to investigate the meaning of pain site in the female experience of chronic pain.

This was explored using Interpretative Phenomenological Analysis (IPA) on the transcribed narratives of women living with chronic pain in a variety of pain sites. Derived themes suggested that these women experienced pain as the decider of their ability to complete activities potentially affecting their sense of self and identity. Pain site influenced beliefs about the normality of pain and when complaint regarding the pain was acceptable. Furthermore, pain site determined both participant's attitudes and their beliefs about health professionals' attitude regarding treatment and management of the pain.

These results showed that pain site is capable of altering the cognitive appraisal of the situation and the ability to achieve life goals. It should, therefore, be considered an important part self regulation in response to chronic illness and of the clinical care of these patients.

Keywords: Chronic illness; women's health, lived experiences, chronic pain.

Chronic pain is defined as pain that persists beyond the normal time of healing, or occurs in diseases in which healing does not take place (Chronic Pain Policy Coalition (CPPC), 2006). It can occur in any part of the body including; shoulders, neck, back, genitals, face, arms and legs, sometimes with a known cause and other times without. Chronic pain conditions such as Fibromyalgia, characterised by widespread muscle pain in combination with greater than or equal to 11 – 18 specific tender point sites (Wolfe, et al., 1990) but with no specific cause are classed as “undefined or unexplained disorders” (Steihaug, 2005, p. 36). This loose definition of chronic pain can lead to problems of legitimisation and those living with chronic pain can be left with no clear understanding or prognosis of their condition (Raheim & Haland, 2006). Furthermore, specialists also have a limited understanding of chronic pain (Kleinman, Brodwin, Good, & DelVecchio - Good, 1994) thus making the relationship between health professionals and chronic pain patients problematic (Werner & Malterud, 2003).

Chronic pain can affect anybody at anytime within their lives for any length of time over three months. Almost 10 million people live with chronic pain in the UK (GfK-NOP, 2005). This includes women, men, children, professionals, retired older adults, unemployed, rich and poor although a bias has been reported in prevalence towards; women, people who are living in council rented accommodations, people who are retired or unable to work due to disability and people with lower education levels (Smith, Elliott, Chamber, Smith, Hannaford, & Penny, 2001).

Chronic pain is not only devastating and disruptive to the individual and their family but also has more global effects. Baroness Fritchie –Current (2009) President of the Chronic Pain Policy Coalition described the impact on the global economy, the exchequer, the National Health Service and the personal effects on the individual and their family as “enormous and alarming” (CPPC, 2006). Education standards are also affected with 13% of 15 -24 year olds experiencing some form of chronic pain preventing them from fully attending to their education and consequently affecting their employment abilities. Furthermore, according to Professor Eccleston (University of Bath, Management Unit) chronic pain is the most costly condition in Western Society (CPPC, 2006).

As mentioned above, the understanding of chronic pain is currently limited, however, it is widely accepted that chronic pain cannot be understood in the same way as acute pain which is believed to occur as a signal of tissue damage (Unruh & Henriksson, 2001). Previous research has demonstrated that chronic pain is not a linear condition but rather is affected by many different factors and in turn impacts on many areas of one's life (Turk & Monarch, 2001). One of the main models used to illustrate this conceptualisation of chronic pain is the Bio – Psycho – Social (BPS) Model which stipulates that the experience of pain is affected by psychological, mental, emotional, behavioural, social, physical and medical factors (Honkasalo, 1998; Turk & Monarch, 2001). Chronic pain has been shown to be affected by age (Elliott, Smith, Penny, Smith, & Chambers, 1999; Parsons, et al., 2007), personality (Pud, Eisenberg, Sprecher, Rogowski, & Yarnitsky, 2004; Conrad, et al., 2007); anxiety (Vlaeyen & Linton, 2000), parental experience (Chambers, Craig, & Bennett, 2002) and previous trauma (Yaari, Eisenberg, Adler, & Birkham, 1999; Goldberg, 1999). In turn, The Chronic Pain Policy Coalition (2006) have published statistics offering insight into the effects of living with chronic pain; 49% of cases lead to depression, 47% have difficulty walking, 48% have difficulty attending social activities and 73% report difficulties doing any form of exercise. This illustrates the subjectivity of chronic pain and the need for studies looking at the experience of pain to control or account for some of these factors.

Another factor involved in the experience of pain is the meaning that is attributed to it (Lazarus & Folkman, 1984). This is a key factor in the Common Sense Model (CSM) – Self regulatory Model developed by Leventhal, Brissette and Leventhal (2003) The CSM Model proposes that there are 5 illness representations involved in the cognitive appraisal of an illness such as chronic pain. These are: illness identity, cause, control/ cure, consequence and timeline. The CSM model suggests that this cognitive appraisal is a major part of the overall perceptions of an illness. Mechanisms within the self regulatory system are used to detect the discrepancy between this overall perception and what Leventhal, Brissette, & Leventhal (2003) term the “Reference Goals” (life goals set by the individual). Perceived success in meeting the reference goals is appraised as part of the feedback loop informing the self regulatory mechanisms of the status of the discrepancy between perception and reference

goals (Leventhal, Brissette, & Leventhal, 2003). Carver & Scheier (1996) stipulated that all goals can be condensed down to two major goals; the goal to survive and the goal to maintain a coherent sense of self. This can be extrapolated into the CSM model suggesting that all reference goals ultimately are related to either the goal to survive or the goal to maintain a coherent sense of self. This coupled with the cognitive, emotional and behaviour processes, generated to reduce the discrepancy between the overall perception of self determines the overall experience of pain. The experience of pain, therefore, is the perception of pain and the behaviours, cognitions and emotions generated in response to it.

This study proposes that in addition to the five illness representations (Leventhal, Brissette, & Leventhal, 2003), pain site is also influential in the perception of chronic pain. The evidence to support this can be found in literature from various different disciplines including psychological, evolutionary and physiotherapeutic perspectives.

Literature on chronic illness discusses how the development of a chronic illness can cause a separation between the person of the present and the person of the past resulting in difficulty relating to the world as well as to themselves and shattering the images of the future self (Corbin & Strauss, 1989; Rosberg, 2000). The manner in which the body was able to exist in the world has been altered due to the change in its abilities (Soderberg & Lundman, 2001). Charmaz (1983) stated that chronic illness disrupts a person's life and challenges the sense of self and can even cause a loss of the self. However, it is hypothesised that change in ability will depend on the pain site and therefore the level of disruption in a person's life and the challenge to their sense of self will depend on the original function or meaning attributed to that pain site by that individual.

This study, therefore, will explore only the female experience of chronic pain to ensure, as far as possible that any findings can be attributed to pain site as opposed to gender which has been found in a recent literature review to affect the experience of pain (Olojugba & Frizelle, in submission, 2009). One difference highlighted is the unique experience of female menstrual pain and childbirth. These phenomenons have led to the understanding that gynaecological pain is part of being a woman and women are, therefore, designed to cope with such pain (Grace & MacBride-Stewart, 2007). Olojugba & Frizelle, (in submission, 2009) hypothesised whether this view that women should

be able to cope with their chronic pain was exclusive to gynaecological pain sites or if this belief was extrapolated across other or even all pain sites. This study aims to explore this further.

Although the literature on chronic pain is vast and progress is being made on the understanding of the physiological processes involved, it still continues to push the boundaries of medical knowledge (Steihaug, 2005) and holds the position of one of medicine's least understood phenomena (Kleinman, Brodwin, Good, & DelVecchio - Good, 1994). It is therefore imperative that the enthusiasm behind chronic pain research is maintained in order for further progress to be made in understanding the causes, maintenance and experience of chronic pain.

This study endeavours to add to the literature around the understanding of the female experience of living with chronic pain. It seeks to deepen the knowledge of the existential dimensions of living with chronic pain as well as attempting to start to define the meaning of pain site within the women's experience of pain. Qualitative analysis of narratives of women living with chronic pain were used for this study because pain descriptors based on structured questionnaires cannot capture all aspects of the experience of pain (McGuire, 1984) however, a richer and more complete understanding of the experience of pain could be obtained from the free narrative of the women living with it (Mishler, 1986).

Method

This study aims to gain insight into the meaning of pain site within the experiences of women living with chronic pain using Interpretative Phenomenological Analysis (IPA). IPA was chosen as the method of analysis because of its roots in phenomenology and symbolic interactionism (for further details IPA see Appendix 15) both of which are important in establishing the a rich and accurate interpretation of the participants experiences.

Participants

A consecutive sample of 8 women with chronic non-malignant pain and recruited from a Pain Management Service which provides medical and psychological support for patients living with chronic pain in the North East of England participated in the study.

In order to control for the impact of some of the factors reported to influence the experience of pain, this study invited only adult English speaking women over 18 years old from a homogenous community and without a co-morbidity affecting their cognitive ability such as dementia or psychosis with active interaction to participate.

The age range of the participants was between 45 and 70 years (mean 56 and standard deviation of 7.96). They had lived with chronic pain for between 1 and 42 years. Six women were married, 1 was divorced and 1 was widowed. Seven participants were unemployed (2 never worked), the other 5 had stopped working due to their pain and 1 participant was retired. Most of the participants indicated more than one area as their most intense pain site. Seven participants identified the lower back as one of the most intense pain sites, 3 included the shoulders, 2 the neck, 2 the arms, 3 experienced head pain (migraines) amongst the most intense pain sites, 3 the legs, 1 in the kidneys, 2 in the hips, 1 the hands, 1 the feet, 1 the knees and 3 described their most intense pain to include gynaecological pain. The participants were currently being seen in the pain management clinic for pain in the sites they described above except for the gynaecological pain. The participants describing gynaecological pain did so retrospectively in order to compare their current pain experience with past experiences of pain in a different site. Participants with pain in their hips believed that their hip pain and back pain impacted on each other, whereas the other participants believed that the pain sites were mutually exclusive from each other.

No payment or incentive of any kind was offered for participation and there was no relationship between the researcher and any of the participants.

Procedure

Ethical approval was obtained from the Local Research and Ethics Committee [Appendix 10], Research and Development approval was obtained from North and East Yorkshire Alliance R&D Unit. At initial and follow up appointments, at the Pain Management Service, patients who met the above criteria were approached by one of two Chronic Pain Specialists. Information regarding the study was given [Appendix 11] and consent obtained for the researcher to contact them via telephone to discuss the study further.

The researcher attended randomly selected clinics to become familiar with the patient's pathways and service experience and also to be available to meet individual women present that day and answer any questions.

Following verbal confirmation, those who agreed to participate were asked to arrange a time for the completion of written consent and the conduction of the interview. A letter was sent to the patient's GP informing them of their patient's participation in the study.

Participants were informed that all identifying information would be removed from the transcripts. Audio recordings of interviews and signed consent forms were stored in accordance with ethical guidelines. All participants chose to be interviewed in their homes. Participants were reminded that the researcher was independent from the Pain Management Service and that they could request that their data be removed from the study and that this would not affect their treatment at the Pain Management Service in any manner. No participants chose to withdraw their interview.

Face to face interviews were conducted using a semi structured interview schedule (Appendix 12) which was piloted on a small group of women who attended a gynaecology clinic to ensure questions were clear and allowed women to respond with rich and coherent information.

The semi structured interview was used to gather information on the meaning of pain site within the experiences of women living with chronic pain. The interview schedule provided a framework from which to gather meaningful information as well as allow the participant to speak freely. The interview began with an introduction explaining the purpose of the interview and its structure (Appendix 12). The questions were developed using the Common Sense Model of Self Regulation of Health and Illness (Leventhal, Brissette, & Leventhal, 2003) as a theoretical framework. The questions explored, using open questions, the role of pain site in determining the cognitive representation of chronic pain; the role of pain site in the management of chronic pain and how pain site influenced relationships with other people and the self. Interviews lasted between 20 minutes and 120 minutes.

Following data collection, all participants were sent a letter thanking them for their participation. Participants were offered options for feedback of findings post-data collection and analysis via a brief written summary by post or email.

Analysis

Interpretative Phenomenological Analysis involves stages of interpretation which move between the whole and various parts of the text.

Stages of Analysis

Naive Understanding

Stage 1 – Researcher enhanced familiarity with the text and an understanding of the whole by reading the transcript twice, once along with the tape.

Structural Analysis

Stage 2 –The Researcher annotated anything interesting or significant in the left margin. This was also carried out by an independent researcher for one of the transcripts and sections of transcripts were submitted to an IPA group of researchers at this stage. Comments were discussed within the group.

Stage 3 – The transcript was read for a third time and emerging themes and links to theory were documented in the right margin.

Stage 4 – Emerging themes and corresponding quotations were printed for each transcript to enable similar and corresponding themes in relation to the aim of the study to be identified.

Stage 5 – Links between themes across transcripts were made and organised resulting in the production of super – ordinate themes each comprising of a number of sub-ordinate themes.

Illustrative quotes from each established theme were discussed with an independent researcher to ensure the themes were grounded in the text. [For a worked example see appendix 14]

Results

These will be described according to stages of analysis

Naive Understanding

The influence of the pain site on the experience of living with chronic pain depended on the meaning attributed to that site by each individual.

Pain site influenced three out of five of Leventhal, Brissette, & Leventhal's (2003) illness representations: timeline, consequence and control/cure. Certain pain sites posed more threat to survival than others and other pain sites posed a threat not to physical survival but to survival of the self as understood before the onset of the chronic pain.

The meaning attributed to the chronic pain site largely influenced the chronic pain's effect on the cognitive perception of the chronic pain and thus the overall experience of it.

Back, hip and leg pain affected the ability to sit, stand and move around. Arm pain was found to have greatest influence in the ability to perform recreational activities including those that were used as distracters from pain in other areas of the body. Head and chest pains posed a threat to survival however; head pain appeared to be the easiest to treat whereas back pain involved the most intrusive interventions with the least chance of success. The overall decrease in ability lead to loss of identity, feelings of uselessness and fear of abandonment.

The women in this study all devised different methods to cope and live with their pain and its effects on their lives.

Structural Analysis

The structural analysis of transcripts unveiled a consistent pattern of themes which were organised into four super – ordinate themes and 12 sub – ordinate themes. The transcripts also displayed a rich diversity of meaning attributed to the pain site.

The structural analysis revealed a wide range of issues that came up for the participants, however, many of the ideas were not broad enough to be established as independent themes but to exclude them would have diluted the richness of the findings. Hence, the first theme became a broad theme to allow for the inclusion of a wide range of issues in order to allow for a richer illustration of the experiences of all the participants.

Each theme is illustrated using verbatim quotations from the transcripts.

Table 2.1 outlines the super – ordinate and sub- ordinate themes.

[TABLE 2.1 ABOUT HERE]

Super-Ordinate Theme: Pain Site as the Decider of Abilities

This super – ordinate theme encompasses how pain site affects the experience of pain by challenging the ability to carry out activities. The need for and meaning attributed to the pain site prior to the onset of the chronic pain greatly influenced the extent to which the pain site affected abilities.

Sub-ordinate theme: Ability to work/play.

Pain site was believed to be crucial in changing the women’s ability to work, socialise or take part in recreational activities.

Back, hip and leg pain were considered to be responsible for reducing the amount of time that could be spent sitting or standing it also impacted on the women’s ability to carry out work which required lifting, handling or a level of stability or mobility such as care or veterinary work. Even housework, shopping and caring for children was often described as a chore:

Even just general housework, everything’s become a task . . . I’m not able to stand for any length of time, after being on my feet 5 or 10 minutes the pain sets in really bad and I need to sit down. I'm not able to walk very far at all. I'm in a wheel chair. If I do try and walk around in the street I’ve got to try and sit down on the nearest little wall I come across and I end up in tears. It brings me to tears if I attempt it.

Reduced mobility caused by back, hip and leg pain also impacted on the women’s perceptions of their ability to socialise. They believed old friends were reluctant to invite them to places and had a sense that they spoilt everything for everyone by increasing the perceived risk to those who went out with them or by reducing the number of activities that could be done:

Oh I can’t be bothered or we won’t invite [name - participant] coz she’s a bit slow now and you know slow on her feet and she can’t walk as fast and she can’t drink like we do coz she’s

on all this medication . . . I mean some of my friends aren't friends any more coz they haven't got the patience to wait for me when we go out.

Most of the women who took part in this study had suffered with migraines at some point in their lives and described them as the most debilitating pain they had experienced. This debilitation was attributed to its effect on the eyes and the ability to think and concentrate. The latter in particular led to feelings of frustration and anger leaving the women who experienced pain in this site hesitant to take up full time work believing they were no longer cognitively able to carry out the duties:

You can't think. You know . . . it's there; it's there in my head. It's there what I want to say. It's there, I know I know inside my own head what I want to say, what I want to do what I'm thinking. It just won't come out. It's like I'm a bumbling idiot.

Arms were more frequently described in recreational activities and occupational activities. Pain in the arms, therefore, had a large affect on the ability to partake in such activities. Hobbies and activities often involved the use of the arms and hands and it was believed that the ability to do these was more necessary than the use of one's legs because there were still other ways of being mobile:

I mean at least while it's in my leg I can sit down and maybe get my keyboard and type or get the table in and plant seeds and things like that. I keep myself busy that way or read a book or whatever, if it was in my arms the pain that I've got. If it was in my arms and that then god! I wouldn't be able to move my arms at all. I'd feel even more useless then! Ermm oh no no! I wouldn't like it in my arms . . . it's bad enough having arthritis as it is in me hands. I wish I could type with one finger I could still type. No I wouldn't like it in my arms or anything like that. I'd feel even more shut off....at least with the pain in your leg you can sit down and you can still do things with your arms. Nah I'd rather have it in my leg. [Pause]

Overall it appeared that the level of loss attributed to having pain in a particular area of the body depended on the function of that site to the individual prior to the onset of the pain. This is in line with theories that suggest the meaning that is attributed to something will determine the ability to cope with it (Lazarus & Folkman, 1984).

Sub-ordinate theme: Ability to manage the pain.

The majority of women in this study used distraction as a mechanism for coping with their pain.

Distraction techniques often involved the use of arms and hands. For example, sewing and craft work or gardening all involved concentrating on something other than the pain and the use of the arms or hands, therefore, were found to be very difficult when the pain site was in the head or the arms:

I just hate head pain! I don't like anything messing with your head. That pain in your head and in your eyes it's so debilitating. I can work through any pain. If I've got pain I can work through it and still do things. I can block it out and I can do things but if I've got pain in my head it's just so hard! It's just so difficult to focus.

Additionally, it was believed that there was more technology and methods for integrating somebody with back pain into the workplace than there were for other areas of the body:

I had to leave work once with a migraine but...When I was first diagnosed with fibromyalgia I was given a special chair and various bits of paraphernalia to help me work which was wonderful. When I hurt my arms I got access to work again and she changed the chair to a better one

Women who found it difficult to manage back pain described pain every time they moved and a sense that pain in the back, because it is the support for the rest of the body, spilled out into adjacent areas and the women, therefore, had pain in more than one area. Experiencing pain in multiple sites impacted on the ability to manage the pain in particular, the ability to get comfortable:

It wouldn't bother me at all if it was isolated, I wouldn't classify it as pain it wouldn't bother me the same as... That's something I could live with, if it was just a limb or something like that I wouldn't class it in the same respect as something that pretty much is ruling your whole body.

Not being able to get comfortable affected sleep and also prevented some of the women socialising feeling it was better to be uncomfortable at home or be able to put their body in whichever position

felt less painful rather than be uncomfortable in public or have to face a barrage of uncomfortable questions:

I just can't, I just can't deal with it. I just can't deal with being out and being sat in pain somewhere. I'd just rather be sat in my own house.

It was believed to be easier to get comfortable if the pain site was in the arms or another extremity rather than a part of the body that is pivotal to general posture – sitting and standing such as one's back:

I'd rather it was somewhere that didn't cause more pain when you move. Where ever you've got pain, it hurts more when you move but with mine predominately being in my back it doesn't really matter whether I stand up or I sit down or I lay down.

Sub-ordinate theme: Ability to take the pain away.

This was an ability that was shared with the health professionals. Sometimes all the responsibility of taking the pain away was given to the health professionals and other time it was believed to have been taken by the professionals.

Women living with gynaecological pain reported relief at being able to have a hysterectomy and have the pain removed permanently rather than be subjected to a life of pain killers that did not work. This was echoed in women who had pain in other sites who expressed a desire to have the pain in an area that could be easily removed:

I don't know. Where would you trade it to? The tips of my hair because I can cut them off...I mean I had a hysterectomy and yes it was painful...If someone had put a cigarette out on my stomach it couldn't have been more painful but that's gone...it went.

There was, however, a feeling amongst the women that the decision as to when they could have this operation was up to the specialist and they would have to live with it until the specialist believed the time was right. In the case of the women who were living with gynaecological pain, they felt they had to wait until the specialist believed there was a significant difference between the pain they were experiencing and "normal" period pain. This is in line with studies that have already been conducted

and highlight the difficulties women are having in accordance to deciphering when their pain is just “normal” period pains and when it is enough to warrant specialist intervention and potentially a hysterectomy (Grace & MacBride-Stewart, 2007):

You’ve got to just put up with it [gynaecological pain]. Women bare it until they [the specialists] decide enough is enough and they want to operate.

Women living with hip pain found age to be a determinant of health professionals’ opinions regarding treatments, opting to favour those over 65 for hip replacement operations and leaving younger women to live in pain for 20 years or more in an effort to reduce the number of times the replacement hip would have to be changed. In line with this, women who were thought to be at an age where they were expected to want to have children were also left to live with the pain until they reached an age that the specialist believed was suitable for them to receive a hip replacement. Resulting in feelings of abandonment from health professions who were supposed to care for and protect them which left these women were feeling rejected:

I was told that I could have a hip replacement when I’m 65. So I’ve got another ummm 20 years to go... ermm they would have done it when I was 21 but then he realised I’d got married and he said well you be wanting children and all things like that so we’ll leave it for a while. And that’s what I’ve had all through my life, we’ve leave it ‘til another 5 years, then we’ll bring you back and have a look and then after 25 yrs, they stopped bringing me back to the consultant at hospital, ermm so it’s like 65 I’ve got something to look forward to anyway and the reason for that is coz I was told they need replacing every 5 years.

Back pain was generally managed using pain killers with varying results; some women felt that they did not work at all, others believed “they took the edge off” and others still felt the pain disappeared but returned shortly after. The option of surgery was one that left these women with a sense of fear that the pain may worsen or they may be left paralysed:

[name- specialist] said the last resort would be surgery but ermm he said it’s very heavy handed, it’s a hammer and chisel job basically so he said that is a road I don’t wanna go down

at the moment. He said that would be, you're talking maybe a few years down the line before I'd even consider it which to be perfectly honest, I don't think I'd want it at this moment. Because it's err ... I know me friends husband had it done ... and 2 years down the line, he's still walking with a stick. So it's just ... it so dodgy near your spine I suppose. So I think, I'm not so sure, I don't want to be anymore crippled than I am at the minute.

Back pain was, one of the pain sites discussed as the site which held the greatest risk and the least certainty of success. The women living with back and/ or neck pain were not only wary of the risk but they were also aware that there was no guarantee of anything:

They [Jewett brace] tend to do more harm than good. I realised that after wearing this thing for the day, I had to take it off at night and my back would just totally collapse. I would have no strength in my back whatsoever to hold it up at all. so yea, they didn't do a lot of good in that respect.

Migraines, similar to back pains, were usually treated with medication but with a much better prognosis. All the women who experienced migraines believed that the medication they were prescribed by their doctors succeeded in keeping the pain at bay:

At one time I used to have a migraine three times a week. It was terrible really bad, not so bad now because touch wood because I have some tablets. They've not been too bad since I've been on them. Then it was horrendous!

So, although migraines were described as the most debilitating pain site, it was also the site that was most easily treated with the least intrusive intervention.

Pain site influenced not only the ability for the pain to be taken away but also the attitudes towards whether or not the pain should be taken away and the risks and costs involved in doing so and the feelings evoked by health professionals either of safety and hope or abandonment and isolation.

Sub-ordinate theme: Ability to fulfil previous roles

Being unable to work and play in the same manner as prior to the onset of the chronic pain subsequently left these women feeling unable to continue with the roles they used to fulfil. For the

majority of the women who took part in this study, the role that was primarily affected was the role of carer, carer of children, husbands, elderly parents and the home in general:

I was doing more than I was physically capable of and that made me feel mad because I wasn't able to do it and when my dad was put in a nursing home I would have happily looked after him but I wasn't able to do it.

For some women whose husbands had retired earlier, the role they could no longer fulfil was the financial provider because they were unable to work.

I used to work, I was doing office work but I couldn't sit for the length of time that you need to sit, you know . . . There's less money coming in now.

Beliefs about retirement and being a grandmother were challenged. Things that had been planned for years were no longer achievable leaving these women feeling frustrated and cheated:

So yea life's cheated me in lots of ways...my husband put saving plans in place years ago for us to travel when we retired and now we're not fit enough to do the travelling we would have liked to do. The travelling is, every year, more and more difficult . . .

Super- Ordinate Theme – Who I Should Be Vs Who I Am

This Super – ordinate theme is tied in with two of the previous sub –ordinate themes; the ability to work/play and the ability to fulfil previous roles. The combination of these two sub-ordinate themes subsequently led to the question, “Am I still who I used to be if I can't do the things I used to do?”

The once coherent sense of self is challenged and potentially results in feelings of worthlessness and helplessness two key components of depression.

Sub-ordinate theme: Beliefs about self/ identity.

The majority of people have experienced acute pain at some point within their lives and potentially try and use this as a template for describing how they react to pain. The women found that this template,

however, was not always accurate when the pain had persisted for several weeks, months and years. Hence, the beliefs about themselves and who they are were challenged further:

I mean having to accept that I'm disabled wasn't easy. Other people are disabled, I just have back ache. That's what I used to think, but now I'm registered disabled....It makes me feel old, and decrepit and past it and useless.

Women with pain in sites that prevented them doing things that they felt were pivotal to the roles that they used to play and thus formed a sense of identity from, struggled with self definition when unable to carry out these roles. The women were left feeling pushed out as if their role could easily be taken away from them and they be rendered useless. They worried that other member of their defined groups; family or social would think they were disposable and their feelings of value and respective importance within that group be reduced:

. . . it does make you feel less valuable. When you're used to doing everything and then suddenly you can't do it, you get mad with yourself.

There was also a sense of loss of what should have been. The women talked about how they had planned their life to be before the chronic pain had begun and how they had been cheated out of it. This was not only in terms of careers but also personal presentation to the world in regards to choice of clothes and showing their personality through the medium of fashion:

When things like that do happen, because you think yea I should be like everybody else and I'm just not.

Cant, I'm sick of not being able to wear heels on me shoes as well. I've got a tribunal on Friday and I though ooohh I'll put me black trousers on go looking smart and I thought I can't, I can't because I can't wear me heels and I won't look right with a pair of trainers on, So I can't wear skirts or dresses or ought like that....like if [name] says do you want to go for a meal ... I enjoyed the meal but I think I can't get dressed up like I'd like to get dressed up.

Sub-ordinate theme: Perceived weakness

The feeling of uselessness evoked due to the inability to define a useful position for themselves within their defined groups resulted in feelings of powerlessness and weakness. Many of the women discussed feeling less independent than they used to be. There was increased dependence on the people around them and a general feeling of being a burden:

They'll do anything they can to help me it's just I feel as if I'm constantly putting on people.

I think people talk down to people in wheel chairs. They tend to. Unless you've got a strong character... it makes you feel sort of helpless.

Being a burden, especially when the people helping were their children, lead to immense feelings of guilt and dissatisfaction with the self. This often led to a determination to do things for themselves and to not let people around them know how they are really feeling insisting they had the capability to do something even though they knew they would be unable to manage:

Its I, I'm trying to think of the word, ermm, I just feel lost I don't feel like me ermm, I put on a front in front of people especially my daughters, I don't want them to see me down or upset or you know and they'll come in [pause] they're just like oh mam I'll do that for ya and it's like oh no I can do it I can do it, no I'll do it for you mam no let me do it. And I can't do it really but I'll try. I just feel useless and upset all the time.

When people around them offered help, although on a cognitive level it was understood that the help was being offered out of kindness and necessity, on an emotional level it, reinforced feelings of weakness and dependence and rose suspicions that others thought the same of them:

If I think I will just try have a slow walk to the shops, usually one of the girls, I'll go mum...no no you can't do it your too slow...But I feel like saying I am not a total invalid I can do things, I want to try and do it....we could be there and back while you thinking about it basically and that it annoys me and upsets me, and I know they are only doing it for my own good.

Super- Ordinate Theme – Threat to Survival

This two sub-ordinate themes within this super – ordinate theme appeal to the one of the most basic and primitive nature drives of human beings, the drive to survive (Khantzian & Mack, 1983). This drive first involves the detection of threat and then a response to it; fight flight or freeze. Literature on acute pain indicates its involvement in the detection of threat, warning of potential damage to the body which could lead to increased threat of death either from the actual damage or the inability to protect the self (Unruh & Henriksson, 2001). Although this is not the case for chronic pain this is not widely understood by the majority of people living with chronic pain who still use model of acute pain from which to draw information concerning their chronic pain.

Sub-ordinate theme: Physical death

As discussed earlier, the meaning associated with a particular area of the body is likely to determine the reaction to the development of pain in that area. Survival can be maintained without certain limbs such as a leg or an arm, but there are certain organs that are essential, the brain/head being one, the heart being another. Other organs or limbs or systems within the body cannot compensate for their role in sustaining alive and therefore, pain in these areas can be very distressing and frightening because of the potential of what might happen - death.

Over the last few months since the heart attack I've just sort of like got the attitude I just can't be bothered to do anything....yea it is frightening because, and it is depressing as well because it's like ermm u get a twinge and or you feel the heart palpitations and it makes me cough and I sit there and I think, oh god, you know, don't let me have another one.

Meaning was also construed on a more personal level. Past experiences of acute or chronic pain can influence beliefs of consequences of pain in that area. It appears that the pain site is more influential than the illness identity or the opinion of professionals in regards the association of past experiences and current experiences:

Well I'm thinking it seems a bit strange [name – maternal cousin]'s got it and I've got it and it runs in the women in the family and its [name – maternal cousin]'s left kidney and my left

kidney it was me auntie's left kidney. Even my late mum had kidney failure! they said no, it was, we didn't have to worry about it because it wasn't a genetic thing it didn't run in the family but our [name – maternal cousin] is terrible with her kidneys and so, and I've started now and I'm thinking well, have they got it right?

The fear of physical death was more significant than the actual pain sensation. When asked where the worst pain was, this lady replied,

Possibly the base of my spine because when I get it in there, that's really, I can hardly walk when I've got it right in the base of me spine. But at the minute, I mean my kidneys sometimes, it just stops me dead in my tracks. So I don't think I'd like, I don't like this pain in my kidneys at all. [Mum died of kidney failure.]

Sub-ordinate theme: Isolation and abandonment

Lack of role, reduced feeling of value, increased dependency and feeling like a burden on all those around led these women to believe that the people around them would want to leave them or push them out of the group:

There's things that they certainly won't ask me to do. If they're going to do something, they won't include me, you know, deliberately because they just know that I wouldn't be able to. If I feel left out? Yes I do, sometimes feel left out.

This feeling was reinforced as the months of chronic pain became years and decades of chronic pain and friends and family stopped responding to illness behaviour with panic and concern but rather understood the behaviour as normal for that person, thus leaving the woman experiencing the pain to believe that they no longer cared:

They [participant's children] don't really understand what I am going through they just see me as normal. If I say I'm not feeling well nobody will do anything or, it'll just be oh well its mam as normal.

This was particularly an experience of the women whose children were still living with them but reaching the age that they would want to move out. Again, cognitively these women were able to

reason that the children were leaving because of the stage they had reached in their lives and therefore would not ask them to stay. The fear, however, that life without them would be very difficult and the reality that they were very dependent on their children for daily living led to heightened anxiety and the desire for them to stay. Knowing they would have to go increased depressive feeling, wanting them to stay created guilty feelings both of which according to the BPS model of chronic pain (Turk & Monarch, 2001) likely worsened the overall pain experience:

Everything goes through me mind, everything so.... I'll just have to see what October brings I suppose. [whispers] I keep hoping she'll change her mind [re: daughter moving away]. But I don't think she will [pause].

Super- Ordinate Theme – Coping

These women were fighters and all insisted on survival both physically and emotionally. All the women had experienced moments when the pain had been stronger than they had been but yet had managed to overcome it and devise ways to live with pain, do things to maintain a sense of value and worth and either developed new roles or developed ways of fulfilling the old ones. All were true examples of the strength of the human spirit.

Sub-ordinate theme: Attachment seeking behaviours

Some of the women, when they realised that their carers, in most cases their children, were leaving, reverted to acting out similar behaviours as a child would when its parents leave. The behaviours included crying, getting angry and refusing to do things for themselves and care for themselves insisting that the only person who can do it was the person who was going to leave:

I mean, its ermm, it's funny on a weekend when they [daughters] go away [voice shaking] and it's like when I'm [clears throat] in here on me own... and it's like ermm... I can't be bothered to eat and they tell me off [clears throat fighting back tears] . . . My mum invites me round when I'm on me own because she knows I won't eat anything when I'm on me own. I forget, I forget to eat ermm or I'll sleep in. I just won't get out of bed.

Some of these behaviours were carried out in the presence of the person who was leaving and others were done behind closed doors because the more conscious and cognitive processes were able to evaluate the behaviours and although not unjustified, as any separation is difficult not less one with someone who acts in a parental role towards you, but unhelpful for the progress of their children leading to a dilemma of which role to play; the supportive parent or the needing patient:

But I won't say nothing to them you see and I say to them oh yea! Alright then! You need this you need that and I've helped them. I don't really want them to move out coz I don't really want to be on me own.

Sub-ordinate theme: Re-establish sense of self

In addition to the more primal reactions to a separation, the fighting spirit within these women encouraged them to re-establish themselves in their new situation. This was not necessary for all the women, only those whose pain site had threatened their ability to perform their roles and their ability to do things. All the women focused primarily on their family as their purpose and the foundation from which they built their sense of self and identity as wives and mothers:

All I ever wanted as a little girl was to grow up, find a nice man, have a nice home and have my babies.

The majority of the women held onto this. With grandchildren nearby some re-established themselves as grandmothers. Those without grandchildren remained very much mothers and wives noting that:

It's not something you can choose, you just have to get on with it. You have not to let it spoil your life. Children rely on you, they need a parent and they certainly don't want a miserable one.

Others found purpose in looking after others or raising money for charities and even though the pain was still severe armed with a new purpose and a reason to exist, these women were able to push through the pain and do it anyway:

I put my name in the list of the local library as a speaker to raise money for CLIMB. I did a talk about the charity and what it's living with a child or children affected my metabolic

diseaseWhile I'm doing things like that, I can forget about the pain ... It's given me a sense of purpose.

Some of the women took solace in the realisation that things could be worse. The women whose pain site was not pivotal to their sense of self realised that had it been, things could have been a lot more difficult. Interestingly, the effects of emotional pain were perceived to outweigh physical pain:

I've lived, I've had a lot of fun probably which outweighs the pain I'm going through and I'm quite happily going to go along just managing as I am because I think there's far worse, greater pains than I'm going through. People have to suffer far worse pains say the pain of losing a child or, it's not until you sit and think about the sorts of pain that there are.

Others simply found peace in the midst of their storm by re-establishing the power in balance between them and their chronic pain with the power being in their favour:

But err, the good thing is when I learnt self hypnosis that was brilliant coz I can, well I can go to bed and go to sleep

Sub-ordinate theme: Fighting against it all

This final sub-ordinate theme was also the ending theme of all the interviews. The women showed their determination to survive and prove they are a valuable member of their groups not to be left trailing at the back preventing the group moving forward. If someone was going to slow things down and at the back it was not going to be them and it certainly was not going to be as a result of the pain regardless of the pain site:

I don't want anything else to go wrong. I don't want to be the one at the bottom of the heap that everyone feels sorry for.

You've got to put pain into perspective, where it belongs and that's not above everything else in your life.

Discussion

The organisation of super and sub-ordinate themes is in accordance with the interpretations of the text and its meaning from the researcher's perspective taking into account the researcher's pre-understanding, naive understanding and the results of the structural analysis to create a comprehensive overview. Although similarities were identified, each woman's narrative was individual.

The nature of human experience and the double hermeneutic make it difficult to neatly categorise the meaning of experiences into mutually exclusive or independent groups which accounts for the overlap and relationship between themes. "One theme always implicates the meaning dimensions of other themes" (van Manen, 1997, p. 168). Figure 2.1 has attempted to formulate the identified themes that were unveiled and to incorporate them with the CMS Model.

[FIGURE 2.1 ABOUT HERE]

The human world of lived experience implicates an interdependence of the human being and his external world (Heidegger, 1962; Merleau - Ponty, 1997). The body has been described as the vehicle used to access the world (Good, 1992) and the foundation for human perception (Merleau - Ponty, 1997), therefore, how it interacts with its surrounding environment are important factors in the development of meaning. It follows that any change to this interaction will challenge the meanings and beliefs that have developed with this interaction as their foundation.

The physical strength and make-up of the body determines our abilities; our abilities influence our activities and occupations and what we do; what we do amongst other factors, influences how we define ourselves. When abilities become inabilities the experience of being in the world is ruptured and our identities challenged (Gadow, 1980). In turn what we believe about ourselves determines the activities and occupations that we attempt and the body develops to fit these activities and occupations. The body as a whole affects our beliefs about ourselves and our beliefs about ourselves affects our bodies.

A change in either of these is to exist in a manner different to before and the sense of wholeness between the body and the self is lost (Charmaz, *The body identity and self: Adapting to*

impairment, 1995). It was proposed that “when chronic illness, crashes into someone’s life, it cannot help but separate the person of the present from the person of the past and effect or even shatter any images of self help for the future.” (Corbin & Strauss, 1989, p. 249). The person is then left to reassemble a sense of order after the fragmentation caused by the chronic pain (Williams, 1984).

The body, although a whole, is also parts. Limbs and organs, and different parts of the body enable different activities and occupations thus will influence beliefs about the self differently. Therefore, a change in one area of the body will affect beliefs on the self differently than change in another area of the body.

In addition to this, the loss of ability and potentially activity, one of the main factors influenced by pain site for the women in this study, can impact on a sense of purpose. Without a sense of purpose or a reason it is difficult to continue to fight through the struggle. Nietzsche stated that “He who has a why to live can bare almost anyhow” (Frankl, 1993). Perceiving oneself to be without purpose and of use can lead to feelings of alienation and of being invisible to those around us, leading to the deepest feelings of loneliness (Younger, 1995).

The nature of chronic pain, particularly the fact that it can last between 6 months and a life times means that new purposes and reasons to continue the struggle need to be developed on a continual basis. For some of the women in this study, the main purpose was to be a carer to their husbands, children and parents. The onset and persistence of chronic pain caused this to change and not only were these women unable to be carers, they also, had to be cared for. With others filling their roles, they were left feeling de-valued and useless. In a systematic literature review exploring gender differences in the experience of chronic pain, women were found to have similar experiences (Olojugba & Frizelle, in submission, 2009). They were found to work hard to resist the sick role and insisted on putting measures in place to allow for the continuation of the fulfilment of their role.

The loss of purpose and the challenge to beliefs about the self can be classed as a threat to coherent identity – one of the reference values in the CSM model.

The other reference value, goal to survive, was also influenced by pain site. In line with the reasoning that different areas, limbs and organs of the body are involved in different life activities and establish different abilities, it follows that chronic pain in an area of the body, when pain is believed to signify damage (Unruh & Henriksson, 2001) can suggest a threat to life. In addition to this, it was shown that pain site influenced abilities and therefore it influenced changes in contribution to and need from a group. Perceived excessive need and drainage on a system can lead to fears of exile and abandonment. Exile and abandonment when unable to care for oneself ultimately means death. Issues around abandonment and isolation can be considered as important as previous research suggested there was an over-representation of insecure attachment styles within patients living with chronic pain (Mikail, Henderson, & Tasca, 1994) which is likely to leave them feeling an increased vulnerability to abandonment and therefore result in a higher frequency of attachment seeking behaviours.

Again the chronicity of chronic pain gives substantial opportunity for friends and family to move on with life and this to be perceived as abandonment. Reduced mobility and increased medication also impacts on the ability to socialise and be part of a group leading to feelings of isolation and further threat to survival.

The CSM self regulatory model is about the discrepancy between these reference goals and the perception of the situation. Pain site influenced illness identity, cause, consequences and control/cure.

When the pain was experienced as gynaecological pain, it was difficult for the women to describe the pain and they often likened it to intense menstrual pain thus blurring the illness identity and the distinction between where menstrual pain ended and chronic gynaecological pain began. This likening to menstrual pain resulted in women feeling they just had to cope with it because it was part of being a woman. This seems to be characteristic of women living with chronic gynaecological pain and was evident in the study conducted by Grace & MacBride-Stewart (2007). Women generally felt a sense of having to cope with pain regardless of the pain site. The reason for this appeared to be less about a predisposition as a woman to cope with pain but more a sense of responsibility towards those around her. The experience of chronic gynaecological pain is exclusive to women and therefore it follows

that having pain in this site is likely to be different from having pain in any other location. The meaning of having pain in this site was indeed different from having pain in sites such as the back or shoulders but the meaning given to it depended on the woman attributing meaning to it. The two illness representations that contributed to the meaning attributed to gynaecological pain were; Consequences and Control/Cure. Some of the women felt very strongly about being a parent and the idea of being unable to have children was far worse than living with excruciating pain for the rest of their lives. For others, the higher likelihood that the pain could be taken away by a fairly common operation (hysterectomy) was more important. This was particularly evident in women who had already had children, for younger women who did not yet have a family this may have been less of an option.

Pain site influenced the perceived cause of the pain to the extent that women were less inclined to believe the diagnosis of the doctor if they had had a prior experience of pain in that area, either personal experience or witnessing a significant other suffer. This was especially true if the ailment had led to death again suggesting a hypervigilance to perceived threats to survival.

As previously, the ultimate consequence for pain site was life or death. By influencing abilities and interactions within groups pain site is able to determine the ability to fend for one's self and to influence roles and usefulness within a group – both of which can lead to immediate death or isolation from the group leading to death.

Finally, pain site influenced not only the ability to control/cure the pain but also attitudes about who and when they should receive which treatments. Factors that determined the distributions included age, financial considerations and beliefs about the pain. In the majority of cases these decisions were made by external bodies and left the women (who were already feeling de-valued, useless and powerless) feeling as if they had no control over the control/treatment of their pain, reinforcing perceived weakness and threat to survival. This was especially difficult as women have been found to experience some doctors as dismissive especially towards menstrual pain and associated problems (Scambler & Scambler, 1993).

The feelings of uselessness and inability also affects the women's perceived ability to be able to control pain themselves or counter what the doctors or specialists have recommended (even if they do not agree) and instead accept any intervention they are given without so much as enquiring what they are being given or why:

It's just recently I've been told that they do not recommend them [Jewett Brace¹] anymore because they tend to do more harm than good. I realised that after wearing this thing for the day, I had to take it off at night and my back would just totally collapse. I would have no strength in my back whatsoever to hold it up at all. So, yea they didn't do a lot of good in that respect...I literally don't think anything can be done. Apart from the injections, and I'm not quite sure what I'm being given. I get them every four months...but even if there was something that, even like that brace that I could wear that would ease the pain when it is really bad. I would wear it, you know, even if it looked unsightly like the other one did.

This was in line with the experience of MacDonald (2004) who described being told she was too young for surgery and responded, "I'm too young for pain too!" (MacDonald, 2004, p. 20).

A reduced level of control was experienced by the women in this study – both between them and their health professionals but also within their families and social groups.

Children now make the decisions as to what is considered acceptable activities and what is not. Friends decide what social events can be attended because they are less strenuous than others and husbands even made decisions about some of the women returning to work or not. Dealing with the loss of control is one of the most difficult aspects of moving to a place of acceptance where acceptance is taking responsibility for building a new life which allows for the chronic pain and does not exacerbate the intensity and frequency of symptoms (Register, 1989).

¹ The Jewett Brace is a thoraco – lumbar – sacral orthoses (back brace). It is fitted to the torso allowing the extension but restricting the flexion of the spine offering support and holding the body upright.

Conclusions and implications

The nature of chronic pain and its' complex interweaving of social, personal, spiritual and medical factors can only really begin to be explored through the researching and acknowledging the individual lived experience of chronic pain (Dill, Brown, Ciambone, & Rakowski, 1995).

Pain site influenced four of the five illness representations proposed in the CSM Model (Leventhal, Brissette, & Leventhal, 2003).

There was also substantial influence on the reference values. Pain site proved to be an influential factor in the experience of pain. Pain site was seen first and foremost as the decider of abilities by dictating the length of time that could be spent sitting, standing, walking or any other form of mobilisation and the level of support that could be provided throughout the body. This, therefore, influenced what these women were able to do and how long they were able to do it. The increased dependence on others, threat to identity and the perceived threat to survival lead to increased emotional arousal; anxiety, guilt, anger and frustration are examples of the affect that was expressed throughout the interviews in response to the prolonged experience of chronic pain. In spite of this, however, the women who participated in this study managed to fight through the hard times and re-emerge with a determination to survive and to gain a new understanding of who they are and how they fit within their environment. One of the main differences between the experiences of acute pain and chronic pain is the timeline. When living with chronic pain, the possibility that it will never go is a tangible belief and therefore it is necessary to fight through the dark times with determination and rebuild the self rather than just cope with the discomfort for a few weeks or months until the acute pain subsides and life returns back to how it was before the onset of the acute pain.

The CSM Model stipulates that once a discrepancy has been found between the perception of the situation and the reference goals, emotional, behavioural and cognitive processes are put in place to reduce the discrepancy. Therefore, the meanings and experiences that are attributed to chronic pain because of the pain site will be involved in determining the different processes that will be activated

to decrease the discrepancy. Some of these processes are helpful and some of them are not as most on ideas formulated from acute pain rather than chronic pain for example when pain is located in a site which required movement a behavioural process may be to decrease movement to prevent further damage or gynaecological pain may be tolerated because beliefs regarding period pains suggest that is what women do.

With this in mind and because knowledge and understanding has been shown to be important for women to re-gain control of their health, reduce feeling of powerlessness and improve health outcomes (Grace V. M., 1994), it is evident that interventions for women living with chronic pain need to include; education on the difference between acute and chronic pain. Measures taken to cope with acute pain are often not helpful when coping with chronic pain, such as, reduced movement and use of the part of the body in pain which actually leads to stiffness and an exacerbation of symptoms (Vlaeyen & Linton, 2000). Increased education on treatment options and clear and person specific costs and benefits of each option would help to dispel beliefs of weakness and useless around the control and cure illness representation.

Psychological interventions should also endeavour to address the issues of loss in terms of role and identity and to aid to the acceptance of the body in its new state but also understanding that it is the meaning that is attributed to the pain site and its function within daily life that determines whether roles and identities have been lost or not.

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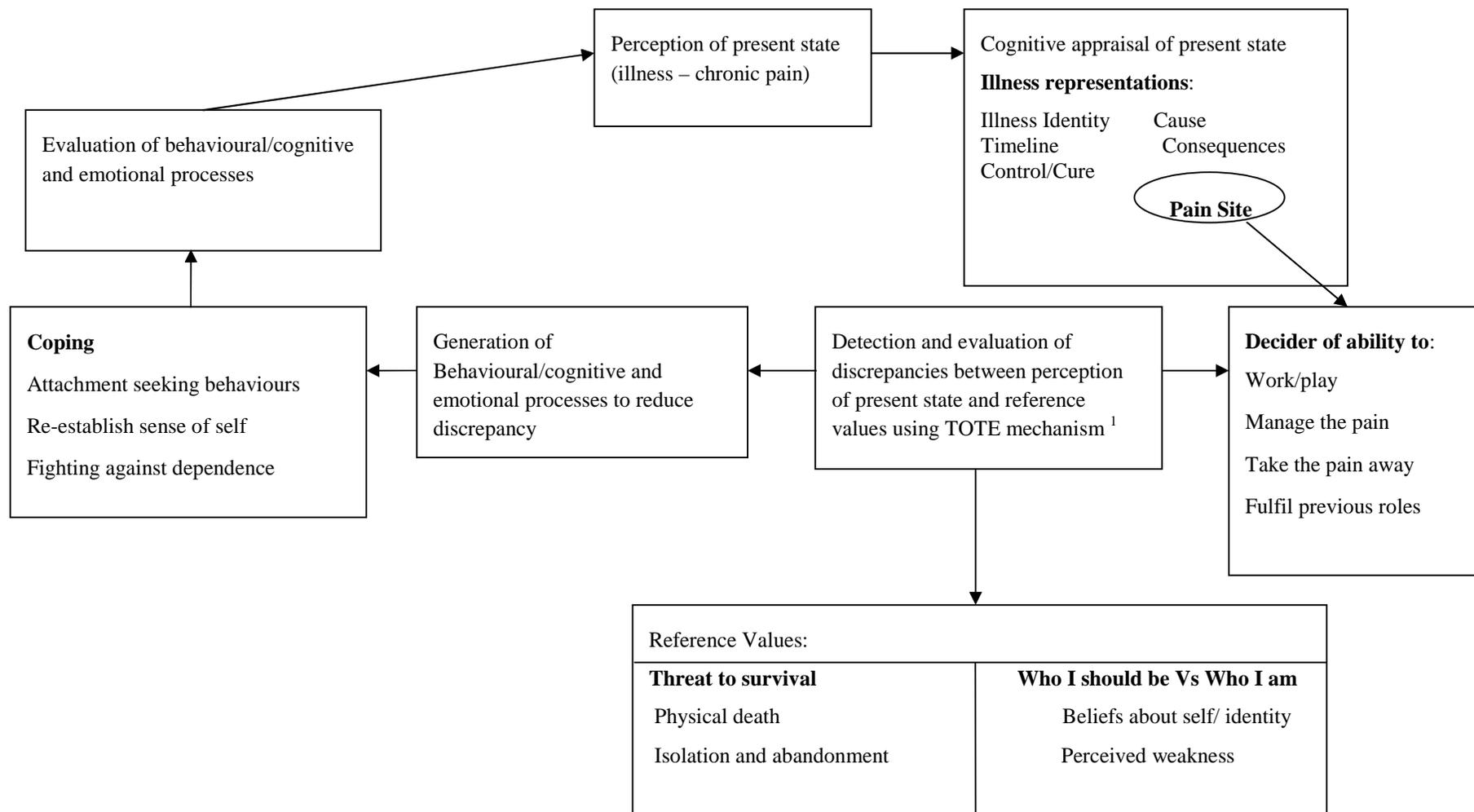
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Table 2.1**Titles of Super and Sub-ordinate Themes**

| Super-ordinate Themes | Sub-ordinate Themes |
|---------------------------------------|----------------------------------|
| Pain Site as the decider of Abilities | Ability to work/play |
| | Ability to manage the pain |
| | Ability to take the pain away |
| | Ability to fulfil previous roles |
| Who I should be Vs Who I am | Beliefs about self/ identity |
| | Perceived weakness |
| Threat to survival | Physical death |
| | Isolation and abandonment |
| Coping | Attachment seeking behaviours |
| | Re-establish sense of self |
| | Fighting against it all |

Figure 2.1

Formulation of Relationship between Themes



¹ TOTE Mechanism: TOTE (Test – Operate – Test – Exit) Mechanism: Feedback loop used to govern the acts of the self regulating system by testing the current status against the reference values, operating to reduce the discrepancy between the current status and the reference values and retesting. This is repeated until the current status and the reference values are suitably matched and the system exits.

Part Three

The Male and Female Experience of Pain: A Systematic Literature Review of Gender

Appendix 1:

Reflective Statement

Reflective Statement

Initially, I chose to explore chronic pain purely for academic reasons. I was interested in chronic pain because of its ability to baffle the medical and scientific worlds for decades. I was keen to partake in the academic challenge of understanding chronic pain or at least adding something to this subject area. It was not until the interviewing process began that the real impact of living with chronic pain hit me. Speaking to the women who took part in this study gave me a new reason to continue studying and working with chronic pain. It was no longer an academic challenge but it was necessary as a clinician who cares for people to offer something to people who are struggling everyday for years with chronic pain.

Whilst conducting this study there were times when I felt hopeless that there was nothing that could be done to help these women and in particular my study was not going to find any miracle cure overnight or even by the end of the year. I felt useless and believed my study to be pointless and of no use to the women who were so kind as to give me their time. It is hard to keep going when you feel this way. It was the determination of the women who in the face of severe chronic pain continued to live and care for their children and find meaning in their situations that encouraged me. If they could do it, I can do it – I can learn from them and produce a worthwhile piece of work. As I analysed the transcripts, it dawned on me the feelings of uselessness and pointlessness were transference feelings from the women who were living with chronic pain. All, without exception, described feeling they had no value and were no longer needed around because they were useless. I think I also picked up on the desperation for a “cure” that although not overtly expressed was felt by the majority of the women. Being unable to deliver this may also have triggered feelings of uselessness.

Originally, this study was going to compare differences between the perceptions of women living with chronic gynaecological pain and women living with chronic musculoskeletal pain. Unfortunately, it was very difficult to recruit the number of participants required from the gynaecology population. Upon reflection, I wondered if one of the reasons for this was because the Consultants and the Specialists hardly ever specifically asked their patients if they were in pain

presuming the GP was dealing with that aspect of the problem and at the same time, the GP thinking that the referral had been picked up that the Consultant was taking over the management of the whole case including the gynaecological pain. On one occasion, when I was attending the clinics, I asked one of the Consultants about helping their patients with the management of pain and she confessed that Gynaecologists are not very good with asking about pain. I found this rather surprising because other than excessive bleeding, the most likely reason to present to a Gynaecologist is pain. I wondered what these women did to cope with the pain whilst waiting for the treatment that the doctor was going to give. I wondered why the women themselves didn't mention that they had pain. What was happening within this dynamic that prevented this conversation happening? I think the answer to this can be found in the results of the Systematic Literature Review and the empirical paper that showed both women's and some health professionals beliefs about women's capability and pre-disposition to live with pain evidenced in menstrual pain and childbirth. This made me think about my own reactions, granted not to chronic gynaecological pain, but to acute pain at least. Did I react differently to acute gynaecological pain than I did in other areas? I believe that I do. I am less worried about gynaecological pain, (unless caused by a distinct physical trauma to the pelvis or lower abdomen)than I am about pain in other areas. I think the reason for this is not because I think as a woman I should be able to cope with it and that I am designed to do so but rather because I can attribute the pain to something familiar and not fatal or damaging. This is similar, in my case, for headaches. I often experience headaches probably because of the light reflecting haphazardly off the dirt particles on my less than frequently cleaned glasses, and therefore when I have headaches although a nuisance, I am not filled with worry and dread. It is not, however, often that I would experience pain in other parts of my body without there being some overt cause for it and my immediate reaction is that it must be something serious like leukaemia and therefore react accordingly.

As mentioned earlier, the initial aim of this study was to compare the perceptions of women living with chronic pain in two pain sites. When the issues around recruitment arose this had to be reviewed. I did not have the time nor the desire to change my topic. It was eventually decided that rather than conduct a quantitative study comparing two pain sites, that a qualitative study looking at

the meaning of pain site within the experience of pain would not only be feasible but possibly even a better alternative.

I think the alteration in the study may actually add more to the chronic pain knowledge base. I realised that my research was not going to uncover all there is to know about chronic pain or lead to the discovery of a miracle cure for everybody that is living with it. It was, however, going to help clinicians understand the differences within the chronic pain phenomena and thus help those living with it with the day to day management of it in their lives by establishing that chronic pain is a term explaining the length of time rather than being an illness identity and that individuals living with chronic pain are not a homogenous group that can be treated as such. My supervisor wondered if this was a continuation of transference and that perhaps my realisation this study is not useless after all and, adapting a Winnicottian phrase, describe it as 'good enough' (Winnicott, 1953) with the potential to impact the lives of women living with chronic pain was in fact echoing these women's journey to acceptance and realisation that they are "good enough" and not useless after all. I agreed this was a possibility.

The new methodology was beneficial both for me and for the women who participated; Grace & MacBride-Stewart (2007) stated that women living with chronic pain reported feeling believed and validated when asked to take part in research and a few of the women said they appreciated having someone to talk to even if only for one hour or so plus the interviews also gave me the opportunity to sit without interruption and listen to the narratives that were told to me. In addition to the benefits of the interviews, the IPA analysis enabled me to fully immerse myself in these women's interpretations of their lives as a result of the chronic pain which in itself is very intense and enlightening experience which I feel privileged to have done.

It was not, however, an easy experience, I often left the interviews feeling a sense of hopelessness and helplessness which, as discussed earlier was reflected in my feelings about my research. During the analysis process, it just happened that my housemates had gone away so the feeling of loss, abandonment and isolation was heightened leaving me in a sense of confusion and

despair, not the best working environment! With the aid of research supervision, peer supervision and the memory of the determination and strength of the women I had met on this journey I was able to continue and come out of the other end feeling empowered and proud of what I had achieved.

This was a challenging and rewarding experience which has encouraged me to make sure that research remains a vital part of my career.

Appendix 2:

Journal Choice

Systematic Literature Review

Written in accordance with the guidelines for Psychology and Health Journal.

This journal was chosen because it focuses on psychological aspects of illness and makes this knowledge available to a wide range of health professionals. This is especially important in the field of chronic pain as much of the research available to clinicians focuses on the biomedical and neuro-pathological aspects of chronic pain. Although important, this is not the complete picture for chronic pain. Factors such as gender differences in the experience of chronic pain are essential knowledge for clinicians involved in aiding the everyday management of chronic pain.

Psychology and Health reported an impact factor of 2.083 in 2008

Empirical paper

Written in accordance with the guidelines for Qualitative Health Research.

Whilst undertaking the systematic literature review this journal was brought to the attention of the researcher because a high percentage of reviewed articles were published in this journal. This suggested Qualitative Health Research is a journal that is widely used as a forum to present research on bio-psycho-social perspectives of chronic pain. Additionally, this journal claims to represent many different perspectives including; psychology, family medicine, public health, medical anthropology, health social work and nursing. With such a wide range of perspectives, it is likely to attract the attention of many different health and social professionals and therefore reach clinicians involved in the care of women living with chronic pain.

Qualitative Health Research reported an impact factor of 1.686 in 2008

Appendix 3:

Guidelines for Authors for the Systematic Literature Review (SLR)

Instructions for Authors

INTRODUCTION

Submission of a paper to *Psychology & Health* will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of editor and publisher. It is a condition of the acceptance by the editor of a typescript for publication that the publisher automatically acquires the copyright of the typescript throughout the world.

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Title page: This should contain the title of the paper, a short running title, the name and full postal address of each author and an indication of which author will be responsible for correspondence, reprints and proofs. Abbreviations in the title should be avoided.

Abstract: This should not exceed 200 words and should be presented on a separate page.

Key words: Abstracts should be accompanied by between three and six key words or phrases. These will be used for indexing and data retrieval, and so where appropriate we recommend using standard MeSH terms (the terms used for indexing articles for MEDLINE)..

Reports of statistical tests should include an indication of effect size whenever possible. Reports of randomised controlled trials should state any registration details of the trial and should follow CONSORT guidelines where relevant (see Moher, D., Schulz, K.F. & Altman, D.G. for the CONSORT group, 2001. The CONSORT statement: Revised recommendations for improving the quality of reports of parallel-group randomized trials. *Annals of Internal Medicine*, 134, 657-662).

Style guidelines

Description of the Journal's [article style](#)

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Please use British spelling (e.g. colour, organise) and punctuation. Use single quotation marks with double within if needed.

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| | Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. <i>Journal of Film and Writing</i> , 44(3), 213–245. |
| Book | Author, A.A. (Year). <i>Title of work: Capital letter also for subtitle</i> . Place of publication: Publisher. |
| | Helfer, M.E., Keme, R.S., & Drugman, R.D. (1997). <i>The battered child</i> (5th ed.). Chicago: University of Chicago Press. |
| Chapter | Author, A.A., & Author, B.B. (Year). Title of chapter. In A. Editor & B. Editor (Eds.), <i>Title of book</i> (pages of chapter). Place of publication: Publisher. |

| | |
|--------------------------|--|
| | O'Neil, J.M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B.R. Wainrib (Ed.), <i>Gender issues across the life cycle</i> (pp. 107–123). New York: Springer. |
| Internet document | Author, A.A., & Author, B.B. (Date of publication). <i>Title of document</i> . Retrieved month date, year, from http://Web address |
| | Chou, L., McClintock, R., Moretti, F., & Nix, D.H. (1993). <i>Technology and education: New wine in new bottles: Choosing pasts and imagining educational futures</i> . Retrieved August 24, 2000, from Columbia University, Institute for Learning Technologies Web site: http://www.ilt.columbia.edu/publications/papers/newwine1.html |
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| | Schultz, S. (2005, December 28). Calls made to strengthen state energy policies. <i>The Country Today</i> , pp. 1A, 2A. |
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| Conference paper | Author, A. (Year, Month). <i>Title of paper</i> . Paper presented at the meeting of the Society, City, State. |
| | Lanktree, C. (1991, February). <i>Early data on the Trauma Symptom Checklist for Children (TSC-C)</i> . Paper presented at the meeting of the American Professional Society on the Abuse of Children, San Diego, CA. |

Appendix 4:

Inclusion and Exclusion Criteria for Studies Reviewed for SLR

Figure 3.1 Inclusion and Exclusion Criteria

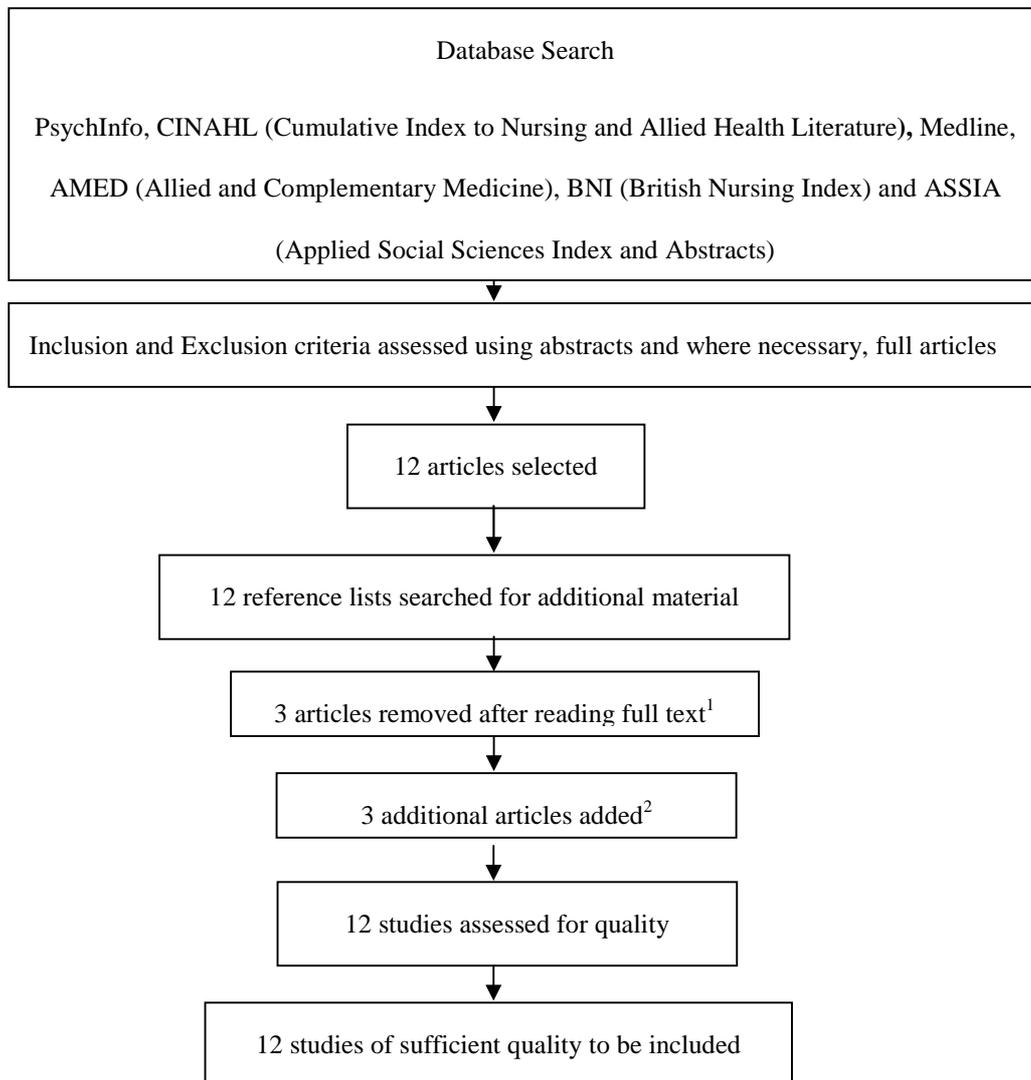
| |
|--|
| <p>Inclusion Criteria</p> <ul style="list-style-type: none"> • Studies that focused on gender issues in the experience of chronic pain • Studies that focused on psychological issues, social issues and the relationship between the patient and their health professionals as part of the experience of pain • Studies that explored men's and/or women's experience of chronic pain • Studies where participants were 18 years old and above • Studies conducted in 1999 – 2009 • Studies that utilised Qualitative methodology <p>Exclusion Criteria</p> <ul style="list-style-type: none"> • Studies that primarily focused on biological experiences of pain - this review is looking at the psychological and social impact of chronic pain • Studies in which gender was not the primary focus – reducing likelihood that impacts of other factors are being falsely attributed to gender • Studies that focused primarily on the assessment process – review is focused on a longitudinal report of experience of chronic pain, onset to present day • Studies that assessed the effectiveness, outcome, benefits or costs of interventions • Review studies - the report of previous studies may be biased or incomplete • Unpublished works and Dissertations, - the review process of these may not have been as rigorous as that of published works. • Case studies – Reduced transferability - ability of results to be applied to similar situations if placed in a new context (Polit & Hungler, 1999)¹ • Studies written in a language other than English - translation may alter the interpretation • Studies conducted outside Europe and Northern America - to control for cultural differences • Quantitative methodology - reported to not capture patient's the experience (McGuire, 1984)² • Epidemiology studies and studies that report only the prevalence and demographics of men and women experiencing chronic pain – do not address what the experience is • Studies awarded a quality assessment rating of (-) – conclusions of these studies are likely to alter if methodology had met sufficient criteria to achieve a rating of + or ++. |
|--|

Polit, D.F. & Hungler, B.P. (1999). *Nursing research: Principles and methods (6th ed.)* Philadelphia: Lippincott.

²McGuire, D. B. (1984). The measurement of clinical pain. *Nursing Research*, 33, 152-156.

Appendix 5:

Flowchart of Selection Process for SLR

Figure 3.2 – Process of Study Selection

¹ Articles removed – Met exclusion criteria: Primary focus of study was not “effects of gender of experience of chronic pain”, Intervention study, Assessment process.

² Articles included – Result from reference search of included studies which met the inclusion criteria and none of the exclusion criteria.

Appendix 6:

Extended Details of Studies Included in the SLR

Table 3.1 Extended details of included studies in Systematic Literature Review

| Author and date | Sample Description | Factors Investigated | Analysis | Characteristics of pain | Themes Identified | Comments |
|---|--|--|----------------------------|--|--|---|
| Grave, VM., MacBride-Stewart, S. (2007) | Total : 40 Gender: Female Randomly selected Age: 18 -50 Country: New Zealand of European descent | Meanings women engage to understand how come they have chronic pelvic pain | Informed by Phenomenology | Chronic Pelvic pain unrelated to dysmenorrhoea or dyspareunia | Six main categories identified: 1. Accepting medical diagnosis 2. Approximating a medical diagnostic 3. Uncertainty through not knowing 4. Women get this 5. After childbirth 6. Painful sex. Hereditry not discussed in article due to insufficient text. Participants found it difficult to distinguish between chronic pain with or without periods. The differentiation from dyspareunia was less blurred. | |
| Gullackasen, A.C. & Lidbeck, J. (2004) | Total : 18 Fibromyalgia-11 Myofascial -7 Gender: Female First 18 fulfilling criteria Age: 23-55; Mean age: 42 60% blue collar workers | Significant aspects and themes in the course of life change because of chronic pain. | Phenomenological framework | 1- 9 years Fibromyalgia (FM) and Myofascial (MF) Pain syndrome as described by the International Association for the study of pain | Three chronological stages with characteristics of each stage, one continuous stage of maintenance. Stage I: Prelude; Struggling to restore life; Self deception; Confirmation; acknowledgement. Stage II: Working through; Sorrow and loss; Losing oneself; Leaving the role of being sick; Defining the problems; Finding solutions; Picture of the future affects coping. Stage III: Establishing the new course of life. Maintenance – Living with pain: Competence of handling future changes; A new attitude to life; Regular self care. | Underlying assumptions are based on a dissertation. Query participants' awareness of researcher role. May influence responses if believe researcher is involved in treatment. |

| Author and date | Sample Description | Factors Investigated | Analysis | Characteristics of pain | Themes Identified | Comments |
|--|--|--|-----------------------------------|---|--|----------|
| Hallberg, L.R. Carlsson S.G (2000) | Total:22 Hospitalised: 10; outpatients: 12 Gender: Female Age:22-60 Strategically selected from a heterogeneous group 19 married Between 7 -15 years of education | What it means to the patient to suffer from fibromyalgia | Grounded theory | Chronic pain associated with endometriosis. | Three descriptive categories each consisting of several codes were generated: 1. Subjective Pain Language – characteristics and perceived origin or cause of pain 2. Diversified pain coping – what they do and think when in pain 3. Pain Communication – how they communicate their pain Higher Order concept: Preoccupied with their pain | |
| Huntington, A., Gilmour, J.A. (2005) | Total :18 Gender: Female Volunteered participation Age: 16 -45 Tertiary level education Working or worked (paid) | Women’s perceptions of living with endometriosis, its effects on their lives and the strategies used to manage their disease | Thematic Analysis Approach. | Fibromyalgia - characterised by pain in all four quadrants of the body and tender points lasting for more than three months in the absence of secondary causes. Symptoms are modulated by physical activity and/or weather; symptoms are aggravated by stress, fatigue, anxiety, irritable bowel syndrome and subjective swelling and numbness | Chronic pain impacted on all aspects of everyday life. The four themes related to pain were: 1. Manifestations of pain. 2. “It comes in waves”: The pain trajectory 3. “I put myself through it and nothing works”: Treating the pain 4. “It’s either suicide or fight”: Controlling the pain | |

| Author and date | Sample Description | Factors Investigated | Analysis | Characteristics of pain | Themes Identified | Comments |
|---|--|--|--|--|---|---|
| Kopenen, R., Kielhofner, G. (2006) | Total: 17 Age: 33-55 Gender: Female Recruited from pain rehabilitation program Country: Finland | How women with chronic pain experience and organise occupations in their everyday lives. | Examination of the underlying metaphors employed by the narrator | Fibromyalgia, Cancer, headaches, Various Musculoskeletal pain and Thoracic outlet syndrome. | A typology of four narratives were identified: 1. Moving forward (hopeful) 2. Slowing down (frustrated) 3. Fighting (fearful) 4. Standing still (dissatisfied/hopeless) Features that distinguished the four narratives from each other were: a) The tone of the narrative b) The meaning ascribed to occupation c) How other's are viewed in relation to one's doing d) How the future is envisioned. | "Occupation involves not only doing but also experiencing and interpretation of that doing..." (Keponen & Kielhofner, 2006) |
| Paulson, M., Danielson, E., Larsson, K., & Norberg, A. (2001) | Total: 14 Gender: Male Age: 41 – 56 years Selected by the same Rheumatology Specialist at a Rheumatic Hospital Married or have a close female partner Homogenous Swedish Cultural background Length of time had pain: 4 – 25 years | How women made sense of their occupational participation and what meaning was found in it. | Content Analysis | Fibromyalgia: Widespread pain in four quadrants of the body lasting for at least three months and eliciting of pain on digital palpations (approximate force of 4kg) of at least 11 out of 18 specified bilateral tender points. | The men's descriptions focused around: 1. Their perceptions of diversified bodily pain 2. Worrying and non-worrying pain 3. Their perceptions of fluctuating pain | |

| Author and date | Sample Description | Factors Investigated | Analysis | Characteristics of pain | Themes Identified | Comments |
|---|--|---|---|--|---|----------|
| Paulson, M., Danielson, E., Soderberg, S.(2002) | Total: 14 Gender: Male Age:41 – 56 years Selected by the same Rheumatology Specialist at a Rheumatic Hospital Married or have a close female partner Homogenous Swedish Cultural background | The meaning of men’s lived experiences of living with pain of Fibromyalgia type. | Phenomenological Hermeneutic Interpretation | Fibromyalgia: Widespread pain in four quadrants of the body lasting for at least three months and eliciting of pain on digital palpations (approximate force of 4kg) of at least 11 out of 18 specified bilateral tender points Length of time had pain: 4 – 25years | Three themes and seven subthemes were identified: 1. Experiencing the body as an obstruction Living with a reluctant body Living day by day with body in pain 2. Being a different man Not being the same man as earlier Not being really understood 3. Striving to endure Living as normally as possible Searching for alleviation Having to nurture hope. | |
| Raak,R., & Wahren, L.K. (2006) | Total: 10 Gender: Female (4) Male (6) | Health experiences, focussed on gender and return to work in subjects with chronic low back pain in a long term perspective | Content Analysis | Non-malignant chronic low back pain. Duration: 5 years except one who had it for 13 months | Five categories were identified: 1. Coping 2. Root causes(explanation of suffering) 3. Control/ influence 4. Pain 5. Sleep | |

| Author and date | Sample Description | Factors Investigated | Analysis | Characteristics of pain | Themes Identified | Comments |
|--|--|--|---|---|--|----------|
| Rahiem, M., Haland, W. (2006) | Total: 12 Gender: Female Age: 34-51 yrs Married/Cohabiting (9); Living alone (2); Living with children (1) 2+ children (11); No children (1) Country: Norway | The existential dimensions of living with fibromyalgia | Hermeneutics Phenomenology Analysis | Fibromyalgia Length of time had pain: 4 -20 yrs. | <p>A main theme was identified. Three subthemes were also identified for three times during the day.</p> <p>Main theme: Lived experience of one's own body – enemy or problematic friend.</p> <p>Subthemes:</p> <p>Lived experience in the morning</p> <ol style="list-style-type: none"> 1. The prison of the body; 2. The body threatens to take full control; 3. Persuading an unwilling body <p>Lived experience in the forenoon or afternoon</p> <ol style="list-style-type: none"> 1. Fighting against the body and giving up; 2. Fighting with or against the body; 3. Forget about the body on the background of taking care of it <p>Lived experience in the evening</p> <ol style="list-style-type: none"> 1. Endless pain, feeling useless and in despair; 2. Overwhelmed by pain and feeling desperate 3. Pain but still coping | |
| Soderberg, S. & Lundman, B. (2001) | Total: 25 Gender: Female Age: 35 - 60 Recruited from a rehabilitation centre and haematological clinic Part time work (12) full time work (2) Sick listed/pension (11) | Transitions experienced by women with Fibromyalgia | Thematic Content Analysis | Fibromyalgia Length of time had pain: 4 -25 yrs | <p>One main theme was subsumed from the five categories identified;</p> <p>Main theme: Fibromyalgia as the choreographer of activity and relationships</p> <p>Categories:</p> <ol style="list-style-type: none"> 1. Transitions in patterns of daily life 2. Transitions in family life 3. Transitions in social life 4. Transitions in working life <p>Learning to live with the changes brought about by Fibromyalgia</p> | |

| Author and date | Sample Description | Factors Investigated | Analysis | Characteristics of pain | Themes Identified | Comments |
|----------------------------------|--|---|---|--|--|----------|
| Soderberg, S. et al. (1999) | Total: 14; Gender: women Age: 35 – 50yrs mean: 43.3yrs Married (9); divorced (3); common law wife (1); single (1). Employed part time (9); full time (2); not working (3). Treated in a rheumatology clinic in a large hospital in Sweden. | Meaning of women's experiences of living with Fibromyalgia | Phenomenological – hermeneutic method | Fibromyalgia. Length of time had pain: 1 -25 yrs Time since diagnosis: 0.5 – 6 years | <p>Three major themes and eight subthemes were identified:</p> <ol style="list-style-type: none"> 1. Loss of freedom <ul style="list-style-type: none"> A body in pain and other bodily sensations Fatigue and loss of energy Living a changed everyday life Economic restrictions 2. Threat of Integrity <ul style="list-style-type: none"> Loss of credibility and the invisibility of the illness Lack of knowledge about Fibromyalgia and negative attitude of society 3. Struggle to achieve understanding and relief <ul style="list-style-type: none"> Seeking explanations and understanding Seeking relief and planning one's daily life in accordance with the illness | |
| Werner, A. & Malterud, K. (2003) | Total: 10; Gender: Female; Age: 26-58 yrs Avg: 26.5yrs Country: Norway Marital relationships (5); Children (6); college education (3) below college education (7); Paid work(5); social benefits (6). Recruited from treatment groups | Self and shame in illness accounts from women with chronic pain | Narrative theory and discourse analysis | Chronic muscular pain – Fibromyalgia and unexplained. Symptoms duration: 1 – 20 yrs; Average: 9yrs | <p>Two illness stories were identified:</p> <ol style="list-style-type: none"> 1. Stories about strength in daily life: “I’ve always been so strong and robust” 2. Stories about the other (whining) women – stories about self: “Some people pour out their troubles...” | |

Appendix 7:

Quality Control Checklist

Quality Control Checklist

The checklist below was used by the National Institute for Health and Clinical Excellence (NICE) when conducting a systematic literature review to inform the development of public health guidance. It was chosen for this literature review because it provided a simple structure for quality analysis and was specifically designed for qualitative studies. It was originally developed by MERGE (Method for Evaluating Research and Guideline Evidence) and has since undergone modification by SIGN Scottish (Intercollegiate Guidelines Network), resulting in a reliable checklist which assesses for key criteria of high quality qualitative studies.

Methodology checklist: Qualitative studies

| | |
|--|-------------------------|
| Study identification <i>Include author, title, reference, year of publication</i> | |
| Guideline topic: | Key question no: |
| Checklist completed by: | |

| Criterion | Is the criterion clearly addressed? | |
|--|--|-----------|
| Epistemology | | |
| 1. Is a qualitative approach appropriate? <ul style="list-style-type: none"> • Does the research seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the question | Appropriate Inappropriate Not sure | Comments: |

| |
|---|
| <p>2. Is the study clear in what it seeks to do?</p> <ul style="list-style-type: none"> • Is the purpose of the research discussed – aims/objectives/research question • Is there adequate reference to the literature • Are underpinning values/assumptions/theory discussed |
|---|

| Study Design | | |
|---|---|------------------|
| <p>3. How defensible is the research design?</p> <ul style="list-style-type: none"> • Is the design appropriate to the question • Are there clear accounts of the criteria used for sampling, data collection, data analysis • Is the selection of cases/sampling strategy theoretically justified • Is a rationale given for the choice of method | <p>Defensible Indefensible Not sure</p> | <p>Comments:</p> |

| Data collection | |
|--|---|
| <p>4. How well was the data collection carried out?</p> <ul style="list-style-type: none"> • Were the data collected in a way which addressed the research question • Was the data collection and record keeping systematic | <p>Appropriately Inappropriately Not sure</p> |

| Validity | | |
|---|---|------------------|
| <p>5. Is the role of the researcher clearly described?</p> <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately considered • Is there evidence about how the research was explained and presented to the participants | <p>Clear Unclear Not sure</p> | <p>Comments:</p> |
| <p>6. Is the context clearly described?</p> <ul style="list-style-type: none"> • Are the characteristics of the participants and settings clearly defined • Were observations made in a sufficient variety of circumstances • Was context bias considered | <p>Clear Unclear Not sure</p> | <p>Comments:</p> |
| <p>7. Were the methods reliable?</p> <ul style="list-style-type: none"> • Was data collected by more than one method • Is there triangulation, or justification for not triangulating • Do the methods investigate what they claim to | <p>Reliable Unreliable Not sure</p> | |

| Analysis | | |
|---|--------------------------------------|-----------|
| <p>8. Is the data analysis sufficiently rigorous?</p> <ul style="list-style-type: none"> • Is the procedure explicit – i.e. is it clear how the data was processed to arrive at the results • How systematic is the analysis, is the procedure reliable/dependable • Is it clear how the themes and concepts were derived from the data | Rigorous Not rigorous Not sure | Comments: |
| <p>9. Is the data rich?</p> <ul style="list-style-type: none"> • How well are the contexts of the data preserved • Has the diversity of perspective and content been explored • How well has the detail and depth been preserved • Are responses compared and contrasted across groups/sites | Rich Poor Not sure | Comments: |
| <p>10. Is the analysis reliable?</p> <ul style="list-style-type: none"> • Did more than one researcher theme and code transcripts • If so, how were differences resolved • Did participants feed back on the data if possible and relevant • Were negative/ discrepant results addressed or ignored | Reliable Unreliable Not sure | Comments: |

| | | |
|--|------------------------------------|-----------|
| 11. Are the findings credible? <ul style="list-style-type: none"> • Is there a clear statement of the findings | Credible Not credible | Comments: |
| <input type="checkbox"/> Are the findings internally coherent <ul style="list-style-type: none"> • Are elements from the original data included • Can the data sources be traced • Is the reporting clear and coherent | Not sure | |
| 12. Are the findings relevant? | Relevant Irrelevant Not sure | Comments: |
| 13. Conclusions <ul style="list-style-type: none"> • How clear are the links between data, interpretation and conclusions • Are the conclusions plausible and coherent • Have alternative explanations been explored and discounted • Does this enhance understanding of the research topic • Are the implications clearly defined • Is there adequate discussion of limitations | Adequate Inadequate Not sure | Comments: |

| Ethics | | |
|--|---|------------------|
| <p>14. How clear and coherent is the reporting of ethics?</p> <ul style="list-style-type: none"> • Have ethical issues been taken into consideration • Are they adequately discussed e.g. do they address consent and anonymity • Have the consequences of the research been considered i.e. raising expectations, changing behaviour etc • Was the study approved by an ethics committee | <p>Appropriate Inappropriate Not sure</p> | <p>Comments:</p> |
| Overall Assessment | | |
| <p>Is this study relevant?</p> | <p>Yes No</p> | <p>Comments:</p> |
| <p>How well was the study conducted? (see table below)</p> | <p>++ + -</p> | |

| | |
|----|--|
| ++ | All or most of the criteria have been fulfilled. Where they have not been fulfilled the conclusions of the study or review are thought very unlikely to alter. |
| + | Some of the criteria have been fulfilled. Those criteria that have not been fulfilled or not adequately described are thought unlikely to alter the conclusions. |
| - | Few or no criteria fulfilled. The conclusions of the study are thought likely or very likely to alter. |

Appendix 8:

Quality Assessment of Studies Included in the SLR

Table 3.2 Quality Assessment of Included Studies

| Quality Control Criteria | Study | | | | | |
|---|---|---|---|--|---|--|
| | Grave,VM., MacBride- Stewart,S. (2007) | Gullackasen,A.C. &Lidbeck,J. (2004) | Hallberg,, L.R. Carlsson S.G (2000) | Huntington, A., Gilmour, J.A. (2005) | Kopenen, R., Kielhofner,G. (2006) | Paulson, M., Danielson, E., Larsson, K., & Norberg, A. (2001) |
| Research question/ Aims clear | Clear | Clear | Clear | Clear | Clear | Clear |
| Appropriate qualitative approach | Appropriate | Appropriate | Appropriate | Appropriate | Appropriate | Appropriate |
| Defensible design | Defensible | Defensible | Defensible | Defensible | Defensible | Defensible |
| Data Collection | Appropriately | Appropriately | Appropriate | Appropriate | Appropriate | Appropriate |
| Clear researcher roles | Not sure | Not sure | Clear | Clear | Clear | Not sure |
| Clearly defined context | Clear | Clear | Clear | Clear | Clear | Clear |
| Reliable methods | Reliable | Reliable | Reliable | Reliable | Reliable | Reliable |
| Rigorous data analysis | Rigorous | Rigorous | Rigorous | Rigorous | Rigorous | Rigorous |
| Richness of data | Rich | Rich | Rich | Not sure | Rich | Rich |
| Reliability of analysis | Unreliable | Not sure | Unreliable | Not sure | Reliable | Reliable |
| Findings internally coherent and credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible |
| Relevant Findings | Relevant | Relevant | Relevant | Relevant | Relevant | Relevant |
| Conclusions | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate |
| Adequately addressed ethical issues | Appropriate | Appropriate | Appropriate | Adequate | Adequate | Adequate |
| Overall Quality Rating (QR) [++/+/-] | + | + | ++ | ++ | ++ | ++ |

Table 1.2 Quality Assessment of Included Studies

| Quality Control Criteria | Study | | | | | |
|---|---|--------------------------------|------------------------------|------------------------------------|-----------------------------|----------------------------|
| | Paulson, M., Danielson, E., Soderberg, S.(2002) | Raak,R., & Wahren, L.K. (2006) | Rahiem,M., Haland, W. (2006) | Soderberg, S. & Lundman, B. (2001) | Soderberg, S. et al. (1999) | Werner, A., et. al, (2004) |
| Research question/ Aims clear | Clear | Clear | Clear | Clear | Clear | Clear |
| Appropriate qualitative approach | Appropriate | Appropriate | Appropriate | Appropriate | Appropriate | Appropriate |
| Defensible design | Defensible | Defensible | Defensible | Defensible | Defensible | Defensible |
| Data Collection | Appropriate | Appropriate | Appropriate | Appropriate | Appropriate | Appropriate |
| Clear researcher roles | Clear | Clear | Not Sure | Not sure | Clear | Not sure |
| Clearly defined context | Clear | Clear | Clear | Clear | Clear | Clear |
| Reliable methods | Reliable | Reliable | Reliable | Not sure | Reliable | Not sure |
| Rigorous data analysis | Rigorous | Rigorous | Rigorous | Rigorous | Rigorous | Rigorous |
| Richness of data | Rich | Rich | Rich | Rich | Rich | Rich |
| Reliability of analysis | Reliable | Reliable | Reliable | Reliable | Reliable | Not sure |
| Findings internally coherent and credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible | Coherent/ Credible |
| Relevant Findings | Relevant | Relevant | Relevant | Relevant | Relevant | Relevant |
| Conclusions | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate |
| Adequately addressed ethical issues | Adequate | Not sure | Adequate | Not sure | Adequate | Not sure |
| Overall Quality Rating (QR) [++/+/ -] | ++ | ++ | ++ | ++ | ++ | ++ |

Appendix 9:

Guidelines for Authors for the Empirical Paper

PREPARING YOUR MANUSCRIPT

GENERAL STYLE

In general, *QHR* adheres to the guidelines contained in the *Publication Manual of the American Psychological Association* ["APA"], 5th edition (ISBN 1-55798-791-2), with regard to manuscript preparation and formatting. [Elsewhere in these guidelines this book is referred to as the *APA Publication Manual* or just *APA*.] Additional help may be found online at <http://www.apa.org/>, or search the Internet for "APA format."

Many universities and private organizations have Web sites devoted to *APA* style. Be aware, however, that whenever guidelines found on those sites, or in the *APA Publication Manual*, conflict with the guidelines included here, ***you must follow the QHR guidelines.***

KEEP IN MIND . . .

- *Qualitative Health Research* is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration; do not send query letters or e-mail messages.
- It is preferred that you write both the abstract and the text of your manuscript in the *first person, active voice*; however, this is not a requirement. If you choose to write otherwise, ensure that the abstract and manuscript "match" in voice.
- We do not publish stand-alone abstracts, *quantitative* studies, manuscript outlines, pilot studies, manuscripts-in-progress, letters of inquiry, or literature reviews. Research articles *must be pertinent to health.*

CONFIDENTIALITY AND PROTECTION OF PARTICIPANT IDENTITY

QHR is committed to protecting the identity and confidentiality of research study participants. With the exception of participant action research (PAR), no information that could potentially allow identification of a participant—or even a specific study site—should be included in a submitted manuscript or, subsequently, included in a published article.

Each study participant referred to in the manuscript should be assigned a pseudonym. Study sites, such as hospitals, clinics, or other organizations, should not be named, but instead should be described; for example: "Study participants were recruited from the coronary care unit of a large metropolitan hospital on the eastern seaboard of the United States." Authors who include participant names and/or photos must submit written permission from the participants to do so.

Manuscripts submitted to *Qualitative Health Research* are "blind" reviewed. *Do not include author information, author references, or acknowledgements in the main manuscript document.*

ELEMENTS OF A MANUSCRIPT

The following elements are ***required*** for each manuscript, and should be compiled in the following order:

1. Title page [submitted as a separate document]
2. Abstract [p. 1]
3. Keywords [p. 1]
4. Main body of the manuscript ([main document"; beginning on p. 2]
5. References

The following elements *may* be included in your submission (they are *optional*):

- A. Notes/footnotes/endnotes [place after the main body of the text, before the reference list]
- B. Tables [place at the very end of the document]
- C. Figures [submit in a separate document]
- D. Appendices are published *only in certain circumstances*, at the editor's discretion [place after the reference list and before any tables]

ORDER OF ELEMENTS

Compile the elements of your main manuscript document in the following order. Each element (except notes) should begin on a new page:

- A. Abstract and keywords - required
- B. Main manuscript text - required
- C. Notes/footnotes (if any)
- D. References - required
- E. Appendices (if any)
- F. Tables (if any)

DOCUMENT SETUP

- Document file type: Submit only documents created in Microsoft Word, and only with the regular file extension of “.doc”; Word documents with “.docx” extensions, PDF files, or other types of documents cannot be accepted for consideration.
- *Do not add any special coding or formatting to your documents that is not described within these guidelines.*

Paper size: Letter, 8.5” x 11”

- Margins: 1” on all sides

* * * * *
- Ellipses/Ellipsis Points: Almost every manuscript contains ellipses. They are used to indicate missing words in quotations, and are to be created in a very specific manner. *Do not* use the “Insert Symbol” function in Word to enter ellipses. The proper way to create ellipsis points is as follows: space/dot/space/dot/space/dot/space (. . .); that is, 3 dots, preceded, divided, and followed by spaces, like . . . this. If it is necessary to indicate missing words between sentences (instead of in mid-sentence), place a period (full stop) at the end of the first sentence, then format the ellipsis points as noted, and begin the next sentence (with a capital letter) immediately after the last space. Do not place ellipses within parentheses or brackets (. . .); the exception to this is in conversation analysis, when appropriate.
- Font Size: 11 point font, including font used for titles, regular text, section headings, and quotations; however, fonts between 8 and 10 points in size should be used in tables and figures
- Font Style, Main Manuscript: Use Times New Roman font. *Italics* should be used *only* (a) as appropriate in the reference list (see *APA*), or (b) to introduce new or non-English words, or new concepts (2 to 3 words), and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular Roman font. *QHR* does *not* use italics for emphasis, and does not use underlining for any purpose other than conversation analysis (conversation analysis does not refer to

regular participant quotations). Bolded font may be used for section headings, as appropriate according to these guidelines, and (sparingly) in tables and figures.

- **Font Style and Formatting of Conversation Analysis:** [*Note that this instruction does not pertain to normal quotations or block quotations.*] Courier font should be used for sections containing conversation analysis (if any). Retain the conversation analysis sections in the desired location among the regular manuscript text, and *do not set them as figures, in a box, or as excerpts*. Use the following steps to apply (required) special formatting to the conversation text only:
 - Set your font at 10 points, Courier style.
 - Set your margins (*only for the sections with this special text*) at 1" on the left, and 4.55" on the right, so the available print area is 2.95" wide, flush left. (*Do not attempt to achieve this with tabs and hard returns; use Word's formatting features in Page Setup.*)
 - The line number, participant pseudonym (or other speaker identification), and transcribed text will need to fit across the 2.95" of printable line space. This is to ensure that the text will fit within the column format of the printed journal.
 - Manipulate your text within this space until you have achieved the desired alignment for all lines.
 - If your article is accepted, be sure to examine the publication proofs of the conversation analysis sections very carefully to confirm that the text is set and aligned correctly.

- **Font Style, Figures:** For printing clarity and ease of reading, "sans serif" fonts are strongly recommended for figures; some common examples include Arial (this is the preferred style), Calibri, Franklin Gothic Book, Tahoma, and Verdana.

- It is recommended that only one font style be used in each figure, with possible variations introduced through bolding, italicizing, capitalizing, or underlining—all of which should be used *sparingly*. It is further recommended that all figures within a single manuscript be prepared with the same font style.

- **Line Spacing:** *Everything, in all elements of the manuscript*, from the title page through the references, must be (exactly) double-spaced. The only exception is text within a figure. To set double spacing, go to Format > Paragraph > Line spacing > Double. *Do not create double spacing with hard returns* (by striking the "enter" key twice).

- **Text Justification:** All text should be left-justified; *do not use full justification* for any portion of your manuscript. The text at the right margin *should be uneven*.

- **Paragraphs:** Indent the first line of every new paragraph by .5" (. inch; do not use two, .25" indentations). Do not insert additional line spaces between paragraphs, or between paragraphs and headings; *the exceptions are (a) an extra line space (hard return) between the abstract and the keywords, and (b) after (not before) each excerpt/block quotation, numbered or bulleted list, or section of conversation analysis*. Use a blank line between block quotes/excerpts if you have placed two or more in a row. *Do not add any special formatting*, such as increased line space before and after paragraphs, or before and after headings.

- **Headings:** *Do not follow APA guidelines for headings*. QHR uses 4 distinct levels of headings (H= level), including:

H1: Centered, Bold, Uppercase and Lowercase Text in Title Case**H2: Flush Left, Bold, Uppercase and Lowercase Text in Title Case**

H3: Indented (.5"), Italicized, Uppercase and Lowercase Text in Title Case

H4: Indented (.5"), italicized, lowercase text in sentence case and ending with a period. At this level, the paragraph text begins immediately after the heading, instead of on the next line.

Use at least two heading levels:

For manuscripts with 2 heading levels, use H1 and H2

For manuscripts with 3 heading levels, use H1, H2, and **H4**

For manuscripts with 4 heading levels, use H1, H2, H3, and H4

- Quotations: Quotations of 40 or more words should be set as separate paragraphs, with the entire quotation indented .5" from the left margin (this is also referred to as a "block quote"). Do not change the right-hand margin. Some quotations of fewer than 40 words may also be set separately for uniformity of appearance. All other quotations should be contained within regular paragraphs, along with regular text.
- Quotation Marks: In general, use double quotation marks (e.g., "Xxxx.") to set off quotations appearing within regular paragraphs, and to set off words being used with "special" meaning (or unusual spelling to convey special meanings within the text; e.g., "busy-ness"). In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., "Xxx, 'Yyy,' xxxx.>").
- Do not use any quotation marks for block quotes *unless* there is a separate quote contained within the larger quote. In such a case, use double quotation marks (e.g., Xxxxxx, "Yyyy," xxxxx.) only for the separate quote within the larger quote.
- Spelling: The spelling of English words varies among the many English-speaking countries of the world. *QHR* is published in *U.S. English*. Use Word's spell check feature to ensure that you have used U.S. English spellings throughout your manuscript. Exceptions to this include (a) direct quotes from *written*, published material, and (b) as appropriate for titles in the reference list.
- Manuscript Length: There is no predetermined page or word limit. Provided they are "tight" and concise, without unnecessary repetition and/or irrelevant data, manuscripts should be as long as they need to be. The editor may require a reduction in length if the manuscript contains superfluous material that does not add anything useful to the topic being discussed. Limits might be imposed on the number/size/length of tables, figures, reference lists, and appendices.

PREPARATION OF REQUIRED MANUSCRIPT ELEMENTS

- A maximum of three (3) *types* of documents should be submitted: (1) title page; (2) main manuscript; and (3) figures (if any). Despite what the online system (Manuscript Central) programming might allow, *do not submit such elements as abstracts, references, and tables as separate documents.*
- Refer to the Sample Manuscript for additional information.

1. Title Page [submitted as a separate document]

The title page should include the following, *in this order*:

- a. Text for a running header (abbreviated title of your article) of no more than 40 characters + spaces in length. Place the running head on the title page only, and do not include it in the main manuscript document [set flush left]. *Do not actually format the text as a header.*
- b. Any author's/authors' notes or acknowledgements (optional), limited to two or three sentences, maximum. [Set flush left]
- c. The article title. Capitalize all important words, and all words with four or more letters. [Set centred; see the heading on this page for an example of title case]
- d. The name (not just initials) of each author, *without* credentials, in order, together with the affiliation of each author, including the institution/agency/organization (but *not* including department or division information); city where the institution/agency/organization is located; the state or province (if any); and country. *Example:* Janice M. Morse, University of Utah, Salt LakeCity, Utah, USA [set centred; all state, province, and country names (except USA) must be spelled out]
- e. Complete contact information for *all* authors, including the proper form of address (i.e., Dr., Professor, Mr., Ms., Miss, Mrs., etc.), name, credentials, affiliation, mailing address (including the country name), primary e-mail address, secondary e-mail address (if any), telephone number, and fax number (if any) [set flush left]
- f. A 1-sentence biographical statement about each author. Use the following example for formatting your statement(s), and be sure to include name, credentials, university or other institution (you may include department or division information here), city, state/province (if any), and country:

Janice M. Morse, PhD, FAAN, is a professor and presidential endowed chair at the University Of Utah College Of Nursing in Salt Lake City, Utah, USA.

The title page may actually be longer than one page. To retain author anonymity during peer review, it is submitted as a *separate document*. Title page information *should not be included* in the main manuscript document.

Manuscript title: A title should convey, as clearly and succinctly as possible, the main idea of a manuscript. It should be clear in meaning even when standing alone. Avoid unnecessary words, such as "A Qualitative Study of," "A Doctoral Student's Investigation of," or "An Ethnographic Study." A good title is generally 10 to 12 words (or fewer) in length. *Avoid* titles with a colon or a quotation unless it/they is *necessary* to convey an important concept or a particular meaning about the article.

Do not (a) type your title in ALL CAPITAL letters, or (b) place a period (.) at the end of your title.

2. Abstract

The abstract should be placed on page 1 of the main manuscript document. It should be a single paragraph, no more than 150 words in length, and briefly describe your article. Briefly state the purpose of your research, the main findings, and your primary conclusions. Whether written in the first person, active voice, or otherwise, the abstract should “match” the voice in the manuscript. *Do not* (a) indent the first line of the abstract, (b) include in-text citations, (c) show the word count, or (d) include the manuscript title.

3. Keywords (See *QHR* Keyword List)

This is a brief list of words related to the topic(s) of your article that readers could search on to find the article (if published). Include all desired keywords *selected only from the QHR keyword list*. You may request that new keywords be added to the list, but the words should be *general* in nature, and not specific to a narrow topic. New keywords will be added at the editor’s discretion. Keywords should follow on the same page as the abstract; leave a blank, double-spaced line between the abstract and the keywords.

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The main text of the manuscript begins on page 2, the page following the abstract and keywords. We prefer articles written in the first person, active voice, but will consider articles written in the third person provided the voice of the abstract and manuscript match (see Abstract, above). Use U.S. English translations of non-English quotations. *Do not include the manuscript title in the main document*. Authors are required to attend to copyright regulations.

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There are very specific guidelines for the use and formatting of in-text citations; refer to the *APA Publication Manual*, 5th edition, for details (the specific edition is very important). Every in-text citation should have a corresponding reference in the reference list, and vice versa.

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The reference list (also known as a bibliography) should include complete references for the sources used in the preparation of your manuscript and cited in the text. Every citation should have a corresponding reference, and every reference should be cited in the text. *You must cite and reference pertinent articles published in QHR in the 12 to 14 months immediately preceding submission of your manuscript*.

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guidelines contained in *APA*. Elements such as spelling, punctuation, spacing, capitalization, and the use of italics or Roman

(Regular) fonts are as important as the content of the reference. (Note that if an author has two or more initials, there should be a space between the initials; incorrect = X.Y.Z.; correct = X. Y. Z.)

References should be listed in hanging paragraph format, in alphabetical order by the last name of the first author. The hanging paragraphs should be created by using Word's Format > Paragraph feature, and *not by using tabs*. Be sure to use italics, rather than underlining, for titles. Non-English titles should be translated into U.S. English, with the English translation following immediately after the original title, in [brackets]. *Proper formatting of the reference list is the responsibility of the author.*

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C. Tips on Tables

HOW TO CREATE YOUR TABLE

- Include only necessary data
- *Neatness counts.* Text alignment, spacing, and consistency of style are all important.
- *Keep it simple,* without unnecessary lines and text.
- Keep the table as small as possible, both in width and length; use only the amount of space necessary to contain your data. To fit within a single column of the journal it should be no wider than 2.95;" to fit across both columns it should be no wider than 6". Narrow the table

columns to eliminate unused “white” space. Only under special circumstances (as determined by the editor) may a table be placed with a vertical orientation on the page.

- Multiple tables within the same manuscript should be similar in appearance and design.
- Create the table the way you wish it to appear when published, then double space all text, including column headers. *Set double-spacing with formatting specifications*, rather than manually inserting line breaks with the “enter” key.
- Use font no smaller than 8 points and no larger than 10 points. Use no more than two different font sizes in one table (one is preferred).
- “Hide” all vertical lines and all horizontal lines except the following: top line of table, bottom line of table, and line below the main column headers.
- Place explanations, clarifications, symbol identification, identification of unusual abbreviations, and other “non-data” information in a note below the table.
- Avoid the overuse of bolded and/or italic font, which can make a table look “busy” without enhancing it in any way.

D. Figures

Like tables, figures should be used sparingly, and only when it is necessary to clarify complex relationships in the text. Avoid shading, the use of color, and the use of multiple fonts. Hand-drawn figures (such as participant artwork) must be dark enough to reproduce clearly when published. Figure placement should be mentioned in the manuscript text, but the figures themselves are to be placed in a *separate document*, with all figure numbers (Figure 1, Figure 2, etc.) and figure titles together, in order, on the first page, followed by the figures—each on a separate page. You may choose to submit each figure separately, but each one should be prepared in the same manner (see the Sample Manuscript). The author should designate placement of each figure within the manuscript by entering (on a separate line between paragraphs) INSERT FIGURE 1 ABOUT HERE. (When published, figures are generally placed following the paragraph in which they are first mentioned.) Detailed formatting guidelines for figures are contained in the *APA Publication Manual*, but note that *regular Word documents are preferred over .jpg or other document types. The figure number and title should be included on the previous page, and not saved as part of the figure itself.* Figure titles should be short and concise.

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 Abortion
 abuse, emotional
 abuse, sexual
 addictions
 administration
 adolescents
 adolescents, health
 adolescents, male
 adolescents, pregnancy
 adolescents, sexuality
 aesthetic analysis
 Africa
 African Americans
 alcohol and alcoholism
 anesthesia
 anorexia

Aboriginal people, North America
 abuse, domestic
 abuse, physical
 action research
 adherence
 adolescent mental health
 adolescents, female
 adolescents, high-risk behaviors
 adolescents, parenting
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 adult education
 Afghanistan, Afghanis
 Africa, West
 aging
 Alzheimer’s disease
 animal-human interactions
 anthropology

anthropology of health
 anthropology, medical
 art therapy
 arts-based research
 Asia, Southeast
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 (ADHD)
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 [28 Oct 2008]

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 weight management
 womanist theory
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 youth, at-risk

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Scan the completed form, save it to your computer, and send it as an attachment to: QHRTE@nurs.utah.edu.

By facsimile:

Fax the completed document to: (801) 581-4642; Attention: Dori Fortune
If you use this method, please send an email alerting us to the pending arrival of the fax.

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Appendix 10:

Ethical and Research Governance Approval

Ethical Approval Letter removed for data protection

Ethical Approval Letter removed for data protection

Research Governance approval letter removed for data protection

Research Governance approval letter removed for data protection

Appendix 11:
Research Packs for Participants

Participant Information Leaflet [Version 2 – 01st December 2008]

Women's Perceptions of Chronic Pain in Relation to Pain Location

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Take time to decide whether or not you wish to take part.

A researcher will contact you in two weeks to discuss what you have read here with you. Please ask if there is anything that is not clear or if you would like more information. You will be given up to 1 month to decide whether you want to participate or not. If you decide to participate and have not agreed a time for the researcher to collect the consent form and questionnaires back within the month, you may receive a friendly reminder. If at this point you choose not to participate there will be no consequences.

The aim of the study will be to determine whether chronic pain is experienced differently dependent on where the pain is in on the body. To do this, participants will be asked to take part in a 50 minute interview about their experience of living with chronic pain.

Part 1

What is the purpose of the study?

This study is being carried out in part fulfilment of a clinical psychology doctorate. It also aims to help investigate factors that may be able to facilitate the treatment and management of chronic pain in the future.

Why have I been invited?

You have been invited because you are attending a clinic for chronic pain.

Do I have to take part?

It is up to you to decide. After you have been given time to read this information sheet, we will contact you by telephone and go through it with you. We will then ask you to sign a consent form to show you have agreed to take part and return to the researcher with the questionnaires. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen if I decide to take part? /What will I have to do?

We will contact you to arrange an appointment to meet and carry out the interview. The interview will last approximately 50 minutes

Please sign and date the consent form and return it with the demographics questionnaire when the researcher come to collect it at the time agreed.

Participation will end here.

Due to time constraints, it may not be possible to conduct an interview for everyone who agrees to participate. However, even if we are unable to conduct an interview with you we will still contact you in appreciation of your offer.

Do I have to take part?

Only if you want to.

Your participation in this study is entirely voluntary and refusal will not affect any other medical treatment. You may, without giving reason, refuse to take part in the trial, and this will not in any way affect your continuing treatment by your doctor.

What are the possible disadvantages and risks of taking part?

None.

Are there any costs involved?

Generally no, but we think the interview will take 50 minutes of your time.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the treatment of people with chronic pain.

What happens when the research study stops?

Your treatment/management at the clinic will continue as normal.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

If you withdraw from the study, we will destroy all your identifiable samples, but we will need to use the data collected up to your withdrawal if they have already been anonymised.

What if there's a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (07737615652). Please leave a message on the 24 hour answering machine and we will contact you as soon as possible. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital/clinic you attend for treatment of your chronic pain.

Harm

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Humber Mental Health Teaching Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part be kept Confidential?

Interviews will be recorded on a tape and written out verbatim by the Chief Investigator.

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the hospital/clinic will have your name and address removed so that you cannot be recognised

The information from this study will be retained and stored on Trust premises until the data are analysed.

Involvement of your GP

If you agree to participate in this study, your General Practitioner and/or Consultant will be informed.

What will happen to my tape?

Transcripts will be stored securely for 5 years. Tapes will be destroyed after being transcribed. Identifiable information will be removed.

What will happen to the results of the research study?

It is intended that the results be used for part fulfilment of the clinical psychology doctorate, published in a national/international journal and presented at conferences. You will not be identifiable in any report/publication

If requested on the consent form a copy of the completed report will be made available to you either by post or email.

Who is organising and funding the research?

The study has been sponsored by Humber Mental Health Teaching Trust.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Hull and East Riding Local Research Ethics Committee.

If you have any questions about the research study, please contact;

Kanny Olojugba
Trainee Clinical Psychologist
Clinical Psychology Department,
Hertford Building,
University of Hull,
Hull,

Telephone No: 01482 464 106

Mobile No: 07737615652

Thank you.

INFORMED CONSENT FORM [Version 2 – 1st December 2008]

Women’s Perceptions of Chronic Pain in Relation to Pain Location

Name of Chief Investigator: Kanny Olojugba

Please tick box

- 1 I confirm that I have read and understand the information sheet dated 9th August 2008 for the above study and have had the opportunity to ask questions.
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 3 I agree to take part in the above study.
- 4 I agree to be interviewed and my interview to be taped.
- 5 I agree to my GP being informed of my participation.
- 6 I would like to receive a copy of the report.

Email address: _____

or

Postal Address: _____

Name of Patient

Date

Signature

Researcher/witness

Date

Signature

Demographic Questionnaire [Version 1 – 01 October 2008]

| | | | | |
|---|-----------------|-----------------|---------------|-------------|
| Age | | | | |
| Marital Status <i>(Please circle as appropriate)</i> | Married | Single | Divorced | Co-Habiting |
| Postcode | | | | |
| No. of Children | | | | |
| How many people live in your household? | | | | |
| How many of these people are dependent on you? | | | | |
| Employment Status <i>(Please circle as appropriate)</i> | Employed | Self - Employed | Unemployed | Student |
| Are you currently on medication for your pain? <i>(Please circle as appropriate)</i> | Yes | | No | |
| Please list any other medication | | | | |
| Have you tried any alternative therapy to alleviate your pain? Please give details | Yes | No | Details | |
| How long did you have to wait before you were seen regarding your pain? | Months _____ | Weeks _____ | Days _____ | |
| Where in your body you feel most intense pain? | | | | |
| Where in your body do you feel pain? | | | | |
| How long have you felt pain in this (the most intense) area? | Years | Months | Weeks | Days |
| Do you know what has caused your pain? | Yes | No | Details | |
| How often do you feel this pain? <i>(Please circle as appropriate)</i> | Hourly | Daily | Weekly | Monthly |
| Does the location of your pain effect how you feel about it? | Yes | | No | |

Appendix 12:

Interview Schedule

Interview Schedule [Version 1 – 01th October 2008]

I would like for you to tell me about what it is like to live with chronic pain for you.

In particular, I would like you to think about where the pain is in your body and what effect that has on living with your pain.

We have about one hour to talk about it but we can have more or less time as we need it.

Please speak as freely about your pain as you like and I'll ask some questions as we go along. Are you ready for me to start the tape?

The following questions were asked during the interview in the order and at the time it was appropriate.

- What has it been like living with chronic pain?

- In what way do you think having chronic [pain site] pain has affected your life?

- If you could move your chronic pain to any other part of your body where would you move it to and why?

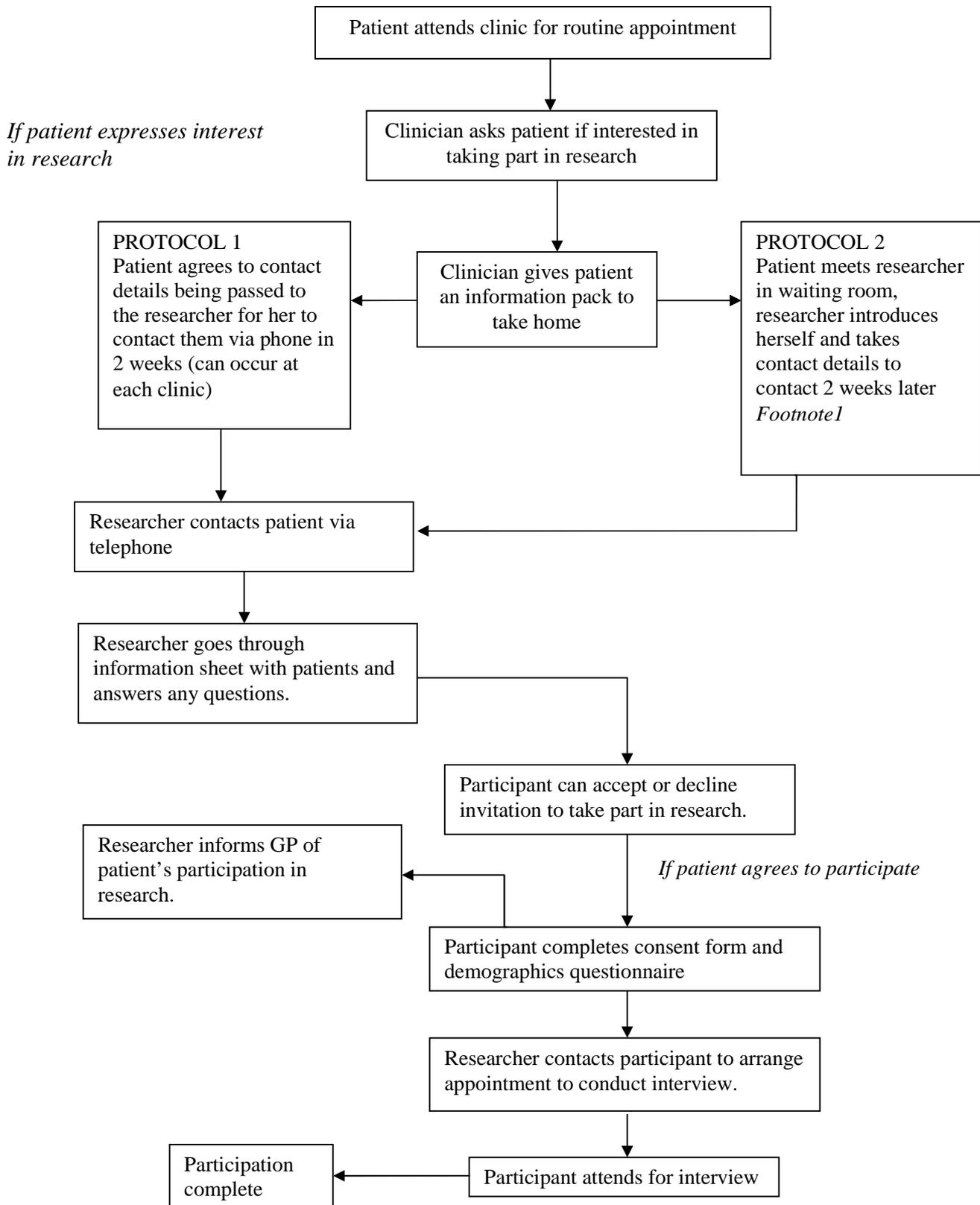
- Where would you say would be the worst place to have your pain and why?

- How do you think pain in your [pain site] differs from having pain in other places?

- Do you think people around you treat you differently or react differently towards you because of your pain and if so how and why do you think they do?

Appendix 13:
Flowchart Mapping Data Collection

Figure 3.2 – Flowchart Mapping Data Collection



Appendix 14:

Worked Example of IPA

Worked Example of Interpretative Phenomenological Analysis – Creation of Themes

A section of transcript is used to illustrate the IPA process. Each stage of analysis is highlighted. This excerpt was from an interview with a woman who had developed chronic pain in her shoulders, her back and her neck following an accident whilst horse riding with friends.

Participant Interview Expert

79 I: It sounds like you feel that back pain took away the joy of...

80 P3: It did, it took away the joy of everything really so, I've often sat and wished there was something that could be done. I can't say that it's any sort of hereditary even though my mum had back problems and she elected to have major back surgery. She was told her spine was like a jig saw puzzle so (laugh) like I say this wasn't hereditary it was just caused by my stupidity for saying I could ride in the first place

85 Res: it seems you blame yourself a lot.

86 P3: I do blame myself for that because in the first place I asked for the biggest horse they had not only couldn't I ride I wanted the biggest on they had [pause] I regret that, greatly. I got up or when I was picked up off the floor, my shoulder was thoroughly deformed so, [pause] I don't know if there's a right lot more we can say about it (sigh) I'm not, you know, I don't seem to be able to do anything on me own first I became reliant on my husband and now I'm more reliant on the children than I feel I should be, because soon my son once he's finished college and he meets somebody and settles down he'll want his own life and I wouldn't even attempt to try and stop them living their own lives and if they do offer me any sort of help, my daughter does day in day out and she will go to the shops for me or take me there or my son does and even at his age I don't think he can find it much fun pushing his mum in a wheel chair. He gave me a very. errr. I had a mishap with him. He put shopping on the back of the wheel chair and he left me for a couple of minutes to go back to the cash

machine and I ended up with my feet stuck up in the air (laughing) it had tipped over! I didn't ever dare show my face back at the shop. Having flocks of people round me! Ermm, over the years I've become very depressed with it. I try and laugh it off at the moment but yes it does bother me and it's not as if you can wave a magic wand or anybody can say well you know when it's going to over you now, you can put a stop to it and you're going to be alright. You just don't. And that's the main thing I feel bad about.

Stage One Analysis

Transcript was read twice to facilitate the researchers understanding of the whole text

Stage Two Analysis

Transcript was read again. The researcher noted statements of interest, observations about what was said, how it was said or contradictions with other statements within the transcript.

Stage two analysis for this excerpt is illustrated below:

| | |
|---|---|
| <p>Wanting to know why</p> <p>Self blame and criticism</p> <p>Self blame and criticism Regret Mourning what could have been</p> <p>Fearful I may blame her too?</p> | <p>79 I: It sounds like you feel that back pain took away the joy of...</p> <p>80 P3: It did, it took away the joy of everything really so, I've often sat and wished there was something that could be done. I can't say that it's any sort of hereditary even though my mum had back problems and she elected to have major back surgery. She was told her spine was like a jig saw puzzle so (laugh) like I say this wasn't hereditary it was just caused by my stupidity for saying I could ride in the first place</p> <p>85 Res: it seems you blame yourself a lot.</p> <p>86 P3: I do blame myself for that because in the first place I asked for the biggest horse they had not only couldn't I ride I wanted the biggest on they had [pause] I regret that, greatly. I got up or when I was picked up off the floor, my shoulder was thoroughly deformed so, [pause] I don't know if there's a right lot more we can say about it (sigh) I'm not, you know, I</p> |
|---|---|

| | |
|--|--|
| <p>Powerless Useless Guilty for relying on others</p> <p>Worry about son leaving her alone with no one else to help</p> <p>Humorous story to deflect away from the fact her son is leaving soon</p> <p>Embarrassment Exposure Vulnerable</p> <p>Defence against difficult feelings and thoughts</p> <p>Hopelessness Never going to go away</p> | <p>don't seem to be able to do anything on me own first I became reliant on my husband and now I'm more reliant on the children than I feel I should be, because soon my son once he's finished college and he meets somebody and settles down he'll want his own life and I wouldn't even attempt to try and stop them living their own lives and if they do offer me any sort of help, my daughter does day in day out and she will go to the shops for me or take me there or my son does and even at his age I don't think he can find it much fun pushing his mum in a wheel chair. He gave me a very, errr. I had a mishap with him. He put shopping on the back of the wheel chair and he left me for a couple of minutes to go back to the cash machine and I ended up with my feet stuck up in the air (laughing) it had tipped over! I didn't ever dare show my face back at the shop. Having flocks of people round me! Ermm, Over the years I've become very depressed with it. I try and laugh it off at the moment but yes it does bother me and it's not as if you can wave a magic wand or anybody can say well you know when it's going to over you now, you can put a stop to it and you're going to be alright. You just don't. And that's the main thing I feel bad about.</p> |
|--|--|

Stage Three Analysis

The right margin is used to document any links to theory or emerging themes following the third reading of the transcript.

| | | |
|--|--|--|
| | <p>79 I: It sounds like you feel that back pain took away the joy of...</p> | |
|--|--|--|

| | | |
|--|---|---|
| <p>Wanting to know why</p> <p>Self blame and criticism</p> | <p>80 P3: It did, it took away the joy of everything really so, I've often sat and wished there was something that could be done. I can't say that it's any sort of hereditary even though my mum had back problems and she elected to have major back surgery. She was told her spine was like a jig saw puzzle so (laugh) like I say this wasn't hereditary it was just caused by my stupidity for saying I could ride in the first place</p> <p>85 Res: it seems you blame yourself a lot.</p> | <p>Searching for meaning/understanding</p> <p>Self blame/ criticism</p> |
| <p>Self blame and criticism</p> <p>Regret</p> <p>Mourning what could have been</p> <p>Fearful I may blame her too?</p> <p>Powerless</p> <p>Useless</p> <p>Guilty for relying on others</p> | <p>86 P3: I do blame myself for that because in the first place I asked for the biggest horse they had not only couldn't I ride I wanted the biggest on they had [pause] I regret that, greatly. I got up or when I was picked up off the floor, my shoulder was thoroughly deformed so, [pause] I don't know if there's a right lot more we can say about it (sigh) I'm not, you know, I don't seem to be able to do anything on me own first I became reliant on my husband and now I'm more reliant on the children than I feel I should be, because soon my son</p> | <p>Self blame/ criticism</p> <p>Perceived Weakness</p> <p>Change in Ability</p> |
| <p>Worry about son leaving her alone with no one else to help</p> | <p>once he's finished college and he meets somebody and settles down he'll want his own life and I wouldn't even attempt to try and stop them living their own lives and if they do offer me any sort of help, my daughter does</p> | <p>Fear of Isolation/ Abandonment</p> |
| <p>Feels like a burden</p> | <p>day in day out and she will go to the shops for me or take me there or my son does and even at his age I don't</p> | <p>Tension between roles</p> |
| <p>Humorous story to deflect away from the fact her son is leaving soon</p> | <p>think he can find it much fun pushing his mum in a wheel chair. He gave me a very. errr. I had a mishap</p> | |

| | | |
|--|--|--|
| <p>Illustration of what happens if left alone</p> <p>Embarrassment Exposure Vulnerable</p> <p>Laughter as defence against difficult feelings and thoughts</p> <p>Hopelessness Never going to go away</p> | <p>with him. He put shopping on the back of the wheel chair and he left me for a couple of minutes to go back to the cash machine and I ended up with my feet stuck up in the air (laughing) it had tipped over! I didn't ever dare show my face back at the shop. Having flocks of people round me! Ermm, Over the years I've become very depressed with it. I try and laugh it off at the moment but yes it does bother me and it's not as if you can wave a magic wand or anybody can say well you know when it's going to over you now, you can put a stop to it and you're going to be alright. You just don't. And that's the main thing I feel bad about.</p> | <p>Fear of Isolation/ Abandonment</p> <p>Perceived Weakness</p> <p>Avoidance of feelings</p> <p>Perceived Weakness Ability to take pain away</p> |
|--|--|--|

Stage Four Analysis

Emerging themes were paired with supporting quotes from all the transcripts to enable the comparison of themes across transcripts.

| Emerging Theme | Supporting Quotes |
|--|---|
| <p>Searching for meaning/understanding</p> | <p>"...I can't say that it's any sort of hereditary even though my mum had back problems and she elected to have major back surgery. She was told her spine was like a jig saw puzzle so ..." P3,p3, L81</p> |
| <p>Self blame/ criticism</p> | <p>"...like I say this wasn't hereditary it was just caused by my stupidity for saying I could ride in the first place." P3, p3,L83</p> <p>"I do blame myself for that because in the first place I asked for the biggest horse they had not only couldn't I ride I wanted the biggest one they had..." P3, p3, L86</p> |

| | |
|--------------------------------|---|
| Avoidance of feelings | “Over the years I’ve become very depressed with it. I try and laugh it off at the moment but yes it does bother me...” P3,p3, L100 |
| Perceived Weakness | “I do blame myself for that because in the first place I asked for the biggest horse they had not only couldn’t I ride I wanted the biggest on they had [pause] I regret that, greatly. I got up or when I was picked up off the floor, my shoulder was thoroughly deformed so, [pause] I don’t know if there’s a right lot more we can say about it (sigh). I’m not, you know, I don’t seem to be able to do anything on me own” P3,p3, L86 “He put shopping on the back of the wheel chair and he left me for a couple of minutes to go back to the cash machine and I ended up with my feet stuck up in the air (laughing) it had tipped over! I didn’t ever dare show my face back at the shop. Having flocks of people round me!” P3, p3,L96 |
| Fear of Isolation/ Abandonment | “because soon my son once he’s finished college and he meets somebody and settles down he’ll want his own life and I wouldn’t even attempt to try and stop them living their own lives” P3,p3,L91 |
| Change in Ability | “I’m not, you know, I don’t seem to be able to do anything on me own first I became reliant on my husband and now I’m more reliant on the children than I feel I should be” P3, p3, L89 |
| Tension between roles | “now I’m more reliant on the children than I feel I should be, because soon my son once he’s finished college and he meets somebody and settles down he’ll want his own life and I wouldn’t even attempt to try and stop them living their own lives” P3, p3, L91 |
| Ability to take pain away | “it’s not as if you can wave a magic wand or anybody can say well you know when it’s going to over you now, you can put a stop to it and you’re going to be alright. You just don’t. And that’s the main thing I feel bad about.” P3, p3, L101 |

Stage Five Analysis

Emerging themes were compared across transcripts to generate sub – ordinate themes and super – ordinate themes. Emerging themes needed to have supporting data from all the transcripts and be supported by the overall narratives given by the women in order to be included as a theme. Themes are supported by quotations from transcripts.

Appendix 15

Methodological Theory and Considerations

Interpretative Phenomenological Analysis (IPA) is used to gain insight into the meaning of experience through the interpretation of fixed text narratives transcribed from verbal face to face interviews. This method of analysis has been widely used in qualitative studies looking at lived experiences and was chosen particularly for this study because of its roots in phenomenology and symbolic interactionism. Phenomenology allows the account of the participant's personal understanding and experience of their chronic pain to be the foundation of the analysis and symbolic interactionism describes the process of creating meaning to be through interpretation and understanding of experiences within the wider social and cultural context.

The interpretative process that occurs within IPA involves the researcher fully immersing themselves into the account of the participant to allow the interpretation of the participant's interpretation. This is a two stage process known as a "double hermeneutic" whereby, "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003, p. 51). With this in mind, it is not the aim of IPA to establish an objective description of the participant's interpretations of their experiences but rather to gain insight into it thus allowing for the complex interaction within the double hermeneutic.

Interpretative Phenomenological Analysis involves stages of interpretation which move between the whole and various parts of the text. The initial stages and the commencement of the immersion of the researcher into the experience of the participant begin with listening to each interview to establish a naive understanding of the whole. This initial understanding provides the basis for the secondary stages of interpretation, the structural analysis which involves the examination of the text in terms of relevant theory. The final stages involve the development of a more comprehensive understanding of the whole rooted in the initial and secondary stages of analysis

Methodological considerations

The purpose of qualitative research is not to produce generalisable results but rather to establish themes that can be applied to similar situations if placed in a new context – transferability (Polit & Hungler, 1999). To reduce potential bias, independent researchers were involved in the structural analysis of a selection of the transcripts and in the compilation of super – ordinate and sub-ordinate themes.

The themes were developed based on the researcher's prior experience and understanding of the external world and therefore can claim only to be one of several potential understandings. Researchers have presented the themes in what is they believe is to be the best way of understanding the meaning attributed to the experience of chronic pain in relation to the pain site.

Appendix 16:

Reflexive Statement

Reflexive Statement for Interpretative Phenomenological Analysis Methodology

IPA requires the researcher to interpret the interpretations of participants in order to generate themes. It is, therefore, important that the researcher is aware of their own beliefs, values, experiences and cultures that are likely to impact on their interpretations.

The researcher was a female Clinical Psychology Trainee of British African descent in her mid twenties who believes that when confronted with illness one has to cope with it in order to make sure that the necessary activities and responsibilities are met. The researcher also, however, strongly believes in a good support network and although one should not necessarily broadcast one's weakness to the whole world in case they are used against them at a later date, it is important that everybody has somebody they can rely on and can be "weaker" with.

The researcher believes that body and mind are very closely connected and similar to referred pain, where damage can occur in one area of the body but the pain felt in another, disturbance or damage can occur in either the body or the mind and manifest in the other. In line with this the researcher believes that disturbance or damage in either the body or the mind is likely to impact on the other, for example, increased and frequent anxiety puts the body in a state of anticipation with the hormone adrenaline being constantly in the blood stream and an activation of the sympathetic nervous system promoting arousal and energy generation whilst inhibiting digestion in preparation for "fight or flight". A prolonged time in this state is likely to lead to health problems. The reverse is also true, health problems have been shown to lead to depression, to increase stress and anxiety.

The combination of both African and British cultures has led to indecision on some matters for example, to what extent does is the government responsible for us and to what extent are we responsible to ourselves and to those in our community.

It is common knowledge that people from ethnic minorities are less likely to present to services than British people, one of the reasons for this, may be due to the culture of some of the ethnic minority groups. Within the culture that the researcher is somewhat apart of, there is great respect in strength and community. Therefore, when one is ill it is up to that person to ensure that their duties are still

met showing strength. The community around will also help the person with their duties or to seek advice for the elders for healing. Very rarely are issues from within a community shared with an outside body which would potentially bring threat to the group. There is also a heavy emphasis on spiritual and religious beliefs which offer explanations, helpful or unhelpful, for their present condition and hence a possible solution to it.

This is different from the British culture that the researcher is also a part of, where the people have come to rely on an external body of strangers to assist them when they are at their weakest. When this external body is unable to explain and/ or solve their problems there is little else to turn to and seemingly general belief that that they cannot cope on their own leading to feelings of abandonment and isolation hidden behind anger.

The researcher is able to see both positives and negatives in what she understands of two cultures and is, therefore, informed by both.

An important issue to consider was that the researcher had never experienced chronic pain, however, had experienced acute pain. It is easy to minimise the difference between chronic and acute pain and the reactions to it. Extensive reading and listening to the experiences of chronic pain enabled the researcher to hold this distinction in her mind throughout then analysis and to not drawn on her experience of acute pain as a reference to chronic pain.

Being a clinician as well as researcher also had a significant role in the interpretation of the transcripts by encouraging the interpretation not only of the narrative but also of the dynamic between the researcher and the participant and how the researcher may have influenced what was said. Being a clinician also impacted on the tendency to want to rescue the participants from their illness and thus increased the likelihood of feelings of helplessness whilst analysing the transcripts.

The researcher holds the individuals experience as vital and important for the furthering of clinical research and therefore, the researcher was aware of her own beliefs, values and culture throughout the research process. The researcher endeavoured to remain as objective as possible to enable an

interpretation that would give each woman who participated a voice in regards to the future direction of service provision.

Appendix 17:

Glossary of Medical Terms

Glossary of Medical Terms

| | |
|--------------------------------|---|
| Dysmenorrhoea: | Pain with periods |
| Dyspareunia: | Pain with penetrative sex |
| Endometriosis: | A chronic and progressive disorder where endometrial cells normally found in the uterus become lodged in another area of the body commonly the lower abdomen or the genitor-urinary system. |
| Fibroids: | Tumours that grow in the uterus (womb). They are benign, which means they are not cancerous, and are made up of muscle fibre. |
| Fibromyalgia (FM): | A chronic condition that causes pain all over the body. The condition affects the muscles, tendons and ligaments (bands of tissue that connect bone to bone), resulting in widespread pain, fatigue and extreme sensitivity to pain. |
| Myofascial (MF): | Myofascial pain is a chronic condition that affects the fascia (connective tissue that covers the muscles). Myofascial pain syndrome may involve either a single muscle or a muscle group. Myofascial pain symptoms usually involve muscle pain with specific "trigger" or "tender" points. |
| Polymyalgia Rheumatica: | A chronic condition that causes inflammation of large muscles resulting in pain. Symptoms include; stiffness, pain, aching, and tenderness of the large muscles around your shoulders, pelvis, and back, tiredness, depression, night sweats, fever, loss of appetite, and weight loss. |