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A phenomenological approach to the experience of chronic pain

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A phenomenological approach to the experience of chronic pain

**Thesis submitted in fulfilment of the requirement for
the degree of Doctor of Philosophy in the University of
Wales, Bangor, April 2007.**

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Section 1:

Context of the study

Incorporating

- Chapter One: Introduction
- Chapter Two: A review of the literature
- Chapter Three: Methodology
- Chapter Four: Analysis of the results

Chapter One

Introduction

1.1 Background

This study uses a phenomenological methodology underpinned by the philosophy of Martin Heidegger to explore the lived and living experience of patients with chronic pain. Pain is a universal phenomenon shared by all and yet is very difficult to define. It can be regarded as a physical sensation, an emotion or even interpreted as punishment for the sufferers 'misdeeds'. There have been many attempts to define the phenomenon with the accepted definition now being that of the International Association into the Study of Pain (IASP) (1994; 1979) that states that pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. This definition attempts to incorporate the multi-dimensional aspects of the pain experience including the range of psychological factors that can influence the experience.

Pain is then further classified into acute or chronic pain. Acute pain is often taken to mean the sudden severe pain which accompanies injury or disease. Chronic pain, however, is pain that persists beyond the time of expected healing often without cause (IASP, 1994). Such chronic pain is believed to serve no useful purpose and although there may be a history of an initial injury or trauma, the pain endures longer than the usual healing period. Pain is considered to be chronic in nature if it persists for more than three months. 'Chronic pain syndrome' is a phrase that has been used to further define the context of chronic pain in terms of a psychosocial disorder where the patients' central focus is solely their pain (Middleton 2004). Sanders *et al* (2005: 304) further define chronic pain syndrome as a pattern of behaviours that "involves the complaint of enduring or recurring pain; has persisted longer than typical for an associated condition, or is associated with an intermittent or chronic disease process; has responded inadequately to appropriate medical and/or invasive care; and is associated with significant and reliable impairment of functional status". They also state that chronic pain patients may show mood disturbance, anger or hostility; however, these are not essential

to confirm a diagnosis of chronic pain. Main and Spanswick (2000: 57) would prefer the use of the term “psychologically mediated pain syndrome” which further indicates that psychological factors have been specifically investigated and proven. Chronic pain is then sub-classified into non-malignant and malignant chronic pain. Within the context of this study, the phrase ‘chronic pain’ is used to indicate pain that has been present for at least three months and for which there is no longer any known pathological cause.

The differences between acute and chronic pain may explain why some health professionals have difficulty in understanding the chronic pain phenomenon and that is because they have not experienced the relentless onslaught that typifies chronic pain. Acute pain although being a universally shared human experience can be experienced at different levels, with the acute pain having been caused through injury or injuries of varying severity. For example not all people will have experienced the acute pain felt after a surgical procedure; however, most people will have experienced, at some time in their lives, the acute pain of trapping their finger in a door. This does not mean that all health professionals can empathise with the acute pain experience and despite the observation by Thomas (2000) who states that nurses who have personally suffered pain are more sympathetic to the patient in pain, it is not practical to ensure that only those health professionals who have personally experienced surgery should care for those patients having surgery. Even if this recommendation could be enforced there will always be the issue of health professionals comparing how they managed a personal pain experience against the patient’s experience and potentially finding that the patient is not achieving the same degree of pain control. This then could lead to the health professional “disbelieving” the patient and assuming the patient to be unnecessarily exaggerating their pain. The issues around believing a patient’s pain experience are many and this is the central focus of this thesis.

This research reported here originated from a desire to discover what it was like to live with chronic pain. As a clinical nurse specialist in pain management I was accustomed to assessing patients with acute and chronic pain, and believed that I was able to differentiate between the varying effects that different types of pain had upon people. Of

interest also, was the different ways in which people managed their own pain, some people appearing to cope well with their pain and still enjoying life whilst others seemed to struggle more. This view, however, was generated from knowing these patients within the context of the pain clinic. It was therefore of further interest to explore their living experience of chronic pain through using a daily diary which chronicled patients' lives as they were lived, outside of the pain clinic setting. Although van Manen (1990: 36) argued that the concept of 'living experience' does not exist as it "can never be grasped in its immediate manifestation but only reflected as past presence". From interviews alone this may be true as the patients were asked to detail their life with chronic pain whereas the diaries allowed for reflection, if the patient chose, whilst giving them an opportunity to present their lives to me as researcher whilst it was being lived with chronic pain.

As all patients recruited to the study were known personally to the researcher there was an assumption that there was already an established relationship between the patient and myself as their nurse. Thus the role of nurse as researcher was one used to full advantage during the interview process which was based on a phenomenological framework was low in preliminary structure but highly focused on the lived experience of chronic pain.

Patients frequently express relief at 'being believed' by health professionals involved in pain management. This apparent need to feel that their pain story is credible appears to be unique to chronic pain patients. The invisibility of the pain, the lack of a diagnosis or label and the accompanying psychological problems can lead a patient to feel isolated, depressed, or even that the pain is "all in their imagination". Having someone believe their account about their chronic pain problem possibly helps patients to take the first step forward in learning to manage their pain instead of being managed by the pain.

There are voluminous amounts of literature pertaining to chronic pain and some studies do explore the lived experience of chronic pain (Blomqvist and Edberg, 2002; Thomas, 2000; Hellstrom and Carlsson, 1996; Seers and Friedli, 1996), this study contributes to that body of knowledge by providing illuminating findings that may provide a deeper

understanding and empathic insight into a phenomenon which can disable patients mentally, physically and emotionally.

1.2 Aims

This study, therefore, had three major aims:

The first aim was to explore the living and lived experience of patients with chronic pain using a hermeneutic approach within a phenomenological framework, through data forming a narrative account obtained from a combination of interviews and patients' diaries.

The second aim was to examine the effect of 'being believed' by the health professional on the patient with chronic pain through an exploration of the effect upon the patient of having health professionals accept the patients chronic pain experience as being credible.

The final overall aim was to develop an understanding of why some patients are able to successfully move from seeking a pain cure to accepting pain management through a qualitative analysis of the transcribed data.

1.3 Structure of the thesis

The thesis is divided into five sections each one incorporating several chapters. The sections have been used to group the chapters for the ease of the reader and have been given titles to reflect the overall content or the aim contained within that section. Thus the thesis is sub-divided accordingly:

Section 1: Context of the study

Chapter one:	Introduction
Chapter two:	A review of the literature
Chapter three:	Methodology
Chapter four:	Analysis of results

Section 2: Exploration of the lived and living experience of patients with chronic pain

- Chapter five: The living experience of chronic pain
- Chapter six: The lived experience of the perceived effect of chronic pain on relationships with families and friends
- Chapter seven: The lived experience of the perceived effect of chronic pain on one family: a case study

Section 3: Examination of the effect of 'being believed' by the health professional on the patient with chronic pain

- Chapter eight: The language of pain: the rhetoric
- Chapter nine: Living with unseen chronic pain
- Chapter ten: Believing the patient with chronic pain

Section 4: Development of an understanding of why some patients are able to successfully move from seeking a pain cure to accepting pain management

- Chapter eleven: Accepting pain management, seeking pain cure –an exploration of patients' attitudes to chronic pain
- Chapter twelve: Accepting pain management, seeking pain cure – an exploration of one patient's attitudes to chronic pain: a two-faceted approach

Section 5: Concluding chapters

- Chapter thirteen: Reflections from the research diary
- Chapter fourteen: Discussion and conclusions
- Appendices
- References
- Bibliography

Chapter Two

A review of the literature

2.1 Introduction

The overarching aim of this research was to explore the living and lived experience of patients with chronic pain, but under this umbrella aim was a desire to explore the effect of having health professionals believe and accept a patient's pain story as being credible. From personal experience of running a nurse led pain clinic it was not unusual for a patient to express gratitude at having their pain story believed and taken on face value. Through seeing these same patients over a number of years it also became apparent to myself and colleagues within the clinic that some patients seem to accept pain management whilst others constantly seek a pain cure, this then became the third aim within the study. The literature was reviewed in order to ascertain whether similar research aims had been previously explored and also to provide foundation knowledge on which to build this current research.

Methodologically there is debate about whether a literature review should be thoroughly conducted prior to actual research or as in ethnography conducted at the end of the research. The argument against conducting a thorough literature review at the beginning of a piece of phenomenological research is that it might provide the researcher with preconceptions, however, it is possible that just by having an interest in a particular phenomenon is enough to create preconceptions which might not be particularly well informed. Working within the field of pain management for several years it has to be acknowledged that I did have some prior knowledge of and views on the topic, which included current and past research issues particularly in view of my work with the University of Wales, Bangor. It also has to be acknowledged that as pain is such an ubiquitous phenomenon literature is constantly being published whether it is through an academic forum or the popular press. It is not uncommon to see articles relating to pain published in weekly magazines or monthly journals such as the Reader's Digest (Johnson, 2006) supporting the universality of the pain phenomena. Transparency of preconceptions through acknowledgement adds to the trustworthiness of a phenomenological study (Lowe and Prowse, 2001) and as it was necessary to review literature in order to write the original research proposal needed to fulfil the requirements of the local NHS Research Ethics committee it was an

impossibility to have no prior knowledge of the phenomenon under study. I felt, however, that the best compromise was to briefly review the literature for the research proposal and then to systematically review the literature after the research interviews had been concluded and analysed. Streubert and Carpenter (1999:20) state that the purpose of reviewing the literature in a qualitative study is to place the findings in the context of what is already known with a brief review of the literature before the start of the study to provide initial focus. Reviewing the literature subsequently became an ongoing process with drafts being crafted throughout the research process until the final culmination of this completed chapter.

2.2 Method

The literature reviewed for this study has been categorised under three headings: the chronic pain lived experience, the effect of the health professional accepting the patient's narrative as being credible, and cure versus management within a chronic pain context. These headings correspond to the three main aims of the study. The literature reviewed was extensive and therefore a systematic review of the literature was deemed to be the most appropriate approach to searching and identifying relevant literature. The search was carried out via Cumulative Index to Nursing and Allied Health (CINAHL), Medline, psychINFO and British Nursing Index (BNI) for the years between 1970 and 2006. The key words used within the search process are given at the beginning of each section for ease of reference. Meta analysis was not possible as the review included mainly qualitative studies, which reflected the personal and lived experience focus of the research.

2.3 Chronic pain lived experience

An initial literature search was conducted using selected key words: 'chronic pain' and 'lived experience/ patient experience'. The key words 'chronic pain' produced voluminous numbers of articles. The only limit used was 'written in English'. A similar search was performed using the keywords 'lived experience/patient experience' and then the two sets of results combined for each of the databases searched. This narrowed the search considerably and in total produced a total of 125 articles although some titles were duplicated across the databases.

Table 1 Search strategy used to identify literature pertaining to the ‘chronic pain lived experience’

Database	Key word	No. of hits	Key word	No. of hits	Total no. of hits when combined	No. of articles deemed relevant following abstract reading.
Medline FirstSearch	Chronic pain	21263	Lived experience/patient experience	189	11	7
BNI 1985-2006	Chronic pain	3	Lived experience/patient experience			
	Pain	5290		2772	40	7
psychInfo	Chronic pain	5498	Lived experience/patient experience	2759	2	2
CINAHL 1982-2006	Chronic pain	187315	Lived experience/patient experience	2219	72	8

All the abstracts were read and the following criteria used to identify relevance:

- Is the paper exploring lived or patient experience?
- Has the paper a pain focus or is the paper about a chronic pain condition e.g. rheumatoid arthritis, migraine, fibromyalgia?
- Is the sample an adult population?

Each abstract had to fulfil all criteria. These very simple criteria reduced the number of articles to 14. Unpublished studies were not sought which reduced the number by a further two. All remaining papers were then obtained in full text via electronic journals and through libraries and library ordering services where necessary. These

articles were then read critically and the main findings are summarised in appendix one. The references used within these papers were then scrutinised and abstracts obtained. Again the same criteria were applied and a further three papers were obtained in full text. The findings of these papers are also incorporated in appendix one but are given an asterisk to denote that they had not been identified by the initial online databases search. This small number of identified studies illustrates that despite the fact that pain is a phenomenon that is experienced by all humans there is very little literature that explores the experience from a patient's perspective. There has been much debate about the strength of qualitative research, however, over recent years there has been increased interest in those studies that reflect patients' perspectives and experiences whether through narrative or interview techniques.

As lived experience is unique to that individual and every narrative has the potential to be very different from any other, phenomenological research aims to uncover shared themes as well as themes that are unique to an individual. The majority of the literature reviewed discusses the shared themes that have been identified from an exploration of the chronic pain experience (Dewar *et al.*, 2003; Thomas, 2000) although many papers explore the phenomenon and relate it to a particular site on the body such as back pain (Lillrank, 2003). Other studies look at the cultural effects on pain (Bates and Rankin-Hill, 1994; Villarruel and de Montellano, 1992; Martin and Belcher, 1986; Abu-Saad, 1984) and within the study by Hwang *et al.* (2004) the cultural effect of women living with rheumatoid arthritis is highlighted. The cultural differences between western women and Korean women although not specifically explored are illustrated through the texts generated from the individual interviews however within the theme cluster "negative feelings" one patient had expressed sadness because "nobody understands my pain". This lack of understanding in relation to the chronic pain experience is mirrored similarly in other studies (Harding *et al.*, 2005). Other studies identify pain as a theme whilst exploring the lived experience of another phenomenon such as peripheral vascular disease (Gibson and Kendrick, 1998) or rheumatoid arthritis (Hwang *et al.*, 2004). These papers still have great relevance although in the case of living with peripheral vascular disease the condition tends to be chronic with the pain that is experienced often being acute in nature. Fibromyalgia is a chronic disease state where there are multiple pain sites consequently there are several papers which explore fibromyalgia lived experience

and cover pain within the thematic analysis (Paulson *et al.*, 2002; Soderberg *et al.*, 1999; Schaefer, 1997).

Despite the vast numbers of studies researching pain there are very few which explore the lived experience or examine the nature of the pain experience from the patients' viewpoints. Seers and Friedli (1996) in a UK study investigated the experiences of 75 people with chronic non-malignant pain. The study appears to have two aims one of which was dealt with quantitatively through the use of a randomised control trial to evaluate the effects of relaxation training with chronic pain patients' immediately after training and in the long term. The qualitative part of the study used an interview technique to provide insight into what it meant to people to experience chronic pain. This study combined both a quantitative and qualitative methodology although this particular paper focussed on the qualitative data and subsequent analysis. The interviews were not audio-taped but were recorded in note form during the interview and then detailed field notes were written following the conclusion of the interview. This could lead to the production of flawed data and it is impossible to go back to the original interview to check for accuracy, completeness, tone and implied meaning. Given that this was not a hermeneutically analysed study it could, therefore, be assumed that the tone of the interview and conversational pauses were not as imperative to the study findings. The data was analysed thematically with nine common themes being identified from the 75 interviews which highlighted the chronic pain experience from the patients' perspectives. The conclusion from this study is that the patient with chronic pain will give the experience meaning and definition depending upon the patient's individual context.

Individual context spans an array of factors which can affect the chronic pain experience. There are many studies which look at varying factors: gender (Robinson *et al.*, 2001; Mullersdorf and Soderback, 2000; Vallerand, 1995); culture (Villarruel and de Montellano, 1992; Martin and Belcher, 1986; Abu-Saad, 1984) age (Yong *et al.*, 2001; Sloman *et al.*, 2001; Jacob and Puntillo, 1999); and depression. Chronic pain is often associated with depression (Naughton *et al.*, 2007; Kothe *et al.*, 2007; Elliott *et al.*, 2003; Upshur and Wootton, 2003; Grey, 2001; Linton, 2000) and there are many arguments surrounding whether the pain brings on the depression or whether there was a depressive element prior to the onset of pain (Ho and Biskupiak,

2004; Ciccone *et al.*, 2000). All of these factors can contribute to the meaning of the chronic pain experience and supports McCaffery's (1968: 95) much repeated definition of pain: "Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does".

In an American study Carson and Mitchell (1998) conducted a descriptive exploratory study with 17 people who live with persistent pain. These interviews were recorded, transcribed and re-listened to whilst re-reading the transcripts in a thoughtful manner. The framework for this study was based upon the 'human becoming theory'. The theory of human becoming is structured on three themes: meaning, rhythmicity and transcendence. It places each person's own quality of life perspective as the goal of nursing practice; it therefore allows for greater understanding of universal experience to better enable nurses to participate with others in the creation of quality of life issues (Parse, 1992).

Many studies used convenience samples for their research studies. Many patients were recruited from pain clinics (for example see Walker and Sofaer, 1998; Bowman, 1994a, Bowman, 1994b) although one Finnish study (Lillrank, 2003) used a writing competition to generate data for a study into back pain. All of these stories were relating to past and present experiences of back pain and how it affected lives and were organised into six categories according to the pain plot within the narratives. This paper covers the analysis of 30 women's stories and the process of being diagnosed with back pain under the category of "diagnostic uncertainty". Exaggeration, imagination or just literary licence was not considered to be a cause of flawed data within this study as it is simply stated within the paper that "honesty lies at the core of Finnish values". A result of gathering this data through a writing competition which awarded prizes for the best stories the accuracy of the data also has to be called into question. Despite these misgivings the analysis and interpretation of the narratives as they progress through many medical consultations seeking diagnoses is illuminative and often comparable to other studies.

Many, although not all chronic pain patients, will attend a pain clinic. The use of such clinics to select a convenience sample has already been discussed; however, the impact of pain clinics on the patients' pain management is another area of research

which can be examined from a patient's perspective (Harding *et al.*, 2005; Robinson *et al.*, 2004; Mullersdorf and Soderback, 2000). Walker *et al.* (1999) used a phenomenological approach to gain an insider perspective on chronic back pain at the point in time that the patient sought help from a chronic pain clinic. This paper particularly focused on the role of the clinic within the patient's experience and the dominant emergent theme of being caught up "in the system". These interviews were audio-taped with the interviews being carried out in the patient's home.

Family dynamics is acknowledged in several papers to be a contributing factor to the overall chronic pain experience (Cano *et al.*, 2000; Smith and Friedmann, 1999; Benjamin *et al.*, 1992). Smith and Friedemann (1999), in a Canadian study, used a range of broad questions within an interview framework to explore the perceived family dynamics of persons with chronic pain. A sample of 30 was used and data analysed using a constant comparison method, the conclusions reached were that further qualitative studies need to be done but families need to be included as their management of the person with chronic pain has a major influence on the pain experience. Perhaps the most relevant paper found was that by Thomas (2000) who used an eidetic phenomenological framework derived from the Husserlian tradition to interview in depth 13 subjects with chronic non-malignant pain. This North American study produced emergent themes of pain as an "untamed monster", "pain as a barrier", "a shrunken life world" and "the altered, recalcitrant body". The North American culture did have an effect within this paper – particularly relating to the cost of treatment which was not successful in achieving a cure. The literature demonstrates that there is a gap in the knowledge in understanding the experience of the chronic pain patient.

All of these papers reviewed offer insight into the chronic pain experience and help to build up a picture of the lived experience of chronic pain. The subjectivity of the pain experience, plus the many factors that can influence the pain experience, ensures that further research which explores the lived experience is essential for furthering the understanding of such a life altering condition.

2.4 The effect of the health professional accepting the patients' account as being credible

The second aim of this study reflected personal experience of seeing patients in a nurse-led pain clinic and have them express gratitude at having their chronic pain believed. In some instances patients claimed that until they attended a pain clinic they felt their pain had never been believed by a health professional.

The literature search was carried out in a similar fashion to that for chronic pain experience with the key words 'believe', 'confirmation', 'attitude' and 'listening to' being combined with the key word 'chronic pain' (table 2).

On reading the abstracts there were very few articles which actually examined the effect of believing a patient with chronic pain. The papers identified from the abstracts were obtained in full text and read specifically for 'being believed' issues. The key word 'believe' often related to the word 'beliefs' and this was not the context being searched for. Most of the articles identified through the search were inappropriate and therefore were disregarded for this part of the review. Many of the articles were found coincidentally whilst searching the literature for chronic pain lived experience. The studies that emerged are mainly qualitative, most using a phenomenological method and many only marginally referred to the notion of the importance of believing a patient's chronic pain experience. This section of the literature review has been previously published (Clarke and Iphofen, 2005) but for the purpose of this chapter has been updated. The papers sourced for this review are summarised in appendix two.

Table 2 Search strategy used to identify literature pertaining to ‘being believed’

Database	Keyword	No. of hits	Keywords	No. of hits	Total no. of hits when results combined	No. of articles following abstract reading
Medline FirstSearch	Chronic pain	21263	Believe*	34723	208	1
			Confirmation	23292	109	0
			Attitude	134698	554	0
			Listening to	5900	17	1
BNI 1985-2006	Chronic pain Pain	3 5302	Believe*	52	2	1
			Confirmation	19	0	0
			Attitude	255	5	0
			Listening to	199	3	1
psychInfo	Chronic pain	5611	Believe*	15736	106	4
			Confirmation	7999	95	2
			Attitude	56349	295	0
			Listening to	6266	70	0
CINAHL	Pain	46100	Believe*	3062	221	10
			Confirmation	918	79	4
			Attitude	33620	1328	see below
			Listening to	2505	109	6
	Chronic pain	4004	Attitude	33620	154	3

Believing a patient’s pain experience has to start with accurate pain assessment (Waterhouse, 1996; Jacques, 1992; Raiman, 1986). Pain assessment is dependent

upon the patient's self report of pain and therefore accurate pain assessment cannot be achieved unless the professional doing the assessment believes the patient describing the pain. Jacques (1992) in an article outlining factors that influence people's perception of pain examined the assessment process and the subsequent interactions between nurse and patient. She stated that a nurse should approach each patient individually and with an open mind, thereby allowing for the subjectivity of that particular pain experience. Factors such as age, gender, culture and personality were considered and the conclusion reached that accurate pain assessment is dependent upon the patient feeling that they are believed by the health professionals. This was not explored any further within the paper.

Waterhouse (1996) prepared a case study following the post-operative progress of a female patient. This article detailed a disastrous post-operative pain management that the author considered was not mismanaged because of inadequate pain assessment but solely because the nurses did not believe the patient's self report of pain. The author concluded that pain relief should be a two-way process between nurse and patient and that believing the patient is the first step in this process. Raiman (1986) qualifies this use of a two-way process by emphasising that pain assessment should be viewed through professional eyes but also through those of patients.

Personal insight into the issue of not being believed is recounted by Ruckert (1995) in an account of her own personal experience of late pregnancy and labour and the concurrent complication of a renal abscess. She felt that her pain was not believed because she was pregnant and that her pregnancy masked all other reasons for such severe pain. She does not, however, explore why it was so important to her to feel believed. She considered listening to people to be of utmost importance and her own nursing practice had changed in that she now questions herself to ensure she is listening and claims that she does believe patients more. Personal accounts of this nature reveal what it is like to feel that pain is being disbelieved and then to have that pain experience vindicated by becoming acutely ill. Such insight from a nurse's own experience illustrates that perhaps pain is viewed professionally as being normal for certain conditions. However, when it purportedly exceeds that norm, rather than exploring it, it becomes easier to perceive it as an exaggeration or as imagination.

Most of the literature sourced was phenomenological. It would seem apt that pain as a subjective experience is best explored by this method. Not only does it allow the person to express what it is like to live with pain but it is also a methodological requirement for a phenomenological approach. Owing to the subjective nature and the uniqueness of individual experience, phenomenological research tends to be regarded as not being easily generalisable but can provide insightful and illuminative data. Bendelow and Williams (1995) state that the use of phenomenological and sociological methods of research enhance bodies of knowledge relating to pain and assist in reclaiming pain from the dominant scientific materialistic paradigm. This emphasises the importance of the pain experience as an individual one. Pain experience cannot be transferred from one person to another. Description does help in providing information about the pain but it does not in any way provide an equal or even similar experience. This phenomenological literature spans several countries and examines themes ranging from “struggling from relief of pain” (Paulson *et al.*, 1999) to “enhanced sensory awareness” (Bowman, 1994a). The topical themes within this literature are very varied; only in a few is ‘being believed’ allocated to a distinct category.

Werner and Malterud (2003) in a qualitative study which utilised in depth interviews, explored the measures to which women patients with chronic pain went to be seen as being credible. This Norwegian study used Giorgio’s (1985) principles of phenomenological analysis to analyse the data. Although only a small sample (n=10) it was apparent that the women all tried to conform to what they thought the doctor would want to see, and did not want to be considered as complainers or moaners. They utilised strategies such as assertiveness, surrendering and appearance to convince the doctors that they were credible patients. Surrendering strategies included patients simply accepting what their doctors said without complaint or comment because they were worried it would create problems for them in the future or getting a third party to support them whilst telling their pain story. Appearance strategies were developed by the women within the study following comments by health professionals about their appearance. Comments regarding how well the patient looked made them feel that they had to achieve a certain ‘look’ that did not appear too smart, too strong or too healthy when consulting their doctors. The authors

concluded that the effort that is put into being seen as a credible patient would be better invested in adapting to a life with chronic pain.

Paulson *et al.* (1999) utilised a phenomenological-hermeneutic approach to interview nursing and medical staff who worked in a rheumatic hospital in Sweden for their experiences of caring for men with chronic pain. This piece of research focuses on the staff's view point rather than the experience of the patient suffering the pain. This gives a different perspective on the pain experience, but the need to be believed was identified within the work. Interestingly from the three themes identified the phenomenon of "confirmation" was noted within each. This idea of confirmation highlighted that the carers felt that they must convince the men in this study that they believed their experience of pain. They felt once this was established the potential to help these men was increased. Similarly, Carson and Mitchell (1998) who used Parse's theory of "human becoming" to formulate questions for their interviews with patients living with persistent pain proposed that understanding the experience of a person in pain is essential to any helping relationship.

An American study (Bowman, 1994a) which looked at individuals' reactions to chronic low back pain found that patients who were already suffering pain found their awareness of others who had pain was increased and in fact they reported that they were more likely to believe others had pain now that they had been subject to that same experience. This is supported by Thomas's (2000) phenomenological study which suggests that nurses who have personally suffered pain are more sympathetic to the patient in pain. However in practice very little use would be made of this finding since it would require ensuring that only nurses who had prior experience of pain could assess and manage those patients with pain.

A qualitative randomized, controlled trial aimed to evaluate the effects of relaxation training with chronic non-malignant pain sufferers immediately after training, and in the longer term, found that having others believe the experience of pain was crucial to many patients (Seers and Friedli, 1996). This English trial with a sample of 75 patients identified nine common themes, in an interview prior to entering the trial on relaxation, following analysis which related to chronic pain. One of these nine themes - "experiencing health care"- was divided into sub-groups of which the first sub group

was categorised as “believing the pain”. This section of the paper was not discussed in any great detail. The comments of the patients at interview formed the main text. It is important however to note that the authors stress that if a patient is led to accept that his pain is within his imagination then it can have “inevitable stigmatizing consequences” (Bendelow and Williams, 1995: 143).

Chronic pain does, of course, have a profound effect on the person experiencing the pain, but also on their family. Smith and Friedemann (1999) conducted a qualitative study to gain an understanding of the experiences of people with chronic pain and their relationship with family members. One of their conceptual categories was titled “inability to share feelings”. Within this theme, again using patients’ own narratives to form the main body of the text, the concepts of being misunderstood or not being believed were raised. The Rogerian concept of ‘congruence’ was seen to run as a thread throughout these themes. Congruence is advocated to allow the person to be honest and to respond genuinely, coupled with empathy and unconditional positive regard it forms the core conditions needed for person-centred counselling (Mearns and Thorne, 1988: 75).

A qualitative study, in which women with fibromyalgia, living in Sweden and the USA, were interviewed, found that the patients' perception of their illness and the lack of objective findings caused deep distress. This was mainly due to the lack of a label for their ill health and fatigue and the physicians’ inability to diagnose compounded this and as a result the women felt disbelieved and as such were unable to deal with their situation constructively (Henriksson, 1995a). The disbelief they felt was founded on the fact that there were no outward signs of illness and the unseen pain within the body coupled with the fatigue made them appear lazy. The women reported feeling understanding, belief and acceptance of their difficulties by seemingly ordinary actions e.g. a cushion placed on a chair by a partner. This gave the woman confirmation that the partner accepted her fatigue and pain and in their own way was trying to offer some comfort. Similar results were found by Steihaug *et al.* (2002) in a Norwegian study where data were drawn from an action research project, examining treatment groups for women with chronic muscular pain. The women again expressed the importance of being listened to, understood and believed.

Understanding and being listened to are frequently referred to within the literature and are associated with being believed (Hwang *et al.*, 2004; Blomqvist and Edberg, 2002; Smith and Friedemann, 1999). Many patients through analysis of their individual interviews have expressed feeling that others don't understand them, often because they have not had similar chronic pain experiences. The invisibility of the chronic pain experience was also associated with not being believed and added to the feeling of not being understood (Lillrank, 2003; Soderberg *et al.*, 1999).

Despite the numerous references to the negative effect upon the patient of not having a health professional accept a chronic pain experience as being credible there are very few papers that explore this particular effect. Confirmation of an experience is almost a necessity in order to give the patient permission to have that experience. W. I. Thomas' quote "If men define situations as real, then they are real in their consequences" (Cosser and Rosenberg, 1969: 246) is often repeated but what is missing is the power of others' confirmation of that reality depending on whether others can ratify that reality. It is this ratification of a pain experience that leads the patient to feel believed and understood. Further research into both the patients' experiences of not being believed and the health professionals' judgement on whom to believe is essential to further the management of chronic pain.

Updating the literature review in March 2007 utilised the same search strategy previously described. No further papers were identified as being relevant following abstract reading, however, as a final effort to check that the review was fully updated all pain journals held on-line were searched with each paper published in 2007 having the abstract read. In this manner I identified several papers (n=7) which I thought worthy of close reading and of possible use as supporting evidence for the thesis. It was this ad hoc manner which identified one further paper for inclusion in this section of the review of the literature.

Frantsve and Kerns (2007) in a secondary sourced paper reviewed literature on chronic pain patients and provider's interactions within a shared medical decision making context. Shared medical decision making is dependent on a "process of collaboration" which incorporates joint decision making and joint treatment planning. Within this paper the authors concluded that patients felt that physicians found it

difficult to believe patients' pain reports when there was no apparent physiological cause. Through an analysis and integration of the literature reviewed preliminary findings included that patients seek understanding from physicians whilst struggling to legitimise their pain concerns. This need to have chronic pain legitimised is further evidence that there is a need for patients with chronic pain to have their pain experience believed and an appropriate label, diagnosis or explanation to be provided by the health professional.

2.5 Cure versus management within a pain context

The third aim of the study focused on the lived experience of those still seeking a pain cure versus those who had accepted pain management. A systematic literature search was performed via CINAHL, Medline, British Nursing Index and PsychINFO using the key words 'self management' and 'cure'. The results were then combined with the key word 'chronic pain' to further focus the search (see table 3 below). A further search was then performed combining the results of the two searches to identify any papers that explored chronic pain self management and cure. This search failed to identify any papers. A final search was then performed using key words of 'lived experience' and 'patient perspective' with the original search. No one paper emerged that actually compares the living experience of those that are able to manage chronic pain with those seeking a pain cure. Many papers do examine differing attitudes and beliefs regarding pain and it is possible that these factors have an influence on individuals.

Table 3 Search strategy used to identify literature pertaining to ‘chronic pain self-management and cure’

Database	Key word	Key word	Total no. of hits when combined	No. of articles deemed relevant following abstract reading.
Medline	Chronic pain	Self-management	469	29
		Cure	247	8
BNI	Pain	Self-management	215	10
		Cure	151	2
PsychInfo	Chronic pain	Self-management	357	17
		Cure	177	
CINAHL	Chronic pain	Self-management	72	19
		Cure	22	4

2.6 Pain Management

Chronic pain is more of a life situation than a sudden event (Clarke and Iphofen, 2005) although the majority of patients with chronic pain can usually recall an initial injury, which preceded the advent of the chronic pain. Chronic pain, therefore, is a living experience. Patients with chronic pain have to deal with it every day and the way it is dealt with may vary from one person to the next. Managing the pain to enable a person to continue with life as normally as possible is considered to be the treatment option of choice, however, not all people are able to accept that there is no cure for their chronic pain and persist in trying to find a health professional who can effect a cure (Main and Spanswick 2000). There is an abundance of text books (Melzack and Wall, 2003; Main and Spanswick, 2000; O’Hara, 1996; Sofaer, 1992), self-help books (British Pain Society, 2004a; Wells and Nown, 1996; Hanson and Gerber, 1990) and articles (McHugh and Thoms, 2001a; Walker *et al.*, 1989) and information available from the world wide web (www.pain-talk.com) regarding the management of chronic pain but if the person is not prepared to live with chronic pain

and manage the disruption it causes to normal life then they are left to struggle from one health professional to another in an often fruitless search for a cure.

The literature reviewed for this section of the chapter is summarised in appendix 3 and 4. Despite there being no single identified paper there were themes or issues that are repeatedly raised throughout the reviewed papers. The papers that were identified through the “seeking cure” search often considered barriers to pain management whereas the papers that considered self management also examined issues which if not achieved became a barrier. This section therefore examines the issues identified through this search of the literature.

2.6.1 Depression

Chronic pain is often associated with depression (Naughton *et al.*, 2007; Kothe *et al.*, 2007; Elliott *et al.*, 2003; Grey, 2001; Linton, 2000) and there are many arguments surrounding whether the pain brings on the depression or whether there was a depressive element prior to the onset of pain (Jerant *et al.*, 2005; Ho and Biskupiak, 2004; Ciccone *et al.*, 2000). Indeed, patients with a more positive attitude towards life appear to be able to cope better than those who tend to take a more negative view (Taylor, 2001). Depression affects the ability to actively self manage pain (Jerant *et al.*, 2005) and can contribute to the emotional distress experienced by patients with chronic pain (Dewar *et al.*, 2003) and can lead to suicidal thoughts (Hitchcock *et al.*, 1994). Emotional distress is associated with multiple psychological factors and emotions such as anger, limited patience, mood swings and negative feelings can all contribute to the overwhelming feeling of depression.

2.6.2 Fatigue

Tiredness or fatigue is also associated with depression but within the reviewed literature is a common theme that emerges as a barrier to pain management (Kothe *et al.*, 2007; Austrian *et al.*, 2005). Lack of energy results in an inability to exercise (Jerant *et al.*, 2005) exercise being one of the components within pain management programmes (Robinson *et al.*, 2004). Pain is often exacerbated by exercise particularly when patients do not have a planned approach but follow an ‘all or nothing’ type of regime. This increased pain level further inhibits the wish to exercise as the patient then fails to see the value in it as a pain management strategy.

2.6.3 Emotional and psychological distress

Many patients with chronic pain often show evidence of distress arising out of previous and inappropriate consultations (Main and Spanswick, 2000). The more a patient's life is affected by pain the more distress they are likely to experience as they make life style changes to accommodate their pain. Younger patients appear more likely to experience psychological distress (Walker and Sofaer, 1998) but the experience of psychological distress is no reason to suppose that the pain is 'merely' psychological in origin. Psychological distress impacts upon daily living, affects function and the ability to cope. The more psychological distress a patient experiences, the less they are able to cope and consequently the less they can manage their pain (Bullington *et al.*, 2003).

Emotional distress as a component of the chronic pain experience is frequently referred to within the literature (Dewar *et al.*, 2003). Emotional distress comprises many attributable factors, several of which can be seen in patients who are unable to manage chronic pain but continue to seek a cure. The emotional distress exhibited often appears to be exacerbated by the patient feeling disbelieved by the health professional and the apparent lack of a diagnosis. Within the reviewed literature there are many references to the need for a patient with chronic pain to have a diagnosis to promote understanding of the chronic pain experience at a more personal level (Huntington and Gilmour, 2005; Witonsky and Whitman, 2005). Having unexplained chronic pain often leads to an increased level of pain (Robinson *et al.*, 2004).

2.6.4 Labelling

Several studies (Seers and Friedli, 1996; Bowman, 1994b; Steihaug *et al.*, 2002) have referred to the patients' need to have a diagnosis to explain their pain. This labelling, it could be argued, helped in their feeling of being believed and gave them some credibility for their pain experience. Iphofen and Poland (1998: 204) stated that the labelling concept views deviance not as a characteristic of the actual behaviour but as defined by the societal reaction to that behaviour. By giving a label to chronic pain patients we are potentially giving them permission to have that pain. Within pain management programmes the aim is to get rid of as many labels as possible. Terms such as 'lumbago' are dismissed and the pain is explained in terms of a painful syndrome. Attempts by physicians to understand chronic pain in terms of the

available narrow medical models fails to do justice to the complexity of the situation (Main and Spanswick, 2000:17). If it is so important to the patient to have their pain experience believed and they feel that by having a label for their pain confirms that belief, then as health professionals a label must be given, however it must not be a label that has negative consequences for the patient physically, mentally or emotionally (Clarke and Iphofen, 2005) .

2.6.5 Finance

The issues explored can be seen as inherent barriers to pain management, by this they come from within and appear to rely on personality and psychological make up as to whether a patient will achieve successful pain management. Within the literature, however, there are several papers that refer to financial issues as acting as a barrier to pain management (Jerant *et al.*, 2005; Austrian *et al.*, 2005; Dewar *et al.*, 2003). The cost of health care differs across the world and the management of health issues is similarly contrasting. As the literature reviewed has been generated from research from several different countries including Norway, the United States of America, Canada, New Zealand, Korea and of course, the United Kingdom, the cost of pain management to the individual varies considerably and may well have an impact upon a patient's ability to seek appropriate pain management clinics. Within Britain despite state health care being 'free at the point of delivery' the provision of pain services differs greatly from area to area. Secondary gain is seen as a benefit for the patient through having ill health or chronic pain. Secondary gain can take many forms and include getting more attention from family or financial gain in cases where some patients are unable to work because of the pain and Department of Work and Pensions benefits pay out more than a low paid job. Financial implications as a barrier to pain management therefore cannot be ruled out or discounted.

2.7 Conclusion

From the literature search and review there appears to be a dearth of appropriate pain-related evidence related to this current thesis, however, qualitative research which explores patients' expectations, understanding, perspectives and related experiences is not as abundant. This type of qualitative research however appears to have been increasing over recent years reflecting the change in the appreciation of the value of patient experiences and lived experience more generally. The literature relating to the

three main aims of this study has been reviewed and although there are studies relating to the lived experience of chronic pain (Thomas, 2000) there are no studies which specifically look at the effect of believing the chronic pain patient other than the already published literature review (Clarke and Iphofen, 2005). A comparison of the lived experiences of those still seeking a pain cure against those who have accepted pain management has not been explored within the literature to date. This study seeks to build on knowledge already gained through phenomenological studies exploring the lived experience of chronic pain whilst contributing to new knowledge regarding the effect of health professionals believing the chronic pain account and the lived experience of those who still appear to be seeking pain cures versus those appearing to accept pain management.

Chapter Three

Methodology

3.1 Introduction

This study adopted a multi-method approach: an extended, low structured audio taped interview with each patient coupled with the patients' diaries, follow-up 'debriefing' interviews and my own research-focussed reflective diaries. It is based on a hermeneutic analytical approach within an overarching phenomenological framework and aims primarily to explore the living and lived experience of people with chronic pain. The second aim examines the effect of "being believed" on the chronic pain patient and the third aim is to develop an understanding of why some patients appear able to successfully move from seeking a pain cure to accepting pain management. By this is meant that it is an exploration of the effect upon the patient of having health professionals accept the patient's chronic pain experience as being credible.

3.2 Ethical approval and considerations

Ethical approval for this study was given by the North East Wales Local Research Ethics Committee (LREC) at the end of April 2003. The LREC was primarily concerned with the welfare of the patient and requested information on whether "vulnerable" patients would be recruited. The argument was put to them that this was not only possible but likely as all patients attending a pain clinic may be considered to be vulnerable as a consequence of their condition. All patients have the potential to be vulnerable simply by being a patient and assuming the rather passive patient role. Some chronic pain patients although not having a confirmed diagnosis of cause of pain, can adopt and display illness behaviour. This all conspires to increase a patient's vulnerability and asking them to relate their living chronic pain experience may expose a fragility and vulnerability they had not previously acknowledged. This means that the nurse as researcher and the nurse as interviewer have a duty of care to the patient. It could be argued that those who consider themselves to be vulnerable, however, would be less likely to self-select and therefore would have excluded themselves automatically from the study. Ethical approval does not mean that all ethical problems have been resolved or addressed once ethical approval has been gained and therefore consideration had to be given to the ethics of the study throughout (SRA, 2003: 43).

Rudestam and Newton (1992: 196) state that the two main ethical issues concerned with social science research are ensuring that the participant gives informed consent and that the participant experiences no harm. To ensure that the patients fully understood the nature of the research and what it entailed they were invited to consider participation at the end of a clinic appointment where I discussed the study. If they were interested the patient information leaflet (which was available in both English and Welsh) was given (see appendix 5). At the patient's next clinic appointment if interest was still expressed in participating then the consent form was given and written consent taken (see appendix 6). The patient was then recruited to the study.

Although care was taken to ensure that the patients within this study came to no harm, issues of coercion had to be considered particularly as the patients included in this study were asked to participate by the clinical nurse specialist responsible for their pain management and care. The dual role of nurse-as-researcher demands that, for the nurse, the care and welfare of the patient is of primary importance whereas for the researcher the need is to advance knowledge for the good of the future patient population (Holloway and Wheeler, 1996: 62). This need to define identities within the dual role may also pose a problem to the patient who may not understand or appreciate this dichotomy and view the researcher primarily as nurse/carer. The very nature of recalling chronic pain lived experience either through the interview process or the task of diary keeping was thought to be a possible cause of distress to the patient and therefore a second interview was built into the research design which would serve as a "closure" or debriefing interview. This would ensure that any issues raised through the research process could be addressed appropriately. Iphofen (2005: 25) states that only the researcher can assess what distress, if any, is being caused through the interview process and determine whether termination of the interview should occur, thereby becoming the "only ethical decision-taker" in the field setting. Through adhering to the Nursing and Midwifery Council's (NMC) Code of Professional Conduct (NMC, 2004) I determined my own identity and ensured that my patients as participants were not harmed by the research process nor were their individual treatments compromised (Iphofen, 2005: 25).

3.3 Sample

The sample (n=8) was a purposive convenience sample, generated from those patients who had been attending a nurse-led chronic pain clinic within a district general hospital within the North East Wales NHS Trust for at least three years. The nurse-led chronic pain clinic was originally developed as a clinic for providing information and instruction in the use of TENS machines, therefore all the patients attending the clinic were referred from the consultant-led chronic pain clinic when the patient had been recommended TENS as a treatment. Over time this clinic evolved into a nurse-led chronic pain clinic as the clinical nurse specialists developed knowledge and skills into this speciality enabling them to suggest medication regimes, give a course of acupuncture or recommend and provide TENS treatment. Today, referrals to this clinic are taken from consultants throughout the hospital and direct from patients' GPs. The length of attendance turned out to range from 3 to 6 years with a mean of 5 years. The sample comprised four men and four women, aged between 37 and 74 years. The characteristics of the sample are shown in appendix 7.

To allow for comparison between those patients who are perceived to have accepted pain management rather than still seeking 'pain cure' a panel of pain specialists from within the Hospital's Pain Service were asked to individually consider named patients from their clinics and categorise them accordingly. To increase reliability in the sample allocation a likert-style rating scale was used (see appendix 8). This rating scale utilised a six-centimetre line, scored from one to six and ranged from "accepting pain management" (score =1) to "seeking pain cure" (score =6). The patients, for whom the entire panel agreed with the categorisation at each of the scale's extremes, (in other words had scored either a 1 or a 6 from each panel member), were then approached to be a part of the study providing the inclusion criteria were met. This rather crude method of differentiating between patients relied on the opinions of the clinical nursing staff. Although crude it offered some minimal degree of construct validity and served to support my own professional constructs. Adams-Webber (1979:7) states that within the context of a personal construction system, every construct through its relationships with other constructs will apply a set of predictions about each of the events to which it is applied. This is the principle that was applied through using the rating scale. As nurses we considered the patients within our care and gave a studied judgement on whether they were managing their pain or still

seeking a pain cure. It was important to acknowledge these preconceptions or judgements to ensure transparency within the study. Equally I did not want to impose my own personal judgements on the data hence inviting the views of other clinical nurse specialists.

An attempt to consider the sample within two distinct groups was ambitious but was in some ways vindicated by the comparative insights offered through the two methods of data collection: diary and interview. Although stereotyping patients is not recommended practice, my own practice experience suggests that through patients' self-report, some patients appeared to manage their pain better than others. Past discussions with colleagues had highlighted that there appeared to be two distinct types of patients with chronic pain and that it would be possible to use such dichotomising categories. Through acknowledging these preconceptions and application of categories or labels to the patients within the sample I did not attempt to impose these constructs onto the data but gave it every opportunity to emerge within data analysis.

To introduce further elements of control to the study the balance of gender of the patients was considered and within each of the two categories there are two males and two females. Confidentiality was preserved through the use of a coding system and the use of pseudonyms for family and friends in the reported narrative data from the diaries and the transcribed interviews.

3.4 Type of chronic pain experienced

The bodily location of the chronic pain experienced was varied. It ranged from back pain (n=4), stump pain (n=1), bladder pain (n=1), abdominal pain (n=1) to foot pain (n=1). The location of the pain was not considered to be a factor within the inclusion criteria as it was the experience of living with chronic pain that was to be explored. It was originally anticipated that by exploring a variety of different pain experiences and pain locations a greater wealth of information might be obtained. This was borne out within the study and it was interesting on analysis to see how similar themes were developed from these differing pain locations, however, due to the nature of the chronic pain locations and its corresponding effect on the patient's life there were also

some issues that were pertinent to only one patient but were worthy of further discussion and exploration.

3.5 Inclusion criteria

The inclusion criteria were:

- Patients who attended a nurse-led chronic pain clinic for at least three years.
- Patients who had not attended a pain management programme.
- Patients over the age of 20 years and under the age of 75 years.
- Patients who were willing to share their experiences of living with chronic pain.
- Patients who were willing to maintain a diary for a period of four weeks commencing from the first interview and ending with the second interview.
- Scored at one of the extremes on the pain cure versus pain management rating scale

3.6 Rationale for inclusion criteria

3.6.1 Patients who have attended a nurse-led pain clinic for at least three years

Combining the use of interviews and diaries as the research tools for generating data was considered to be a very personal, and perhaps, sensitive experience for patients with chronic pain. To ensure that the data was as honest and true to the lived and living experience as possible it was considered necessary to ensure that a trust base could be established between the patients under study and me as researcher. The patients who had attended the nurse-led pain clinic for at least three years were by then very familiar with me as part of the clinical team, and might be thought to trust me as an interviewer. Although the tape recording of the interviews caused a little uneasiness in the early stages of the interview, I judged there to be no distrust and perceived no evident continuing discomfort shown to myself. This then helped to provide an amicable relationship that allowed the patient to talk about their experiences of living with chronic pain. It was anticipated that this relationship, based on mutual trust, and in some instances a degree of acquaintanceship bordering on friendship, would have a positive effect on the diary keeping and prompt the patient to write about personal and sensitive issues. In some cases this proved true and some of the diaries provided a rich wealth of data relating to a life of living the chronic pain

experience. I was on first name terms with all of the patients and there was already a history of shared personal information: for example, all of them were already aware that I had two children, and often the interview began with exchanging pleasantries about life in general. One interview began discussing a wedding I had been about to attend when I had last seen the patient in clinic:

The thing is if you go to a winter wedding you've got to be warm...I went to one last year, my nephew...and I just wore a suit and I just prayed on the day it wouldn't be a cold day [F56]

3.6.2 Patients who have not attended a pain management programme (PMP)

Patients were excluded who had previously attended a pain management programme (PMP) (although within the North East Wales catchment area no such programme is available) as those patients would, hopefully, already have been taught coping strategies. One of the aims of the study was to examine the lived and living experience of patients with chronic pain and it was felt that as the sample was only small that by introducing another variable of having previously attended a PMP might skew the data by adding another dimension. It would, of course, be interesting to compare both categories of patient in future research.

3.6.3 Patients over the age of 20 years and under the age of 75 years

The age group was chosen to comply with the requirements of the local NHS Research Ethics Committee. The Committee were concerned to exclude minors and the very elderly on the grounds of their supposed vulnerability. The final two criteria, therefore, were decided by the patients themselves as to whether they were prepared to share their experiences and willing to maintain a diary for a period of four weeks. Each of the eight patients complied with the criteria.

3.6.4 Patients who were willing to share their experiences of living with chronic pain

All studies that explore human experience rely on a patient's willingness to share the experience under study. I was very fortunate during the recruitment period of the study that I only approached nine patients in order to get my sample of eight. The one

patient who declined did not decline outright but asked if she could be included at a later date when her personal circumstances would better suit.

3.6.5 Patients who were willing to maintain a diary for a period of four weeks commencing from the first interview and ending with the second interview

The use of a diary for four weeks detailing the patient's life living with chronic pain potentially has the ability to increase the awareness of pain through focusing on the experience. The use of a second interview, at the time the diary was returned was to ensure that any problems raised by the research could be discussed. Follow-up pain clinic appointments were also offered to the patient for the same reason, although only one patient requested this and it was for repeat acupuncture treatment rather than post research counselling.

3.6.6 Scored at one of the extremes on the pain cure versus pain management rating scale

The rationale for this is discussed in section 3.3.

3.7 Trust

Trust can be defined as having a firm conviction in another's reliability, integrity, honour; and can imply implicit confidence, faith and reliance (Wyld, 1958:1293). Jary and Jary (2000: 647) state that "basic trust" in others and institutions, is often viewed as essential to satisfactory long-term social relationships. It was the basic trust already established between nurse and patient that was used to advantage within this study.

The patients had a trust in the pain clinic as an institution and had trust in the nurse in that institutional context as someone to help and care for them without quite acknowledging that person as an individual. Trust is very difficult to prove and although some trust issues could be confirmed and established through patient information giving, consent to participate, permission to withdraw consent at any given time and the guarantee of anonymity and confidentiality it is probably by analysing the data provided by the sample that trust could actually be more fully demonstrated. By this I mean if a patient trusts the interviewer it is possible that they will provide data that is extremely personal and in some instances extremely insightful. This indeed proved to be the case, although there were differences between the data generated from interviews and data generated from the diaries. Some were

happier to write personal and sensitive information whereas others found it easier to talk; occasionally some were able to do both and thereby provided a wealth of rich, insightful, descriptive lived experience. This supported the combined use of both interview and diary keeping as methods of data collection.

3.8 Phenomenology

Phenomenology was chosen as the underpinning methodology for this research as it recognises the value of human experience. Phenomenology is defined as a science of essential Being (Husserl, 1913/1931:44) although the earliest definition attributed to this science was in 1764, when Immanuel Kant stated that phenomenology was a study of phenomena or things (Cohen, 1987). Today phenomenology is accepted as being a philosophical method (Mautner, 2000: 421), which seeks to understand and place meaning on lived experience. This method, predominantly, has its origins based in the works of Edmund Husserl.

Husserl (1859-1938) was a German philosopher who developed the science of phenomenology at the beginning of the 20th century. His book "*Ideas: General Introduction to Pure Phenomenology*" was first published in 1913 and the contemporary literature suggests that this text is as relevant today as it was nearly a century ago (Dowling, 2004; Porter, 1998; Paley, 1997; Koch, 1995; Walters, 1995). Despite having been translated from the German (Husserl, 1913/1931) much of the original meaning has been maintained.

Since the original contribution by Husserl, there have been many followers of the discipline, who have added their own traditions and perspectives to a developing science, so that today, there are various approaches and methods within the science. It is one of these followers, Martin Heidegger, who has provided the philosophical underpinning of interpretative phenomenology used for this research. However, as Heidegger built on Husserl's work before developing his own school of phenomenology it is necessary to examine both methods and provide a rationale for why one was chosen over the other as being the most appropriate for researching the lived experience of chronic pain. There are two main schools of phenomenology - eidetic or descriptive which is guided by the philosophy of Husserl; and interpretive phenomenology which is guided by the philosophies of Heidegger and Gadamer.

There is a third school of phenomenology beginning to emerge called the Dutch school of phenomenology, which is guided by Van Manen and is a combination of both descriptive and interpretive phenomenology (Dowling, 2004).

3.9 Descriptive phenomenology

Husserl's phenomenology aims at being a descriptive theory (Husserl, 1913/1931: 209). It examines experience from the person's natural standpoint, this standpoint being that of the subject's everyday life. It is very important to appreciate that it is the person's experience that gives the essence of the experience and it is not based on previous theory, logical conceptions or presuppositions. Husserl placed a great emphasis on the individual as an individual. The experiences of the person are unique to them and how it is interpreted by that person is entirely subjective. It is necessarily existentially unique. One person's experience of a glorious double rainbow bridging the dark cloudy sky whilst a splitting of the black clouds by sunrays from behind may not be the same to another. For example, a child may see it as part of a great fantasy and wonder where the pot of gold is, one adult may see it as a promise from God, others may see it as a romantic moment to hold in their hearts forever and indeed another may view it as simply an arch of colours formed in the rain by diffraction of the sun's rays. Each is different, none of them are wrong within their individual experience and perception and within phenomenology the truth is assumed to be changeable (Sadala and Adorno, 2002).

Experience and perception are irrefutably linked. The way an individual perceives an experience will have bearing on how they relate to that particular experience. Culture, gender, beliefs and intuition will reflect on these experiences as the person sees them and, again, one person's experience will not be the same as another even in apparently identical circumstances. This, perhaps, can be viewed as being "subjective". To be subjective is to be dependent on personal taste or views and is based on a person's emotions. Subjectivity exerts an effect upon the lived experience and this subjectivity needs to be examined and held in high regard whilst attempting to explore the deeper understanding of the phenomena in hand. Experience, subjectivity and perception are all part of a circle that links to form the basis of the unique approach of phenomenology.

3.9.1 Bracketing

To use descriptive phenomenology as a framework it is essential that the researcher puts aside all thoughts of self and allows the subject to re-live the experience via their account of it. An empathic understanding is of great benefit but must not impinge upon the experience as lived, empathy serving as a support to the person to recount that lived experience under consideration. This recalled experience will demonstrate the person's natural standpoint as they see it and will allow the researcher to see and hear that person as someone who "perceives, represents, thinks, feels, desires and so forth" (Husserl, 1913/1931: 104). This standing back from the topic area should prevent the researcher from exerting any influence over the experiencing person. This is essential in descriptive phenomenology, as the researcher needs to bracket, or put to one side, the real and absolute meaning of the lived experience. By setting aside the limitations to knowledge that are essentially involved in every form of human investigation the restricted line of vision to the understanding of the experience can be deflected and becomes phenomenological reduction (Husserl, 1913/1931: 43), in other words, phenomenological reduction is a suspension of judgement (Kvale, 1996: 54). Walters (1995) describes phenomenological reduction as being the process that the researcher uses when changing from the natural attitude to the philosophical attitude. The "natural attitude" referring to the relationship between consciousness and everyday experience and the "philosophical attitude" being the more detached questioning of the natural attitude.

3.9.2 Reflexion

Although descriptive phenomenology requires the person who has the experience to provide the description it is the researcher who with the art (skill) of reflexion is able to discover the deeper meaning, whilst developing insight into the phenomena under study. The phenomenological method proceeds entirely through the acts of reflexion (Husserl, 1913/1931: 215). Reflexion is described by Husserl (1913/1931: 219) as "...an expression for acts that the stream of experience with all its manifold events can be grasped and analysed in the light of its own evidence". This may be clarified by Taylor (2000: 3) when she defines reflection as "...the throwing back of thoughts and memories, in cognitive acts such as thinking, meditation and any other form of attentive consideration, in order to make sense of them, and to make contextually appropriate changes if they are required". Reflective practice is a means whereby

nurses examine, either individually or with others, an incident that has caused concern or provoked thought. It is used as a way of improving practice, sharing experience and consequently a lessening of the stress caused by the incident (a debriefing activity), however, it can be used as a mental whip, constantly trying to improve when improvement is not possible unless circumstances are changed (Clarke, 2004; Johns, 1995; Schon, 1983; Carper, 1978). Reflexion allows for analysis of an experience in the light of its own evidence. It is perhaps an immanent perception. Husserl (1913/1931: 306) provides warnings though when he suggests that it is vital that whilst the researcher is attempting to increase insight that the researcher must accept the phenomenon as described. In other words what the subject presents to the researcher, the researcher then presents this data to her own mental insight, reflexion and intuition and must not alter its original meaning but must describe it honestly. The process of bracketing is continued through the reflexive process, which enables the researcher to disassociate from the experience and instead of living in the experience he/she is able to reflect and thereby arrive at the absolute Being. Phenomenology is associated with understanding rather than a truly empathic approach and seeks to understand rather than explain phenomena (Sadala and Adorno, 2002). Reynolds *et al.* (2000) state that the extent to which empathy as an emotion can contribute to an understanding of another's experience is poorly understood. Husserl (1913/1931: 150) considered phenomenological science as presenting us with "essential possibilities for the setting up of understanding". Understanding can be defined as showing insight or sympathy whereas empathy is the ability to identify oneself mentally with a person (McFerran, 1998: 145). It would seem that although an empathic viewpoint is preferred whilst discovering/researching the lived experience, it is the deeper understanding of the phenomenon under study that is the crux of the matter. It could be argued that it is an almost impossible task to separate empathy from understanding from the pain viewpoint due to the ubiquitous nature of the pain phenomenon. All human beings, with very rare exceptions, have had pain experiences and therefore empathy for someone in pain is often demonstrated. Understanding also of a pain experience can be developed through prior experience of a painful condition, hence the merging of empathy with understanding within a pain context.

Some descriptive phenomenology methodology involves returning the description of the phenomenon and the purported deeper understanding to the person who provided

the original description. This is done to achieve clarification and validation of that lived experience. Not all traditions within the Husserlian discipline advocate this approach so within descriptive phenomenology some phenomenologists, such as Colaizzi, advocate returning the findings to the person who provided the lived experience and others, such as Giorgi do not (Kleiman, 2004).

3.10 Interpretive/ hermeneutic phenomenology

Martin Heidegger (1889 – 1976) further developed Husserl’s contribution to the phenomenological movement. His interest in philosophy is reported to have originated after he had read works by Franz Brentano, another forebear of the phenomenological movement (Inwood, 1997: 1). Heidegger studied with Husserl and they shared many commonalities and beliefs. Heidegger’s phenomenological school of thought is based on the philosophy that the understanding of human experience can be developed through the interpretation of language, history and culture, with the emphasis on where that person sees himself within the world as a starting point.

3.10.1 Dasein

This emphasis on where a person sees himself within the world is at the core of Heidegger’s philosophy (Mautner, 2000: 121). *Dasein* is German for existence however Heidegger uses the term *Dasein* as meaning “being-there” (Moran, 2000: 193) and suggests it is *Dasein* that poses the question “what is Being” (Inwood, 1997:20). The German translation for *Dasein* is existence, Jasper (2004: 104) however states that the word *Dasein* is left in its original German because the interpretation that Heidegger places on it leaves it virtually untranslatable. Heidegger suggests that *Dasein* has a preliminary understanding of Being which contributes to the engagement with others and themselves (Inwood, 1997: 21). Being is then further described as being everywhere, everything and nowhere. In selecting *Dasein* as the starting point for his enquiry Heidegger considers all these entities. Furthermore, *Dasein* (as a noun) is not used by Heidegger as it has been used by other philosophers to denote the existence of other entities but Heidegger uses it solely in application to human beings and is Heidegger’s manner of indicating the human-being as well as the Being that is human (Waterhouse, 1981:134), therefore, a human being is whatever it wants to be. This, Bauman (1978: 159) confirms, is the distinction between a person’s existence (*Dasein*) and the world in which that person exists. Heidegger further

clarifies his use of the term *Dasein* to indicate not the properties of what it is to be human but the very essence of Being. This focus on the human being, their experiences and how they perceive these experiences within the world as they see it is the crux of his school of phenomenology.

Interpretative phenomenology, therefore, examines everyday phenomena and the everyday meanings that provide insights into such phenomena. Carman (2001) states that phenomenology, as a task, is not simply just to provide a descriptive and objective report of an experience. It also aims to allow the ordinarily hidden aspects to become more evident. Heidegger uses hermeneutics to assist in this process of discovering the deeper meaning. Carman (2001) further argues that for Heidegger phenomenology must be hermeneutical as the phenomenon he is concerned to uncover is not something already given and self-evident. All experience is based on interpretation whether personally or by others. Suspending personal interpretation of an experience (or bracketing) is a method adopted when a neutral view is required. Husserl advocated bracketing as a means of preventing presuppositions and personal judgements from impacting on the exploration of lived experience. Heidegger rejected this process of bracketing and identified the importance of the interrelationships between people as well as recognising that people's lived experience was affected by the way they viewed the world, their beliefs, their own unique identity and perceived reality. Heidegger sought to replace this method as he felt that the outcome of any investigation would be enhanced by considering our place-in-the-world and would then provide "an experience of truth as revelation" (Moran, 2000:235) this equally applies to the researcher's place-in-the-world.

3.10.2 Hermeneutics

Hermeneutics is a method for exploring the "beingness" of human experience, providing a technique to explore lived experience whilst concentrating on ordinary language which is based on the assumption that as humans the world is experienced through language and that it is language that provides understanding and knowledge (Byrne, 2001a). The study of ordinary language is a philosophical school in its own right; sometimes referred to as "linguistic philosophy" it holds the view that speech acts, not sentences are the primary bearers of truth (Recanati, 2004). Ludwig Wittgenstein (1889-1951) influenced ordinary language analysis and held the opinion

that the meanings of words live within their ordinary uses (Ihara, 1991), in other words, language has to be taken in context. The ordinary language used by the patients within the study was a source for analysis although not exclusively. All language and forms of communication, verbal and non-verbal, had a potential for analysis. By using Heidegger's hermeneutics to interpret the text gained from the conversations of the interviews, the context in which the language is spoken, the culture, beliefs and mindset of the individual was taken into account.

This is one of the major differences between Husserl's descriptive phenomenology and Heidegger's hermeneutic phenomenology. Heidegger's central belief was that any philosophical account of human beings must consider the whole of his lived existence and not just the manner of knowing. This was a complete deviation from Husserl's phenomenology which gave the problem of knowledge precedence over ontology and consequently viewed man as a knower divorced from the world (Waterhouse, 1981: 134).

Hermeneutics is defined as an interpretation of texts (Mautner, 2000: 248), and its main purpose is to gain a valid and common understanding of the text (Kvale, 1996: 46). Through interpretation of the texts gained from the interviews (spoken word) and diaries (written word) a detailed and comprehensive picture begins to develop of a Being within a chronic pain context. Cultural influences are acknowledged to play a role in the acceptance or non-acceptance of the chronic pain experience and its outcome and effect on life and living. These cultural beliefs form an integral part of that Being's essential core and will also influence relationships and that individual's standing in the world. Heidegger's use of hermeneutics to explore experience from the experiencing person's viewpoint and standing in the world allows consideration and places importance of all these other influences and conditions that contribute to that lived experience to enable deeper understanding of the phenomenon under question.

3.10.3 Semiotics

Semiotics as the science of signs was also the term used by Charles Morris for the general inquiry into, or theory of, linguistic meaning (Mautner, 2000: 516; Van Manen 1990: 185). Writing is a major part of the method of phenomenology and it is

semiotics that links phenomenology to hermeneutics. Phenomenology describes the lived experience, hermeneutics is the interpretation of the phenomena and semiotics is “the practical linguistic writing response to the method of phenomenology and hermeneutics” (Van Manen, 1990: 4). De Pompei and Hotz (2001) state that language and communication is the heart of learning, living adequately in society and developing one’s own unique personality. Without competence in communication, they argue, the very essence of the person and the way in which they live can be compromised. Language and linguistics has a pivotal role in life and society as we view it. De Saussure (1959: 7) in a short chapter examining linguistics and its relations with other sciences puts speech as being more important culturally than anything else in the lives of individuals and societies. As the science of signs semiotics includes any form of action and communication that is capable of interpretation (Mautner, 2000: 516). This then includes body language, non-verbal communication, gestures, facial expression, tone of voice, inflections and the words used. There are, however, differences between language and speech. Speech relies heavily on the voice to give it emphasis, tone and denote mood and is the production of sounds that make up words and sentences (DePompei and Hotz, 2001) whilst the non-verbal communication of body language adds further emphasis to implied meaning. Body language can itself be as powerful as speech making speech unnecessary in the communication of certain meanings (Clarke and Iphofen, 2006a). Within this research study the lived experience of chronic pain revealed a pain language with many varying descriptions being used to describe the pain that each experienced.

Semiotics has to be appreciated and given consideration within any hermeneutic inquiry. The tools for data collection are audio-taped interviews (spoken word) and the patients’ own diaries (written word). Language therefore is a vital component of the analysis. Following transcription of the interviews, conversation became text, therefore allowing analysis of text. The text then takes on the status of a “research product” of its own kind. This conversion from conversation to text was of such vital importance that I transcribed the audiotapes myself. I sought to include laughter, pauses and silences as well as change of tone, gestures and expression that occurred during the interview. Without these “stage directions” misinterpretation of the text

and loss of essence of the lived experience could occur. Consider the following example, firstly written word for word without any directions:

Kath: Overall do you think that pain has greatly affected your life then?

M48: No, I don't know.

Kath: Do you think your life would be any different without the pain?

M48: Yes. I would think I was dead.

Now consider the same example with directions as they occurred now recorded:

Kath: Overall do you think that pain has greatly affected your life then?

M48: No, I don't know. (Said very hesitantly, unsure, I think he doesn't quite understand the question so I rephrase it)

Kath: Do you think your life would be any different without the pain?

M48: Yes. I would think I was dead. (Patient laughs, loud and long, clapping his hands, I also laugh)

Without the directions the first example potentially reveals a depressive personality, add the directions in and the personality is revealed to be quite the opposite, gregarious, positive and in control.

The ongoing interrogation of the produced text, its 'dialogue' with the researcher/analyst requires such detail of mood, ambience and tone. It is also important to note that phenomenologists are not simply interested in the experience for experience's sake but also in the manner of the telling. The words used, the inflections in the voice and, to a smaller degree, the body language all help to create a better understanding and a clearer insight into the experience as lived, thus supporting personal transcription. The consciousness of the unobserved but subsequently observable background in perception and memory and therefore the experience will promote a deeper insight and through the re-reading of transcripts, the repeated listening of taped interviews, the researcher will be able to draw out the full meaning whilst connecting the meanings together in a phenomenological manner. The remembering of an experience also has its place in this method. Memory has its own kind of inadequacy (Husserl, 1913/1931: 393) but despite the fact that different

recollections can take place over a period of time these memories (relating to the same experience) can be taken together and viewed as “the unity of one memory” (Husserl, 1913/1931: 393). It then becomes of interest what has been remembered, what has been omitted and why.

Van Manen (1990: 4) links thinking to writing and it could be argued that the depth of thoughtfulness that is required within phenomenology would not be possible without the reflective written word. Writing is a major part of the method of phenomenology. Phenomenology relies on reflection and intuition (Husserl, 1913/1931: 215) and it is the writing and rewriting process that helps within the reflection, allowing the researcher to seek the deeper meaning without requiring the researcher to make suppositions about that experience.

Heidegger believed that language, culture and history were important considerations when interpreting a person’s given lived experience. By recruiting patients who had been attending pain clinic for at least three years, I had some awareness of the patients’ personal history. Cultural background was very similar between all subjects recruited, simply due to convenience sampling. All were white, of Welsh/British culture, had Christian beliefs and had lived within a 30 mile radius of the district general hospital for the last 20 years. Although this had not originally been a consideration in the sample selection/inclusion criteria, on reflection it helped prepare a level playing field for interpretation, particularly as I, also, fitted the previously outlined cultural factors.

3.11 Empathy

Interpretive phenomenology as a research method advocates the use of skills of intuition, empathy and understanding in the analysis of the data, which is the very personal, subjective, unique experience of the human being who has experienced or is still experiencing the phenomenon under study. It envelops the natural world and develops “a belief, a real belief” in the researcher (Husserl, 1913/1931: 323).

Empathy for the related lived experience is advocated both within Husserl’s and Heidegger’s phenomenological frameworks. All human beings can empathise with the acute pain experience, although severity and circumstance regarding the acute pain experience can vary from one individual to another, it is possible to assume that

understanding, insight and sympathy could be given to the chronic pain experience simply on the basis of having experienced acute pain.

Standing outside of a person's living experience, however, can be very difficult, particularly if a patient gets distressed during the telling. Patient stories, narratives and personal experience are extremely powerful with patient stories being used within nursing clinical leadership programmes to encourage nurses to listen and respond to the individuals' experience (Cunningham and Kitson, 2000). Reflective practice plays a significant role within nursing education and personal reflective accounts of patient experiences are often seen within health professional literature (Clarke and Iphofen, 2006b; Clarke, 2004).

3.12 Phenomenology within nursing research

Phenomenology as a methodology is greatly extolled within the nursing research literature. Koch (1995) describes the process as how insights about the human condition are generated, interpreted and communicated. Rose *et al.* (1995) concludes that phenomenology has the potential to generate knowledge for practice from practice and this method is congruent with nursing ideals where humanistic knowledge is valued. Van der Zalm and Bergum (2000) present an examination of the results of phenomenological inquiry and compare it to the types of knowledge that are considered important for nursing. They conclude that hermeneutic phenomenology contributes knowledge that is practically relevant for nursing practice in that it provides understanding of the person's reality and experience, one that is able to value individuals and embrace the nurse-patient relationship.

Academic rigour is discussed by Rose *et al.* (1995) where issues pertaining to credibility, consistency and congruence with the stated discipline are examined. To illustrate how academic rigour can be achieved within the methodology the paper explores the lived experience of researchers using phenomenological methods. Through narrative provided by the researcher within a research journal the advantages and disadvantages of the method is discussed. Method slurring stands as one major disadvantage. Some work can lend itself to a variety of methodologies and triangulation can be recommended as a means to increasing the validity of a piece of research, however, method slurring may lead to methodological inconsistency and

within phenomenology the more robust works have stayed true to the identified method. Rose *et al.* (1995: 1128) state that phenomenology is able to “generate knowledge for practice from practice” and therefore is an ideal method for nursing research. Similarly Koch (1995) in a paper that discusses the influences and applicability of Husserlian phenomenology and Heideggerian hermeneutics on the nursing research agenda recommends that nurses appraise the philosophical underpinnings of the methodologies that they pursue.

Paley (1998) argues that Heidegger’s phenomenology does not have the methodological implications that are often ascribed to it in nursing literature. He states that positivism and science are not the same thing and by assuming that they are nurse researchers fail to see that Heidegger’s work implies scientific realism. This can lead to nurse researchers focussing on the ‘lived experience’ rather than the philosophical underpinnings which commit the researcher to a study of social practices, and to showing how these practices are at the root of the constitution of subject and social object. Paley considers the misinterpretation of Heidegger’s principles to be caused by secondary reading of his work rather than the original texts. Again this reinforces the argument that nurse researchers must be fully aware of the philosophy which they are following to ensure that their study has academic rigour.

In an earlier paper Paley (1997) had discussed nursing’s attempts to make use of phenomenology which is based on Husserl’s philosophy. He makes the charge of poor application of this particular methodology due to secondary reading and states that although Husserl is often referenced he is rarely quoted. Of course, in defence, it must be noted that the original text was written in German and that the majority of nurses within Britain have to rely upon translations and within the translation some subtleties of meaning can be lost, particularly when an idea is conveyed using a word that cannot be translated. Paley (1997) focuses upon Husserl’s concept of essence and eidetic reduction and claims that as nurses cannot define essence then nurses are not entitled to make use of Husserl’s terminology or to attempt to ground research within his philosophy.

Omery (1983) considers three different phenomenological methodologies: Giorgi, Van Kaam and Colaizzi and their application within nursing research. Each

methodology provides a step-by-step guide to data analysis. All rely on qualitative data but it is the method of analysis that allows for variety in the exploration of human phenomena. She advocates this methodology as being highly suited to nursing research as it assists in the understanding of the human experience.

3.13 Rigour in phenomenological research

All research has to confront measurement issues of reliability and validity but there is a difference to how this is accomplished in qualitative research in comparison to quantitative research (Gillis and Jackson, 2002:438). Within qualitative research rigour is taken to mean trustworthiness, reliability refers to dependability and validity is credibility. For issues of generalisability, which is rarely possible within phenomenological research as small numbers make up the sample, transferability is often applied and objectivity becomes confirmability (Holloway and Wheeler, 1996:256). In effect rigour is the trustworthiness of the study (Koch, 1996). Koch (1994) recommends the use of a journal to allow others to understand and follow the decisions the researcher has made ensuring that there is transparency of process and method. Within this study a research diary was kept which detailed the progress of the work as well as personal reflections. Slevin and Sines (1999/2000) recommend several methods which can be used to enhance rigour. These included keeping a journal as well as providing rich and dense data. The use of these and other various methods enhance overall credibility.

Rigour in phenomenology can also be achieved through validating the findings of a study and Jasper (1994) describes two methods: participation validation and team analysis. Participation validation involves asking the participants to verify that the findings are a true record of their lived experience while team analysis involves a process of inter-rater reliability. It was the latter that was chosen to strengthen rigour within this study and is discussed in chapter four (4.2.4).

In essence rigour in phenomenological research strives to demonstrate that the research has truth value and that all decisions made were thought out and considered ensuring that the findings become well examined and well explained (Cohen *et al.*, 2000:95). The scientific status of phenomenology depends on both a systematic and transparent approach.

3.14 Chronic pain as a lived experience

Bendelow and Williams (1995) state that the use of phenomenological and sociological methods of research enhance bodies of knowledge relating to pain and assist in reclaiming pain from the dominant scientific paradigm. This emphasises the importance of the pain experience as an individual one. Pain experience cannot be transferred from one person to another. Description does help in providing information about pain but it does not in any way provide an equal or even similar experience. Pain is a phenomenon of which all humans have experience albeit more commonly in its acute state. It acts as a warning of potential or actual tissue damage (IASP, 1994) and for most is a short-lived although memorable experience. Chronic pain is not experienced by all and although some may have a chronic painful condition such as migraine, the pain is still of an acute nature with chronic recurrence.

Research of this nature could be divided into two camps: experience that has happened and reached a conclusion or experience that is still happening. An exploration of chronic pain falls into the latter camp. The chronic pain experience is ongoing and is unlikely to have a conclusion; therefore, this present study does not simply explore lived experience but focuses on living experience. Meaning is generated whilst the experience is being lived through.

Phenomenology allows the researcher to attempt to explore the lived experience of a person with chronic pain whilst exploring any deeper meanings behind the experience. It is through an analysis of the data that deeper meanings are sought. Patients may or may not hold beliefs regarding the meaning of their chronic pain; some may view it in a purely superficial manner whereas others may hold deep beliefs surrounding this living experience. These deeply held beliefs may then contribute to the living and lived experience.

3.15 Rationale for choice of method

Phenomenology is a philosophical science, which strives to give meaning and seeks a deeper understanding of human experience. It is the primary aim of this research to explore the living and lived experience of chronic pain in an effort to further understand and give meaning to the phenomenon (Byrne, 2001b). Both descriptive phenomenology and interpretive phenomenology would be appropriate for this topic,

but the chronic pain experience has so many facets such as past pain experience, personal coping mechanisms, mood and personal outlook on life (Main and Spanswick, 2000: 40) that it was felt a deeper understanding would be better gained through a phenomenological interpretive approach which provides a research method that allows for the recollection, reflection and analysis of lived experience (Van Manen, 1990: 11).

3.16 Methods of data collection

Two methods of obtaining data were identified as being the most appropriate for this research: interviews and diaries. Interviews, as a qualitative research method, can provide privileged access to a person's experience of the lived world (Kvale, 1996: 54) whereas writing forces the person into a more reflective attitude (Van Manen, 1990: 67) and diaries may allow the researcher access to more intimate situations (Gibson, 1995).

3.16.1 Interview

Interviews are defined as a method of social data collection on an individual level (Jary and Jary, 2000: 314) and can be described as a conversation with a purpose (Rose, 1994a). Rose (1994a) states that an interview is a social interaction between two people, with the emphasis on the phenomenological interview as being the sharing and understanding of lived meanings (Sorrell and Redmond, 1995). Johnson (2000) sees the interview as being more than a means to collect data she also views it as a conversation that connects the interviewer and interviewee.

Interviewing as a method within phenomenological research is used to elicit a life story or narrative from the subject, in this case, the chronic pain patient. The aim of phenomenological interviewing is to discover knowledge related to specific phenomena (Sorrell and Redmond, 1995) and hermeneutic phenomenology is concerned with interpreting concealed meanings in phenomena. The purpose of the interview, therefore, is to derive shared meanings by drawing from the patient a vivid picture of the lived experience, complete with the richness of detail and context that shape that experience. The purpose of interviewing is to gather data through a blend of listening and narration. Van Manen (1990: 66) states that the interview serves two specific purposes: firstly as a means of gathering data to provide an understanding of

that experience and, secondly, to develop a conversational relation with a partner about the meaning of the experience. The essence of the phenomenological interview is the description of the lived experience not how the interviewee or interviewer interprets it (Sorrell and Redmond, 1995) therefore it is essential that within the interview there is room for the mutual sharing of information.

There are different types of interview ranging from unstructured to structured. Within this study the emphasis is on low (semi) structure. It is usual to use a low structured format, which is highly focused and allows the patients to tell their own experience in their own words with little or no prompting from the interviewer. The interviews within this study although they remain focused on the pain allowed the patient to lead the interview this then provided the 'full context' of the lived experience of chronic pain to be shared. The format of interviews can range from structured to unstructured with formats that also fit in between the two. On Gillham's (2000: 6) table of verbal data dimensions (see table 4) these interviews can be seen to be formatted towards the lower end of the unstructured scale. As the interviewer I planned to start the interview "proper" with a lead-in question. I held in mind the three research aims and I had some professional understanding of the phenomenon under study, chronic pain; coupled with a professional acquaintance with each of the patients recruited into the study. Rose (1994a) describes a semi-structured interview as one that allows the interviewer to focus on issues of relevance to the research question through clarification of comments made during the conversation. It is frequently argued that an unstructured interview is almost impossible to achieve as the interviewer always has some purpose in mind (Rose, 1994a).

Table 4 Verbal data dimensions (Gillham, 2000: 6)

Type of interview	Levels of structure
Unstructured	<ul style="list-style-type: none"> • Listening to other people’s conversation; a kind of verbal observation. • Using “natural” conversation to ask research questions. • “Open-ended” interviews; just a few key open questions, e.g. “elite interviewing”.
Semi-structured	<ul style="list-style-type: none"> • Semi-structured interviews i.e. open and closed questions.
Structured	<ul style="list-style-type: none"> • Recording schedules: in effect verbally administered questionnaires. • Semi-structured questionnaire multiple choice and open questions. • Structured questionnaire simple, specific, closed questions

The interviews were conducted between October 2003 and September 2004. The selected patients were approached during a routine clinic appointment and asked if they were prepared to participate. Written information was provided and written consent obtained if they agreed to take part. Eight initial interviews between 50 and 90 minutes were audio taped and transcribed verbatim by the researcher. All interviews were conducted by me to reduce the likelihood of introducing another potentially confounding variable – that of a transcriber, mediating between interviewer, respondent and interviewer as data analyst. The second interview, also audiotaped, lasted between 15 and 30 minutes and was used as a closure interview. The subjectivity of the interviewer/researcher is an important consideration of Heideggerian phenomenology. I had experience of chronic pain from a pain

management health professional viewpoint. In this role I had witnessed the impact of chronic pain on patients' lives, working ability and relationships. I certainly had my own preconceptions and these I tried to make as transparent as possible by allocating, following discussion with colleagues in pain management, patients involved in the study to one of two groups: pain manager or still seeking pain cure. It has been argued that making transparent one's preconceptions contributes to the trustworthiness of the research (Lowe and Prowse, 2001). These preconceptions although made transparent through this categorical allocation of patients, had to be revised following analysis of interview and diaries. This interesting point is discussed further in Chapter twelve. All patients were selected as a sample of convenience from those patients that had been attending a nurse led pain clinic for a period of not less than three years as it was assumed that there was an already established trust base. Both interviewer and patient were known to each other in the nurse/patient relationship. I was aware that this change of role from nurse into interviewer/researcher could be a potential disaster although the local NHS Research Ethics Committee did not raise this as an issue of concern. I was concerned however that the patient might have seen our encounter as an extended clinic appointment or even have sought advice or treatment options during the research engagement. Lowe and Prowse (2001) consider the two roles of nurse and researcher and argue that, although it may be seen as being conflicting and raise concerns about researcher bias and even be considered by some to be untenable, it can actually strengthen validity as the nurse as interviewer/ researcher has to rigorously and openly address these issues within the research encounter. This could have the effect of increasing trustworthiness (Lowe and Prowse, 2001).

I considered employing a research assistant to conduct interviews in order to establish a degree of independence and objectivity. On reflection the benefits gained from my perceived trustworthiness and the concept validity and mundane realism gained from conducting the interviews myself seemed to outweigh notions of objectivity. All human beings hold notions of pain constructs and no interviewer could be considered a "stranger" to the concept and, therefore, in some respect no more independent than me. Consequently I opted to become the nurse/interviewer. I decided that the trust base already established between patient and nurse was too great a benefit to the research to lose by employing a stranger to conduct the interviews. I was convinced that given the opportunity to talk about their chronic pain lived experience my

patients would feel comfortable enough to provide me with very personal and insightful detail. In some of the interviews this was proved to be the correct choice and I was privileged to be told very personal details of a patient's life:

F56: It's something to look forward to because I've got nothing in my life (Tearful) Sounds pathetic doesn't it? I have got things in my life and I know what's important but I don't go out, er I don't sleep with my husband, so we don't have the close sexual thing...

This outpouring of loss due to living with chronic pain is just one example of the rich, thick description that was recorded during the interviews that I feel sure would not have been provided within an initial interview with an independent stranger.

Evidently all interviews and the narrative account which forms the 'product' of the interviews are "co-constructed" – an accomplishment of both interviewer and interviewee (Iphofen, 1990). In some instances the interviewee can become co-investigator within the study and, providing the trust base is sound enough, can even be consulted/collaborated with upon the analysis of the transcription of the interview (Walters, 1995). Within this research this form of clarification of analysis was not used. Sorrell and Redmond (1995) describe a "unique intimacy" that can exist between interviewer and interviewee that often allows the respondent to reveal more in conversation than they would have within, say, a questionnaire. This intimacy must therefore be allowed for and the environment within which the interview is taking place needs to be one that affords privacy and the displaying of emotion if necessary.

3.16.1.1 Setting

These initial interviews were held in either the patient's home (n=1), whilst an inpatient on the ward (n=1) or in a private room within a clinic setting (n=6). The follow up or closure interviews were held in either the patient's home (n=1), whilst an inpatient on the ward (n=1) or in the same room as the initial interview within the clinic setting (n=4). Only six follow-up interviews were obtained due to my own personal ill health, however, both of the patients who did not have a second interview were offered a follow-up appointment in the nurse-led pain clinic to see another clinical nurse specialist to ensure any issues raised by the initial interview and in

maintaining a four week diary were resolved. This was designed to ensure closure for the research process for that patient.

The setting for the interview was an important consideration within the research design. Privacy, comfort and relative quiet were needed for the interviews to be conducted with a minimum of distractions. McCann and Clark (2005) state the ideal conditions for an interview to take place are in a private and relaxed atmosphere that avoids unnecessary distraction however they also say that if ideal conditions cannot be met that it should not necessarily prevent the interview going ahead. Interviewing the patients at home was an option given to the patients to promote their feeling of security and limit their inconvenience in having to travel to the hospital. The two homes I visited for the purpose of the interview suited the conditions of a private and relaxed atmosphere far more than that of the interview room used within the hospital. The settings for the two interviews which were conducted whilst the patient was an inpatient were not ideal. A treatment room, within the ward, had to be used for the interview, the chairs were not as comfortable and the tape recorder was balanced on another chair and yet the quality of the data revealed within the interviews did not appear to be affected by the setting. It must be stressed that both of the interviews carried out within the ward setting were done purely at the request of the patient. I was quite willing to conduct the interviews after discharge when they felt well enough, but both felt it was an ideal time for them and, one patient in particular, who had small children, felt it was less of an inconvenience to have the interview whilst currently being an inpatient. Within the district general hospital there is an orthopaedic multidisciplinary suite of clinic rooms, which are based in what was once a six-roomed ward reserved for private patients. This ward had become redundant following the building of a nearby private hospital. This ward had then been utilised by the orthopaedic multidisciplinary team to see outpatients. Each single room became a clinic room with a desk, chairs and an examination couch. It was one of these rooms which were then used for the interviews. The room was carpeted and had curtains as well as vertical blinds at the one window. Painted in a soft pastel green, the room overall had a soothing, calm atmosphere. The desk was positioned at an angle against the wall and the two chairs were positioned at an angle facing each other, by the corner of the desk. This allowed space for tissues, a jug of water and glasses and

the tape recorder to be placed on the desk. The tape recorder was plugged into the mains electricity - ensuring battery failure was not a concern.

The setting for the interview conducted whilst the patient was an in-patient was not quite as comfortable. The ward sister provided a room which served as a storage area and a second treatment room when the need arose. This room was furnished only with an examination couch and I had to borrow two chairs from the ward office. The tape-recorder was positioned on a third hard chair which was placed between us but slightly to the back of us. The usual box of tissues, water and glasses were placed on the work surface within the room. Although we were not disturbed during the duration of the interview the noise from the ward could be heard quite clearly. This interview was not as productive as the others and the setting may have played a role in this.

The last patient to be interviewed requested that the interview took place at his home. This was possibly the nicest interview setting. We sat in the kitchen at a small table. The tape recorder was plugged into the mains electricity and was placed on the table. The patient was obviously more at ease being in his home in comparison to some of the previous interviews I had done. His wife made me very welcome and made us a cup of coffee before we started and then she very kindly left to go shopping because as she candidly told me it would have been difficult for her not to join in with the conversation otherwise. It would be very interesting in the future to interview partners to compare both experiences of living with chronic pain.

The follow-up or closure interview, which was conducted in a patient's home at his request, also proved to be a more convivial atmosphere. This took place in the living room of his parents' home. Again, I was made to feel very welcome. This time we were seated on the sofa with the tape recorder on a coffee table in front of us. Refreshments were provided by his mother who then left us while she prepared dinner in the kitchen. Of course, an invitation to the patient's home is at the discretion of the patient and the researcher has to be aware of personal safety but on reflection both the interviews that were conducted in the patients' own homes proved to be of great value in providing rich information. I would consider that this was due to lack of apprehension on the part of the patient being at ease in their 'own' environment.

3.16.1.2 Interview commencement

Each patient was met in the main outpatients department by myself and taken to the interview room. This allowed time for general pleasantries, to answer any questions, and gave me another opportunity to express my thanks for their participation in the research as well as to again confirm consent to participation verbally. Although this was not required by the Research Ethics committee I felt it important to re-state that whether or not they continued to participate this would not have any effect on their future care within the hospital.

On arrival at the interview room a hot drink was offered and then we made ourselves comfortable. The tape recorder was switched on almost immediately and although this caused some consternation initially it appeared soon to be forgotten. To overcome this before the lead-in question was introduced, general conversation started the interview, with topics ranging from proficiency at using the tape recorder to people we might know:

I think her surname 's.,... very unusual name... [F37].

This had the effect of relaxing both the patient and me and usually after the first five minutes the tape recorder was ignored and the interview proper commenced. This fact was often borne out as the tape needed changing after 45 minutes and quite often as the machine stopped the patients would comment that they had forgotten its presence. Once the patient appeared to have relaxed and settled into general conversation a lead-in question was introduced. This varied from:

I just really want to know what its like living with chronic pain

to

Tell me about your pain. When did it start?

This first question is of the utmost importance as it doesn't just start the interview proper but it leads the patient to describe in their own words the phenomenon under study. The interview, although not highly structured, must enable the researcher to focus the interview on the relevant topic. A lead-in question (rather than a leading question) commenced the interview using appropriate prompts as necessary. An open

ended question is advocated to be the most effective way of commencing a phenomenological interview as it gives the patient permission to relate their story freely (Sorrell and Redmond, 1995). From this one question the interview proceeds with the researcher taking their lead from what the patient is saying (Burnard, 2005) and often little prompting is required (Sorrel and Redmond, 1995) unless the interviewer particularly wants to explore something the patient has said. This can be done simply by asking questions like “How did that make you feel?” or “Can you tell me a little more about that?” as a result of taking the lead from the patient the format of interviews can be extremely different one from the other (Burnard, 2005). For the purpose of these interviews I did not use an *aide-memoire* as recommended by McCann and Clark (2005) to help me recall anything within the interview as my prime aim was solely to listen to the respondents’ chronic pain experience.

The aim of exploring the effect of belief on the chronic pain patient, in other words, the effect upon the patient of having a health professional accept the patient’s chronic pain experience as being credible was actually introduced by seven out of the eight patients being interviewed without any prompting, supporting the importance of this aim as an issue within pain management. The one patient who did not spontaneously mention it was asked a direct question at an appropriate time. The patient was describing his relationships with his General Practitioner, district nurse and practice nurse and I asked, “*Do you think that they always accept what you are saying...?*” The answer was immediate and in the affirmative. I took this to mean he did not have an issue with being believed by the health professional and so did not proceed with that line of questioning. I did not want to lead the conversation and possibly bias the outcome by potentially prompting the patient to say what he thought perhaps I wanted to hear.

3.16.1.3 Emotion

Through the use of the low structured interview that focused on the lived and living experience of chronic pain, the patient was given an opportunity to externalise the pain. This potentially can have a therapeutic effect (Walker, 1991) and benefit can also be derived through a sense of being listened to (Plant, 1996), however, it is possible that by having the patient focus on their chronic pain during the interview there is a potential to cause an increased awareness of the pain (Banks and Mackrodt,

2005:76). Sorrel and Redmond (1995) consider a phenomenological interview to be potentially healing or cathartic through the medium of story telling whilst McCann and Clark (2005) reiterate the duty of care the interviewer has to the patient and emphasize the need for all interviews to be carried out in a sensitive and caring manner.

Nearly all of the patients interviewed displayed some form of distress during the interview: all showed emotion of some sort whether anger, regret or sadness. For the first interview I had not provided a box of tissues and it was fortunate the patient being interviewed at the time had a pocketful. This was an oversight corrected for all following interviews. Rose (1994a) considers distress caused through patients recalling painful life events for purpose of a research interview to be an ethical dilemma, which may prompt the termination of an interview. I would argue that allowing the patient to talk through their distress could be of greater therapeutic benefit than abruptly ending the interview and leaving the patient not just distressed but potentially bewildered. It must be emphasised however that if a patient experienced distress and requested termination of the interview then it would be ethically and morally incorrect to continue. This did not occur with any of my participants.

3.16.1.4 Silence

Within the interviews there were often pauses - some quite lengthy - with the patients obviously reflecting on a thought. These silences are hard to transcribe but are vitally important within the interview process (Gillham, 2000: 36). Silence, it must be remembered, is also an important source of data. The thought must occur about what has caused the silence: the “stillness of reflection” (Van Manen, 1990: 99); or “a fulfilled silence” (Bollnow, 1982:46); or an “uncomfortable” silence. The latter may warrant a prompt to maintain the conversation whereas the first two do not need disturbing with unnecessary prompts. A silence that is not awkward allows the patient to recollect thoughts and feelings about the experience being described. Often they are very emotionally charged and it would be damaging to disturb the train of thought, particularly if a patient is dealing with something emotionally or psychologically painful (Denscombe, 2003: 177). The interviewee has to be comfortable with silence in order to listen to the powerful silence that may “... speak more than words”

(Sorrell and Redmond, 1995). This should provide a dialogue between interviewer and interviewee, controlled by the latter that promotes a non-directive approach enabling the patient to tell their story in their own preferred way (Koch, 1996).

Respecting silences is an interviewing skill. The interviewer has to be comfortable with silence and occasionally patience and silence from the interviewer may be a more tactful way of prompting the patient to reflect and then to continue with their narrative (Van Manen, 1990: 68).

F56: I got struck off by one set of doctors (silence of 20 seconds, then sighs) because they didn't believe me.

3.16.1.5 Holistic understanding

Pain has previously been described as being a subjective experience (Hough 1986) and, as such, is experienced in a very individual and personal way. Using a method that utilises the study of persons can only promote a better understanding of the phenomenon that is chronic pain. Carson and Fairbairn (2002) argue that the use of narrative text and story telling should be paramount in any research that has human lives and human well being as its focus. The use of low structured interviews provides a forum for the patient to tell their own individual story of living with chronic pain.

Holistic understanding underpins the whole ethos of interpretative phenomenology. The term “holistic” being defined here as an approach in which the physiological, psychological and social factors are all taken into account (Fergusson *et al*, 1998: 212). Rather than simply exploring chronic pain as an independent issue the impact of living with chronic pain and its effects upon living are explored as fully as possible.

Understanding is a concept in its own right. Mautner (2000: 578) defines understanding in a philosophical context as being a method of gaining knowledge, appropriate in the human sciences, and contrasted with the method characteristic of the natural sciences of experimentally testing hypotheses. Understanding is also described as a mental activity, involving interpretation, which then links closely with hermeneutics. Hermeneutics is regarded as a theory of interpretation of texts, human action and varying features of culture and society (Mautner, 2000: 248). Jary and Jary

(2000: 375) consider meaningful understanding and explanation within a sociological context to be the comprehension of persons' "beliefs, motives, purposes and reasons which automatically constitute an explanation of their action of the social occurrences to which these give rise". Consider these definitions within the context of chronic pain as a human phenomenon and holistic understanding can then only serve to provide a deeper meaning to these individual accounts of living with chronic pain.

Professor Sir Michael Bond in a foreword to a pain management text book (Main and Spanswick, 2000: xi) confirms that psychological and social factors are extremely important concepts necessary to the understanding of pain and associated behaviour. This further supports the case that holistic understanding within the context of exploring chronic pain is a vital ingredient.

3.16.1.6 Audio taping

Audio taping of interviews has its advantages as well as disadvantages. It allows the researcher to capture the tone of voice, the pauses, the silences and to some degree the emotion of the interview but misses the touch, the gestures, and the facial expressions. Analysis of the spoken word will focus on two levels, the semantic level and the mantic level. The former concentrates on how the story is told, the first sentence being vital in order to maintain linguistic meaning. On the mantic level, the personal expression is explored, the tone of the narrative and the emotion of the story. Combining these two levels of analysis will provide a deeper understanding of the experience as related.

Audio taping can cause problems as a result of associated technical difficulties and can cause physical and emotional discomfort. In all cases the tape recorder was turned on as soon as the patient entered the room and quite often the first part of the interview centred on the use of this piece of technology, feeling uncomfortable with it (the tape recorder) and general chit chat on how people felt that day, how the family were, and possible venues for holidays to help to establish some ease in the relationship. Once it was felt that the patient was more relaxed they would then be guided into the actual interview with the aforementioned lead question. In most cases this approach worked very well and as mentioned earlier only when the tape ended and needed to be turned over would the patient remember the tape was recording.

This did not always work, however, and in one case the patient insisted on addressing the tape recorder throughout the interview even though it meant turning his chair to allow himself to look at the machine. This particular interview proceeded like a radio or television documentary, and this is quite obvious from the “woodenness” and the systematically recounted clinical details of his transcription:

M37: These fistulas are like what I can describe as a cone and they don't really want it to heal over the top of the cone and leave like a cavity behind, they just want it to heal from the inside. So what they use is, it's actually a seaweed... and this is packed into the wound and it gradually heals from the inside just as the doctors want it to.

3.16.2 Diary-keeping

The aim of diary keeping is to capture the patient's thoughts, feelings and emotions as they live their life of chronic pain and has been proved to be of use in gaining insight into everyday illnesses (Miller *et al.*, 1999). Historians are finding that the recording of events and the subsequent personal experience of those events as they actually occur are valuable and can become important primary sources (Keeling, 1997). Diary keeping, in contrast to interview, may provide a more detailed and different sort of reflective account as the person focuses on the chronic pain experience. Focusing on pain, however, can be a negative experience and from a pain viewpoint may serve to concentrate the person on that experience and effectively increase the pain (Broome and Jellicoe, 1987: 67). Conversely in a study by Schumacher *et al.* (2002) the use of pain diaries with patients suffering from cancer was used to heighten the awareness of pain to encourage more detailed definition of the pain experience.

Diary keeping is a very private affair and it is a great privilege to gain access to a diary with the consent of the person writing it. With this in mind the patient was given the right to change their mind about parting with their diary. The content of the diary was left entirely up to the individual and each was instructed to write only what they felt comfortable with as an individual but to consider the impact living with chronic pain had on their daily lives. Patients were also reassured that the diaries would be kept in a locked cupboard when not being used for this study's purpose and, although

they might individually recognize themselves from the printed word, all means of identity would be removed from the quotes used.

The literary demand and compliance of keeping the diary may jeopardise the study and it may be necessary to place an ability and compliance to diary-keep within the inclusion criteria. Regular diary-keeping may however help a person to reflect on significant aspects of his or her past and present life (Van Manen, 1990: 73) that may well contain accounts of human experience that are of phenomenological value.

I have been an avid writer of my own personal diary since I was a teenager. I wrote descriptively most evenings until my early twenties. My diary writing improved dramatically in 2004 when I was diagnosed with cancer. I found my diary became a great outlet for hopes and fears, something I could rail at when angry and also a way of expressing my deepest fears, which I did not wish to share with family for fear of upsetting them further. Until that point in my life, I had forgotten what an ally a diary could be, so it was purely by default that when considering my research question I had opted for a dual-tool approach to data gathering. My original rationale was that the interview may give what the patient thought I wanted to hear whereas I hoped the diary would allow the patient more freedom to describe the experience of living with chronic pain. The diaries more than fulfilled this initially rather naive expectation and when I compare some of those entries with those I wrote at the time of my illness and treatment I can recognise the same passion and emotion contained within their words.

The patient was presented with a blank diary during the first interview. They were asked to write in the diary as frequently as they wanted but not to focus entirely on the diary. In essence I did not want a pain diary that detailed type of pain, onset and duration. I wanted to explore their lives as they lived the chronic pain experience, so I reiterated that I was interested in their ordinary lives, good days and bad. The diaries it was considered expressed living experience, the only other method which could gather living experience more accurately would be that of a video diary or an observational study, although an observational study would not provide in-depth personal and reflection data. The interviews were of a more reflective nature as the patient related what it was like to live with chronic pain by thinking on past experience.

Each diary was a small hard backed lined book, which was small enough to fit into a lady's handbag or a man's jacket pocket. There was no structure to it at all, the book was new, contained no instructions and had no key points for the patient to consider whilst they wrote. The only instruction they had was verbal and it was simply to record their everyday life, living with chronic pain, with as much detail and thought as they wished to share, however personal or trivial. The diaries were maintained for approximately four weeks and were collected from the patient at the time of the second interview. In the case of the two patients who did not have a second interview, I wrote to each, explained the circumstance under which I was cancelling the interview and enclosed a stamped addressed envelope for the safe return of the diary. Both patients complied with this request; therefore compliance with diary-keeping was 100%.

The eight diaries all varied in length. All patients wrote a daily diary entry and the quality of data differed from patient to patient, as well as entry-to-entry. All were transcribed exactly as they had been written, including spellings, grammar, use of punctuation and capital letters. Interestingly, the diary that gave rise to the least data was from a patient that had provided a very detailed interview whereas another patient, who had been obviously uncomfortable with the presence of the tape recorder, wrote a diary that was full of passion, pathos, description and reflective thought as it detailed his daily life. My rationale for using both interview and diary as the tools for data gathering had not anticipated that by using both I had effectively managed to gain thick description and great wealth of detail from each of the eight patients within the sample. Had I only used one as the data collection tool the detail and depth of data would have been compromised.

Diaries can take many forms, they may be used simply as a log to record appointments meetings and events or they may be used as an intimate journal that details thoughts and emotions (Gibson, 1995). Some diaries can almost take on the role of friend and confidante such as the diary that Anne Frank kept during her time hiding from the Nazis in occupied Holland. On the 12th June 1942 she commenced her diary with:

I hope I will be able to confide everything to you, as I have never been able to confide in anyone, and I hope you will be a great source of comfort and support (Frank, 1991: 3).

This type of detailed and intimate diary produces a vast amount of thick description, although not necessarily relating to the phenomena under study. It was my private hope that at least some of the diaries that I sought from my respondents would be of this nature. Gibson (1995) states that diaries that are written at the request of a researcher are ‘solicited’ documents and as such may vary in depth and detail making comparison and analysis difficult. This was borne out on collection of the diaries. One diary [M48] had been used very much as a log although it maintained a chronic pain focus:

A good night. Wake up 7.00

Shoulder hurt a bit.

Going swimming when Dave rings. Do me good. TENS on for about half hour.

Got up 8.30 Went to the shop

Went swimming for 1 1/2 hours. Feel good.

TENS on for 1 hour. Hope to sleep.

In comparison, another patient [M37] had written a detailed account of his day, divided into time slots:

04.45 – I have been woken from my sleep by pain. I have acute pain in the stomach with what seems like pain in the lower back as well. I also feel very sick, despite having an injection for sickness.

08.45 – I am lying on my bed after an injection for pain. I am shaking a little because of the pain – so my handwriting is not very good.

I am washing the tail-end with warm wet hand towels in the bathroom after going to the loo – I am in too much pain to tackle a bath – and it’s a good way to ease the soreness. Every time I go to the toilet I feel that I am going to faint. The sensation I am getting is one of obstruction in my lower stomach/rectum. I am pretty sure that this pain is not an obstruction but probably inflammation.

I am positive that this is no coincidence that every time that I am feeling “under the weather” at home, I get a slight pain at the base of the fingernails and toe nails. My joints are quite sore also and I feel very shaky.

I feel very thirsty at the moment. I appreciate that drugs can give you a dry mouth but I also feel that the Crohn’s disease makes you feel dry because you are constantly losing nutrients going to the loo so often. I also did not mention that in times when I am in a lot of pain, I find it difficult to pass water. I can only guess that it is the pain/inflammation which disrupts my bladder. I do eventually pass water but it is usually when I am at bursting point.

5.45pm – I had a new pain killer (oxynorm – that’s how it’s pronounced). Unfortunately I am having some very nasty spasms and pain. My feet are beginning to sweat due to the pain.

8.00pm – I have just been given an extra pain-killer – they don’t seem to be working.

11.00pm – I can’t seem to do anything right sometimes.

3.16.2.1 Literacy

Maintaining a diary does require a degree of literacy as well as commitment. Differing degrees of literacy can be seen within the diaries. Spelling and mastery of the English language caused some patients concern when first given the diary and this was captured on the audiotape:

The only trouble with me is I can’t read or spell very well [M48].

The differing levels of literacy also affected the wealth of data contained within the diaries. Some diaries merely detailed the day, with little information. The following is an extract from the patient who had expressed concern about his reading and writing skills:

Good night sleep. Wake 7am. Had a drink. TENS on for an hour. Not too bad. Shoulder good. Had shower. Been to the shop. TENS on for half an hour. Not a bad day.

Whereas other diaries provided a wealth of information and gave insight into living with chronic pain:

My friend Margaret came for coffee. She went to Alton Towers last Monday last night she went to the theatre, she's off out to lunch today, out tonight and off to a late afternoon wedding tomorrow... the last time I went out was in March, when my daughter, son-in-law and my son took me to play bingo for mother's day. I remember the car journey. I was in tremendous pain and going over bumps was painful... I couldn't wait to get home I was so uncomfortable. Hearing of my friend's social life makes me realise what a normal life must be like. I'm a little jealous [F56]

Not one patient expressed concern about the content of the diary, each patient took me at my word and wrote as little or as much they wanted to, depending upon the day they had been having.

3.17 Personal reflection/research diary

The use of field journals to record the researcher's thoughts, views and observations of the research in progress is a common and recommended practice within phenomenological research (Ely *et al.*, 1991: 69) and also helps to establish rigour (Koch, 1994). I commenced my own field journal as soon as I registered for my PhD so my initial entries were collated under the heading of "PhD Ramblings" Koch (1994) suggests that the aim of a field journal is to provide material for reflection whilst increasing self-awareness. Initially this journal was used to jot down ideas, rationalise what I was thinking and formulate research questions whilst establishing my aims. As my knowledge and understanding of the philosophical methodology I had identified as being fit for purpose grew I realised that a field journal would not just increase self-awareness and establish rigour but would be a source of data that captured information gathered from the interviews. To achieve this I needed a framework that would serve as an *aide memoire* for reflection on the

interview both as a participant and as a researcher. For this purpose Maslow's hierarchy of needs was used. Abraham Maslow, in 1954, first proposed his hierarchy of human needs. Maslow's theory is frequently cited in the nursing literature and is commonly used as an underlying framework for clinical practice (Leidy, 1994) but in today's nursing culture of reflective practice Maslow's Hierarchy of Needs can be utilized as a framework for reflection (Clarke, 2004). Gross (1992:902) states that according to Maslow we are subject to two completely different sets of motivational state of forces:

- 1) Those that ensure survival by satisfying basic physical and psychological needs (first 3 steps).
- 2) Those that promote the person's self-actualization, i.e. realising one's full potential (steps 4-7).

It is the second of these forces that can be used as a reflective framework. To enable oneself to self-actualise, the individual has to be aware of their own potential and when that potential has been reached. This framework is therefore based on self-awareness, integrity and self-appraisal.

Maslow's theory is hierarchical (see diagram 1); overall meaning that each step has to be achieved before the next step can be accessed. However, as a reflective tool steps can be missed out completely or accessed in any order (see table 5). By choosing this particular model to act as a reflective framework it prompted me to look at the basic physical and psychological needs (the first three steps) before allowing for a more in depth reflection of the experience. It proved interesting to see the insight that I as the researcher gained from each interview prior to the laborious task of transcription, and provide a paper trail of thinking that helped to develop intuition, ideas and phenomenological insight as the work progressed. It was anticipated that I could use this reflective account as a measuring stick of my own personal development as a phenomenological researcher whilst allowing me to share the experience of complying with diary keeping with the person with chronic pain.

Keeping a field journal or diary of the interview process provides data and memory prompts of the actual interview. Video-recording would have provided the visual aspect but was ruled out as being too intrusive. It was therefore important that I recorded in my journal whether non-verbal indicators played a part in the interview as

a whole and what form they took. Atmosphere is very difficult to capture, being perhaps as subjective as the phenomenon of pain itself. The atmosphere of the interview needs to be recorded by the researcher and if possible matched by the interviewee's perceptions. Not all atmospheres will be as apparent as that of an uncomfortable one; an interview that goes well will be noted for its depth of information, lack of awkwardness and smooth running.

3.18 Conclusion

Combining the use of interviews and diaries within phenomenological research is not new (Dyck and Forwell, 1997; Lauterbach, 1992) however there is very little literature that examines the possibility of increasing reliability and validity through using this combination (Clarke and Iphofen, 2006a). Both methods rely heavily on trust being established: between interviewer and patient; researcher and diary keeper; to encourage and develop a spoken or written dialogue that can provide insightful data into a very common and misunderstood condition. The use of language, in both the written and verbal context provides a means of communication that is the foundation of living, learning and developing the unique characteristics of personality (DePompei and Hotz, 2001) and also provides illuminative data for analysis. Literacy, although usually applied to the written word can also reflect upon oral communication but in cases where the diary revealed little data, the parallel interviews produced a wealth of information. Conversely in one instance the opposite was true and where the patient felt uncomfortable with the tape recorder, the diary gave a truly reflective, honest and often emotional insight into living with chronic pain. Combining the two methods has proved to be advantageous in the gathering of data for phenomenological nursing research, by providing contrasting and complementary data for hermeneutic analysis.

Diagram 1 Maslow's Hierarchy of Needs

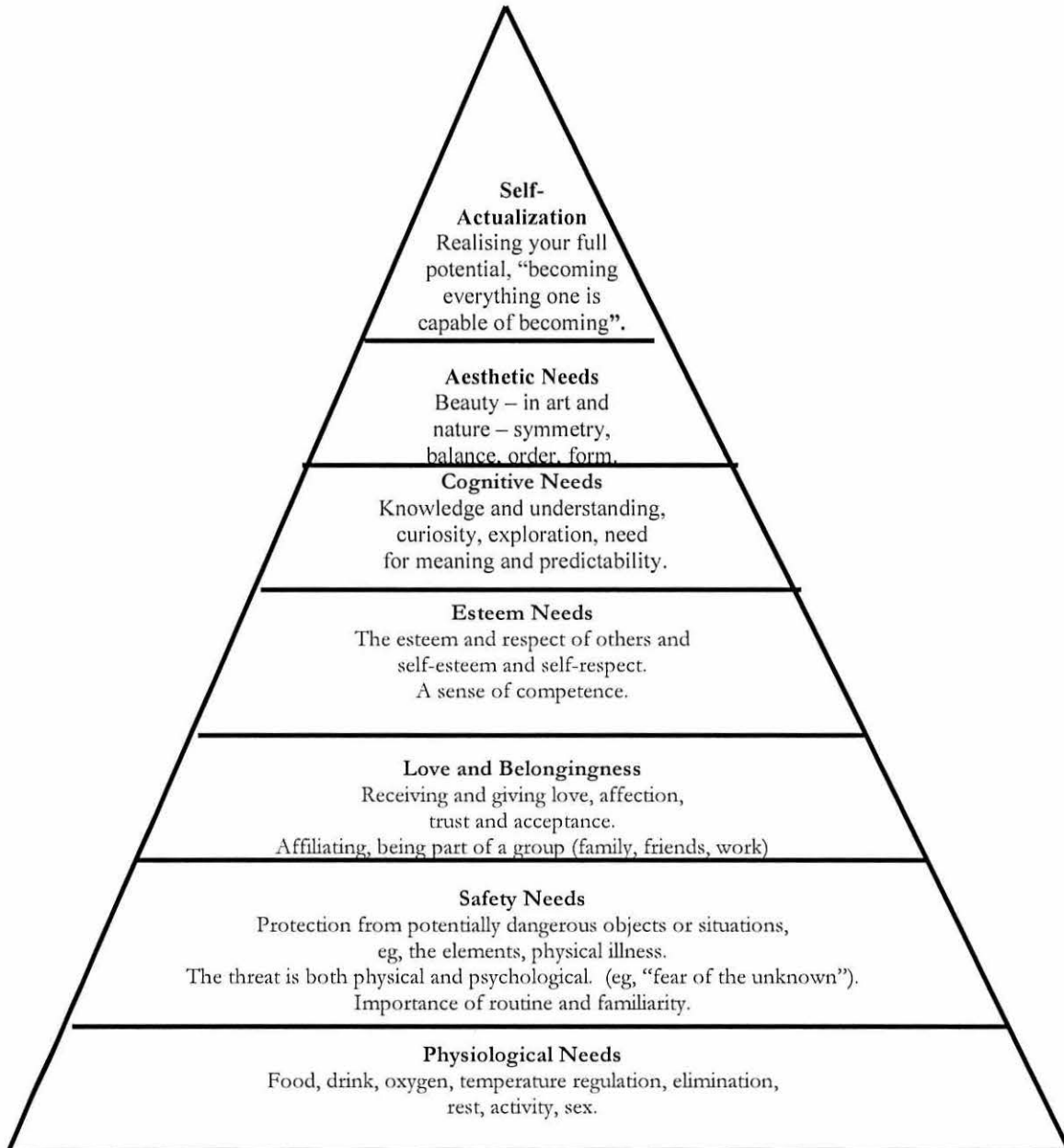


Table 5 Maslow's Hierarchy of Needs as a Reflective Framework for the Nurse-as-Researcher

STEP	MASLOW'S H of N	REFLECTION
1	Physiological needs	Interview room environment Drink available Tissues
2	Safety needs	Health and Safety Room temperature
3	Love and Belongingness	Trust base Atmosphere
4	Esteem needs	Competent nurse. Skilled nurse. Competent interviewer Skilled interviewer
5	Cognitive needs	Knowledge and understanding of pain, of patient, of research. Questioning, listening. Dynamic.
6	Aesthetic needs	Order. Smooth running.
7	Self-actualization	Did I achieve my full potential?

Chapter Four

Analysis of results

4.1 Introduction

This chapter describes the methodology utilised in the hermeneutic analysis of the data obtained from the interviews and diaries.

4.2 Methodology

Hermeneutic analysis is not a linear process (Cohen *et al.* 2000:72) but in an attempt to demonstrate the process undertaken to analyse the data obtained, the course taken is explained in a step-by-step format although it can at best be described as an ongoing process with understanding and enlightenment developing and deepening as the interpretation proceeds and is the basis of the hermeneutic circle (Heidegger, 1962:38).

The steps used to analyse the data are those given by Cohen *et al.* (2000: chapter 7) and were used as a framework in order to gain hermeneutic understanding:

1. Orientation to interpretation
2. Data management
3. Data analysis
4. Teamwork

4.2.1 Orientation to interpretation

Interpretation begins the second the researcher commences collecting the data. As interviewer and transcriber of both audio tapes and diaries, I became very familiar with the data through repeated listening and reading and re-reading. Through the process of reading the text generated from all interviews and diaries the analysing and interpreting of meaning is commenced from a very early stage of the research process. The data, therefore, exists on two levels, that of material gathered as part of a study – the field text, and secondly, as narrative text, which is used to convey my personal understanding and interpretation of the data to others.

Hermeneutics considers each small unit, exploring its meaning, whilst placing each meaning into its own context to enable an understanding of the whole. Metaphorically, this is similar to that of throwing a pebble into water: the initial smaller unit (the pebble) and the ever increasing wider ripples which emerge from it (for example in practice: an exploration into the use of adjectives to describe pain develops into an exploration of rhetorical devices and helps provide an understanding into the language of pain that is employed by patients in an effort to make pain more visible). As such, this ensures that the smallest of statements must be understood in terms of the largest of contexts which includes historical, cultural and social background, and language (Koch, 1995).

Hermeneutics also considers the person's lived experience within the context of "being-in-the-world" (common background understanding) and the co-constitutionality of "person-world" (the constructs of the world in which we live simultaneously constructing this world from our own experience and background) (Heidegger, 1962:121).

The listening to the audio-tapes and reading and re-reading of the transcribed data cannot be over emphasised. To be able to gain understanding of each small statement and then place it within a wider context to elucidate the understanding of the lived human experience of chronic pain prompted an intimacy with the data which being the only researcher involved in this study was essential and unavoidable, however, to ensure validity of the hermeneutic process and subsequent interpretation, colleagues from the hospital's pain service were co-opted to read and re-read both the field text and narrative text.

4.2.2 Data management

I personally transcribed verbatim all the data obtained from the patients' interviews and diaries. This was initially because there was no one else to do the transcription but once I had begun, what I initially thought of as an arduous task, I developed a familiarity with the data I might not have otherwise had. Transcribing the interviews commenced the same day that the interview had taken place, and although a slow process, it enabled recall of body language used, tone of voice, pauses and periods of silence to be recorded on the data sheet. The transcribing took place in a quiet room using the tape recorder

operated by a foot pedal which allowed for the easy stopping and rewinding of the tape whilst word-processing the transcript; head phones were used to ensure confidentiality of the content of the tapes. As they developed the transcripts resembled a script for a play with the speaker noted on the left hand side and the text alongside with any actions placed in brackets within the text where they occurred:

*F56: Erm, well I put it in there (pointing to diary) that I felt stupid (both laugh)
for a start*

Kath: Was that because you were tearful?

I was interested in developing a narrative text where the language flowed and represented the story that was told to me at the time of interview. To this end I used punctuation as it was sounded, a comma for a breath and a full stop when the patient paused to indicate the end of the sentence. Paragraphing was not used within long periods of text. A pause was noted but within brackets as previously described and I did not feel overall it was worth timing unless exceptionally long. I also attempted to transcribe sounds such as “erm” as the patients perhaps paused to gather their thoughts.

As the diaries were collected on the same day that the second interview took place the interview transcription took precedence with the diaries being transcribed within one week of being received. The accuracy of the transcription was checked through listening to the complete audio-taped interview and comparing to the printed transcript. Although all the transcripts were stored digitally, hard copies were printed with wide margins and double spaced to enable the annotation of the data. It was at this stage that the coding system was developed to identify each participant and each patient was given a front sheet where pseudonyms were allocated to names of family members, friends and other persons named within their diaries and interviews. This ensured consistency throughout.

The format used for the transcriptions followed the guidelines provided by the Economic and Social Data Service (ESDS) Qualidata. This is a specialist service which provides access and support for social science datasets and its focus is on acquiring digital data

from qualitative and mixed methods research. In this way the data becomes available for secondary use across research, learning and teaching communities. Consent was given by all participants for the transcripts of the interviews and diaries to be shared in this manner and confidentiality was assured through giving pseudonyms to all people mentioned within the transcripts. An application has been lodged with ESDS Qualidata (www.qualidata.essex.ac.uk) for the inclusion of the data from this study and therefore only examples of one initial interview transcript, one diary transcript and one debriefing interview transcript is included in the appendices (appendix 7, 8, 9).

Some textual analysis was conducted using the computer package *NVivo*, which serves as a data management programme. Using *NVivo* it is possible to create several databases to manage data gathered from transcriptions of the interviews and diaries. The study data was divided into three for the purpose of analysis: first interview; diaries and debriefing interview. Each of these then became an independent project within the software. The steps taken to manage the data within each project remained essentially the same (see box 1).

The computer software *NVivo* was used only for the initial stages of the analysis. It acted as a data management system only as it did not allow for analysis of tone, voice and verbal expression and I wanted to retain as much of the thick description and atmosphere as I could. It did, however, allow the allocation of theme labels to text which assisted in the manual analysis.

Manual analysis utilised a variety of methods as the text was searched to develop an understanding of the phenomena under study. In some instances I highlighted text, using different coloured pens, for ease of identification (see diagram 2) and on other occasions I manually cut up the text to form individual piles of text which I stored in labelled envelopes. Frequently I referred back to the audio-tapes to ensure that I was capturing the essence of the interviews.

Box 1 Summary of NVivo (Richards, 1999: 5)

- The transcriptions are imported in a rich text format into the project database where they are managed in an Explorer window which can be browsed and edited at any stage.
- Within a second database, ideas, concepts and categories for considering the data are developed. These are termed nodes, and can also be browsed through an Explorer window. Within this node browser all the data coded at a particular node can be explored and edited.
- Attributes of documents or nodes is stored and available for use in all search processes. Attributes, in general, contain information.
- Data documents and nodes are linked to other projects as the data is developed.
- Data documents or any part can be coded at nodes to show where concepts occur in the text.
- As the project develops in complexity the project is shaped and ideas are managed in trees of nodes, group documents or nodes in sets. These are then filtered, explored and developed as the analysis progresses.

4.2.3. Data analysis

4.2.3.1 Immersion

Using a hermeneutic phenomenological approach for data analysis means moving from the field text, which has been created by data collection, to a narrative text. This narrative text should be complete in its entirety and should be able to stand alone for scrutiny by other readers (Cohen *et al.*, 2000:76). This movement from one text to another commences at the beginning of the study and the reading and re-reading of the field text as well as repeatedly writing and re-writing of the narrative text is an essential process within the hermeneutic circle. The process of reading and re-reading is sometimes known as “immersing oneself in the data” (Cohen *et al.* 2000:76) which aims to develop initial interpretation which will later inform the coding of the data.

Cohen *et al.* (2000:76) state that analysis actually begins during the interviews, as the researcher actively listens to the participant and consciously thinks about the meaning of what is being said. As I was the interviewer I would agree with this – it was difficult not to get excited when I listened to some of the narrations. The patients, once they became comfortable with the tape recorder, overall were quite at ease with the process and chatted freely as they described their lived experience of chronic pain.

4.2.3.2 Reduction

Through the repeated reading of the transcripts to allow myself to become familiar with the data and a process of reflective thinking a gradual awakening of the hidden meanings of the narratives began to emerge. Streubert and Carpenter (1999) term this “interpretive reading”. The data was grouped and re-grouped under umbrella themes such as “the family unit”, “unseen pain” and “rhetoric” to enable the essence of living with chronic pain to emerge. Once an overall understanding had been developed, text was highlighted, the margins were used for annotations and data was analysed line by line and labels applied.

From these umbrella themes developed smaller units termed categories which helped to capture the essential meanings of the initial themes. The process of writing and rewriting reflexively in the phenomenological sense is “the untiring effort to author a sensitive grasp of being itself” (van Manen, 1990:132) and it was through this continuous process of re-reading and re-writing that the emerging categories were developed.

4.2.4 Teamwork

As a lone researcher I was very privileged to have very supportive colleagues within the hospital’s Pain Service who were prepared to read and re-read the field text which was generated from the data and my subsequent narrative text. The umbrella themes and the categories as they emerged were discussed as a team providing some validity and reliability to the analysis.

4.3 Conclusion

Each chapter which follows details the analysis of each umbrella theme and their associated categories. Although each issue is initially dealt with individually it can be seen that each chapter and subsequent analysis interlinks to form a complete whole. The results, therefore, are subdivided into three sections to illustrate each of the three aims of the study and all data from the three projects: first-interview, diaries and debriefing-interviews are amalgamated unless otherwise stated.

Diagram 2 Data management and analysis (manual)

September 15th '04

Got up 7.45 took my kapake (2nd).

analgesia

9.00am Sharon went to the post office so I made tea and toast for when she got back. Back still aching but easier to move, less painful to move but still have headache.

house work

10.00am Headache easier but still a bit muzzy.

analgesia

12.00am Headache back again. (took 2 kapake). Fed dogs, cleaned parrot cage. Had 10 minute break while cleaning cage, my leg was aching.

nlw

2.15pm Went to town for new kettle, back about 2.45pm still no let up, hip still aching. Watched telly until tea was ready, then took 2 kapake, waited until they had some effect on my aches and pains and then washed tea time dishes.

out
tlw
analgesia
nlw

Nothing to do now except telly and crossword until 8.30 then it's time to collect William from karate.

tlw
hobby

Watched telly till 10.00 took 2 kapake then went to bed at 10.30pm.

tlw
analgesia

September 16th '04

Got up at 7.15am, took kapake with a cup of tea, headache and hip aching as usual. 7.50am took Kate to catch her bus for college and William to school. Fed dogs and Robbie (parrot) and had toast.

analgesia
family
nlw

8.30 Headache eased now but hip still painful. Washed dishes and tidied kitchen, now I feel really tired and rough. Woke up several times last night with hip aching.

nlw

10.00am Went for lie on top of bed, difficult getting comfortable position but did manage to get a bit of sleep in between tossing and turning. Got up at 1.00pm, felt better, hip very painful though. Had a sandwich for lunch and then took 2 kapake. Nothing much to do as weather is wet and overcast. William stayed at school until 5pm, picked him up and on the way back waited for Kate's bus to arrive.

rest
analgesia
family

Had tea, watched telly and took 2 kapake.

tlw
analgesia

9.00pm took 2 kapake watched Doc Martin

10.00pm had bath and straight into bed.

analgesia/tlw
bath.

Section 2: Exploration of the living and lived experience of patients with chronic pain

Incorporating

- Chapter Five: The living experience of chronic pain
- Chapter Six: The lived experience of the perceived effect of chronic pain on relationships with family and friends.
- Chapter Seven: The lived experience of the perceived effect of chronic pain on one family: a case study

Chapter Five

The living experience of chronic pain

5.1 Introduction

The primary aim of the study was to explore the lived and living experience of chronic pain. The diaries helped to explore the living experience. Lived experience refers to the beingness of a phenomenon approached through various methodologies each dedicated to a different school of phenomenology spearheaded by philosophers of note. There appears to be no literature that actually examines living experience and as such there is no accepted definition. To this end I have provided my own definition of living experience: defined as experience that is currently happening. This definition forces the assumption that 'lived experience' is oriented to past time. Van Manen (1990: 104) argues that there are differences between lived time and time as 'told' by a clock. Examples given are how time appears to slow down or speed up depending on how the experiencing person is feeling at the time. Heidegger states that lived experience is not just a sequence of experiences running their way in time but is "grounded in the ecstatic unity of the making-present which awaits and retains" (1962: 355). My definition of living experience appears to be time-dependent. I use it, however, to express the importance of the day-to-day effects of living with the ever present and continuous nature of chronic pain whilst also acknowledging that the minute the patient recorded anything in their diaries it immediately becomes past – a necessary consequence of the "recorded present".

Any experience that is reported or recorded becomes necessarily 'lived' due to the nature of it having happened in the past but such a rigid and accurate existential orientation excludes a subtle but vital distinction between the data sources. A diary written on and for the day has more 'recency' allowing more proximity to the experienced phenomenon and was used here to attempt to capture the ongoing nature of the chronic pain experience. The interview is less likely to capture the experience as it is being lived since it is being mediated to some extent by my questions and probes although the patient was allowed to determine the nature of their recollections within the context of living with

chronic pain. Using the diary as a data source provided me with an opportunity to get closer to the 'living' experience. The diaries have, then, produced data which it could be argued has a different phenomenological status from the data obtained from the interviews however the method of interpretation remains the same and the principles of Heidegger's hermeneutic phenomenology were adhered to.

Within the context of the interviews the patients reflected on their chronic pain experience, often giving examples of how pain had affected their lives, as well as detailing varying emotions such as depression and frustration. Although at the time of the interview all the patients had some chronic pain I did not ask them to describe their pain but, in the low structured manner that phenomenologists favour, I allowed them to narrate their experiences to me in any manner that they chose. As a result the interviews produced data that could largely be considered lived experience whereas the diaries revealed living experience through a closer proximity to having lived that experience as recorded with accounts of day to day events and provided additional insight into how these patients were living with chronic pain.

5.2 Methodology

The diary was given to each patient at the end of the first interview with the instruction to write in it anything they wished about their daily lives with chronic pain, whether it be a straightforward account of their daily activities or a reflective account of personal thoughts and feelings – I stated that I did not want them to focus purely on the pain as I felt this had the potential of adversely affecting their pain experience for that four week duration. As a result the diaries received after the four week period were varied in content and ranged from brief bullet point entries to in-depth detailed accounts of events, thoughts and feelings.

All the transcripts from the diaries were read and re-read to allow familiarity with the data as well as a developing sense of the whole. Line by line the transcripts were examined for meaning, themes and patterns as well as the unique experience whilst keeping in mind a sense of the whole. The initial sense of the whole was that despite their

chronic pain the patients were still able to do things or activities and to get on with their lives. The diaries detailed social activities, household tasks and thoughts and feelings and therefore a matrix was developed to show all the activities performed and thoughts and feelings expressed by the patients during the four week duration of diary keeping (see table 6). The number of times each activity was mentioned was noted on the matrix although this has no particular relevance as each patient had been given very little guidance on what to write some patients had used the diary to detail when they had taken analgesia whereas others had hardly mentioned medication at all even though they took regular prescribed medication for the relief of pain. On careful consideration of these activities and the context in which the patient had discussed them it was possible to then subdivide them into social activities, mood and coping strategies used by the patients to deal with their chronic pain on a daily basis (see table 7). Activities allocated to the coping strategy category were only allocated if that activity was solely used for coping with chronic pain. One patient used driving occasionally as a distraction from chronic pain but not always, therefore, driving remained in the activity category. However, as there were obvious inter relationships between certain activities being used as coping strategies and also some activities clearly caused a change in mood, usually negatively. This was represented diagrammatically as a set diagram (see diagram 3) and are genuine sets given the data I had, for example, chess could only be categorised as an activity and not within the coping strategy category because that was not made clear in the data.

Heidegger's goal in developing the methodology of hermeneutics is not to explore the meaning of everyday practice but to explore the meaning of 'Being' (Crotty, 1996:81). The very essence of 'Being' is unique to the individual and therefore each account from the diaries is of importance and although hermeneutics allows for thematic analysis it is also a method for exploring the unusual. Hermeneutic analysis of living experience with chronic pain revealed both commonalities and individual themes, which are treated with equal importance.

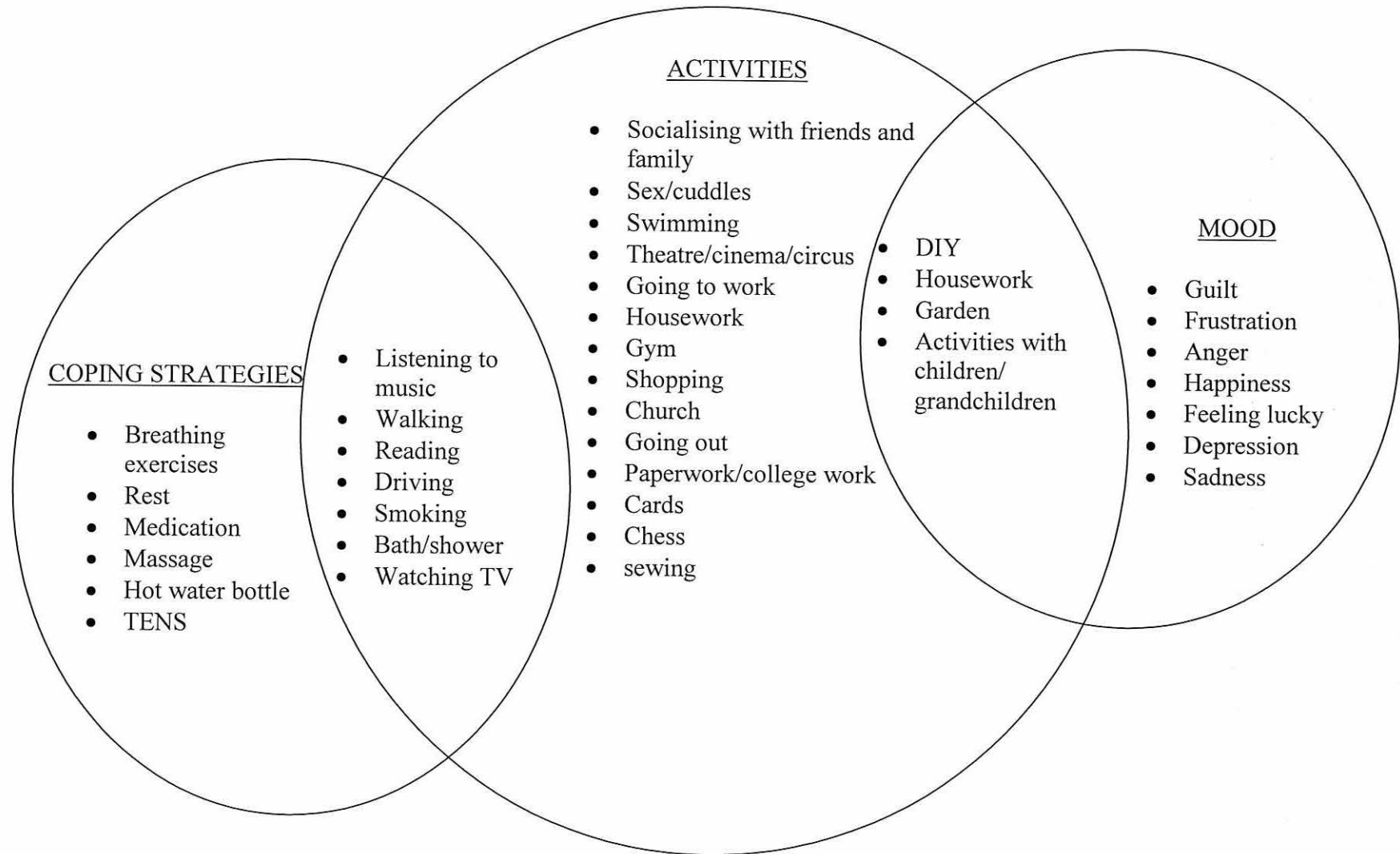
Table 6 Matrix to show the ‘living’ experience of chronic pain

	F56	F37	F58	F44	M74	M58	M37	M48
Activities with children/grandchildren	3	1	4	-	1	16	-	-
Bath/shower	1	1	11	1	2	13	3	22
Breathing exercises	-	1	-	-	-	-	-	-
Cards	-	-	-	-	-	-	-	4
Chess	-	-	-	-	-	-	-	2
Church	-	-	4	-	-	-	-	-
DIY	-	-	-	-	4	11	-	-
Driving	-	-	4	-	5	-	-	-
Gardening	-	-	-	3	5	-	-	-
Going out	1	1	7	3	5	-	1	4
Gym	-	-	-	-	-	-	10	-
Hot water bottle	6	2	2	-	-	-	-	-
Housework – own	7	1	5	1	-	19	-	-
Housework – others	7	-	1	-	-	-	-	-
Listening to music	-	-	-	-	4	-	-	-
Massage	-	2	2	-	-	-	-	-
Medication	10	25	1	20	8	43	15	16
Mood	4	9	8	8	3	5	9	4
Paperwork/college work	1	-	-	1	-	-	1	-
Reading	-	-	-	-	2	-	-	-
Rest	3	5	3	5	2	5	4	-
Sewing	1	-	-	-	-	-	-	-
Sex/cuddles	-	-	4	-	-	-	-	-
Shopping	2	2	4	1	1	14	-	10
Smoking	-	-	-	-	-	-	1	-
Socialising with friends and family	4	1	11	-	3	-	-	11
Swimming							1	2
TENS		9	-	29	4	-	-	40
Theatre/cinema/ circus	-	-	4	2	-	-	-	-
Walking	3	2	-	1	-	-	2	1
Watching television	1	-	1	-	2	21	2	4
Working	-	-	-	4	-	-	-	-

Table 7 Matrix to show social activities, coping strategies and mood

Social activities	Coping strategies	Mood
Activities with children/grandchildren	Breathing exercises	Happiness
Bath / shower	Hot water bottle – use of	Anger
Cards	Massage	Frustration
Chess	Medication	Depression
Church	Rest	Lucky
DIY	TENS	Guilt
Driving		
Gardening		
Going out		
Gym		
Housework – own		
Housework –others		
Listening to music		
Paperwork/college work		
Reading		
Sewing		
Sex/cuddles		
Shopping		
Smoking		
Socialising with friend and family		
Swimming		
Theatre/cinema/circus		
Walking		
Watching television		

Diagram 3 – Diagrammatical representation of the interrelationships between activities used as coping strategies and activities which have an effect on mood.



5.3 Findings

The reading and re-reading of the transcripts generated from the diaries gave a sense of the essence of living with chronic pain. Only the data from the diaries was used as the focus for living experience as the diaries were judged to be a more reliable source of data to reflect 'living' experience as the patients had recorded their activities and thoughts and feelings as they occurred within that 24 hour period, whereas the interviews had more of a sense of lived experience as the patients retrospectively discussed their life with chronic pain. In essence the diaries' focus was on living whereas the interviews focused on the lived. The overall "feel" of each diary differed from one person to another as would be expected but through gaining a sense of the whole through a deepening familiarity with the data it could be demonstrated that the diaries reflect the living experience of chronic pain as ranging from one obviously joyful and happy life to one struggling with life itself, with the other diaries placed on a continuum in between these two extremes. Through gaining a sense of the essence of living with chronic pain it could be seen that patients enjoyed various hobbies, socialising with friends and family and that life in general comprised a number of activities. Some of these activities were employed solely for the purpose of coping with chronic pain. Living with chronic pain also had an effect on mood and how the patient was feeling was often recorded. Therefore the initial categories were labelled as "activities", "coping strategies" and "moods". Within each category emerged sub themes which although intimately interwoven with each other could be seen as separate entities each reflecting a different aspect of living with chronic pain.

The sub themes that emerged from the category "activities" were labelled "passing the time pleurably", "those sleepless nights", "pain won't stop me", "making the most of pain-free moments", "feel good feeling" and "having good times". The "coping strategy" category contained the sub themes labelled "solely for relief" and "occasional coping" and the "mood" category contained the sub themes relating to emotion, feelings and well-being: "the negative mood experiences" and "elevated mood" (see diagram 4).

Diagram 4 – Diagrammatical representation of the findings of an exploration of living with chronic pain

Umbrella theme:

Living with chronic pain

Categories:

Activities

Coping strategies

Mood

Sub themes:

- passing the time pleasantly

- solely for relief

- the negative mood experiences

- those sleepless nights

- occasional coping

- elevated mood

- pain won't stop me

- making the most of pain-free moments

- feel good feeling

- having good times

5.4 Activities

5.4.1 Passing the time pleasurably

The various activities could be divided into those that could be considered sedentary or requiring little physical effort, and those that were moderately physically demanding. Sedentary activities such as reading, “*lazy morning reading Sunday papers*” [M74] watching television “*watched telly*” [M58] or playing games on the computer “*played chess, played whist*” [M48] were often used to pass the time pleasurably.

5.4.2 Those sleepless nights

Without exception all the patients mentioned the effect pain had on their sleeping pattern. It was obviously important to all that they had a good night’s sleep and when sleep had been disturbed it warranted quite detailed diary entries:

Woke in the early hours in horrendous pain from my back. I had to wake my husband to get me an oramorph. Did not sleep for the rest of the night [F37].

For some, the pain was that severe that they felt they had to get up from bed and occasionally watching television in the middle of the night was used to distract from the pain:

Pain started when I was in bed at 2.30 am, had to get up. I’m glad we have Sky TV, it’s something to do while I’m downstairs [F56].

Many complained of disturbed sleep:

I slept really well until 4.20am, then tossed and turned [F44].

Bad night. Kept waking up, foot was hurting [M48].

But equally when a good night’s sleep had been had, it too was also considered worthy of an entry:

Good night's sleep, feeling okay this morning [F44].

Overall a good night's sleep was usually followed by a day where the pain was better controlled; a poor night's sleep usually heralded a day of pain:

Bad night again. Had a job to do this morning, my hip and back are killing [M58].

Lying awake at night because of pain, unable to get to sleep, as illustrated above added to the distress of living with chronic pain. One patient [M74] reflected on why having pain at night was worse than experiencing it during the day:

I find being awake at night and in pain is much more frustrating than during the day even though the pain is just as severe. Distraction is easier in daytime”.

5.4.3 Pain won't stop me

Throughout the diaries there were examples of patients determined to continue with activities associated with normal living despite having chronic pain. These activities were usually associated with housework, household chores (such as shopping) or do-it yourself projects.

Still aching from yesterday, but bedroom has to be finished. 1.00pm had a sandwich and carried on painting [M58].

Still aching, but decided to make a start on hall and landing. Wiped paintwork down with sugar soap [M58].

Occasionally physical activities (such as walking and driving) were used as methods of distracting from the pain as well as pleasure. This quite often served to break the monotony of a pain-day:

Decided to get out and we went for a walk around Chester, my pains had started before I left the house and I thought I would work through them by taking my mind off them, it didn't work, the pains were severe but it was good to get out...I was even in pain going to bed, but at least the day hadn't been humdrum [F56].

The need to go out and enjoy life as well as socialising with family and friends was frequently recorded. Within the diaries were accounts of shopping trips, visits to grandchildren, barbeque engagement parties, visits to the beach and helping out friends and family. This gave a feeling of worth and well-being despite knowing that some activities were likely to increase the intensity of the pain:

I have to help two friends with two parties today. It will get me out of the house. After four hours of preparing food and doing the party I am nearly in tears [F37].

I'm not going to be idle today I'm going to clean my kitchen cupboards[F56]

I am forcing myself to go to the gym. It is my way of getting over it [M37].

5.4.4 Making the most of pain-free moments

Pain-free moments were infrequently mentioned within the diaries but when a patient stated that they had little or no pain the most was made of the experience. One female patient took the opportunity to go shopping:

Hardly any pain in morning, went to Chester (pm) for a bit of shopping, had a nice couple of hours. It was good to get out [F56].

Whereas another male patient simply recorded “a rare almost pain-free day” and then gave no further detail of how he had spent his day.

5.4.5 Feel good feeling

Despite living the chronic pain experience the patients still took pleasure in the small things of life. Walking, swimming, going to the gym and enjoying good weather all combined to make patients feel better in themselves:

I came back from a walk with a feel good feeling. It was a nice dry day and crisp [F56].

Going swimming, do me good. Had a good swim. Water was warm. I feel good [M48].

Took a slow walk to the local post office but had to get back home in the car as my back, legs, shoulders were all very painful, but it felt good to be out in the fresh air [F37].

I had an hour of indulgence with an invigorating shower and used some expensive clinique body cream which smelt lovely, it's nice to feel nice [F56].

5.4.6 Having good times

All of the diaries with an exception of two gave details of the patients having enjoyed themselves. This was grouped separately to the “feel good feeling” as the patients used the word “had” rather than “feel”.

Felt well, so I went for a walk with some friends early evening. Had a good time [F44].

Pain was only mild today, very unusual. Grandchildren called with their mum and dad and I was able to play with them, had a lovely time [F56].

One female patient during the four weeks she kept her diary started to plan her second marriage after many years of being a single woman. Her happiness was reflected in every

word she wrote in her diary, and although her days were still full of pain she had found that the pain did not affect her mood as much.

I just want to be with him. I have never laughed so much in my life and Beryl (daughter) said she has never seen me so happy [F58].

5.5 Coping strategies

Coping is defined as the personal effort a person makes to manage and minimise the negative effects of an experience (Banks and Mackrodt, 2005:23), a strategy is nothing more than a plan. It could be debated whether the patients in this study have “planned” their coping strategies or simply discovered them experimentally over time. There were several activities that, within this study, the patients used solely for relief of pain and therefore could be termed a coping strategy: the use of hot water bottles, breathing exercises, the use of TENS and analgesic medication, massage and rest. There were details of other activities which some patients used as a distraction from pain on occasion.

5.5.1 Solely for relief

As this study uses a phenomenological approach and is a naturalistic method of inquiry which focuses on understanding the human experience as it is lived (Polit and Beck, 2006:16) the quantification of the data is of little relevance, however, within the early line by line analysis of the diary transcripts the number of times an activity was recorded was noted. This served to inform further analysis on whether that particular activity was individual to one or shared by many. Having a sample of eight participants cannot provide results that can be considered generalisable to a population but they can be enlightening and as hermeneutic phenomenology is interested in the unique as well as the commonalities of an experience using numbers to ascertain these basic facts seems to offer a sense of how important these issues may be via a frequency account. The numbers generated, therefore, can not be used in any way other than as an indication of commonality due to the lack of guidelines provided with the diary at the outset of the month long diary-recorded exercise. What was important was for the patient to record

anything they wished as they lived with chronic pain, not a pain diary which detailed number and type of analgesia taken and its effectiveness. Despite this, however, it is interesting to note how many experiences were shared and to what extent patients had felt necessary to record this information although in part this is not surprising taking into account that the patients were keeping the diaries at my request.

The use of analgesic medication was one activity that was recorded by all the patients at some time within their diaries although the detail of the reference differed vastly from patient to patient.

Some patients recorded when they did not need to take analgesia or were able to take a reduced amount:

My pains were not as bad as previous days, so didn't warrant a lot of medication [F56].

Others recorded how an exacerbation of pain required an additional drug which then produced unwanted side effects:

I take Co-Dydramol and diazepam – it's difficult to get dressed – so I don't. I rest on the bed. 12 noon – I put the TENS on as I'm drowsy after the tablets [F44].

One patient [M58] was so familiar with his analgesia that he abbreviated the names of his analgesia, also recording on a daily basis at what time he had taken his regular medication:

Finished at 9.00pm, had cup of tea and took my A and C (amitriptyline and carbamazepine). Before going to bed took two kapake at 10.30pm.

Within the nursing and medical literature there are various papers on poor analgesic prescribing (McNeill *et al.*, 2004) and the untimely administration of medication by

nursing staff (MacLellan, 1997; Willson, 2000) often related to initial ineffective and poor pain assessment (McCaffery *et al.*, 2000). One 37 year old man whose diary was commenced during a hospital admission for acute exacerbation of his Crohn's disease is a perfect example of these previous findings:

You wouldn't bloody believe it. After waiting all day for a doctor to write me up for morphine the doctor won't write me up for it. I am down as having a slight allergy in the past – I was all right last night! So what if I itch a little? She has gone to see the house officer – I am devastated.

Detailed accounts of the varying amounts, different types of analgesia and alternative methods of pain relief were documented by one female patient:

Had to take two oramorph vials where I had been trying to only use one. Used the TENS machine on my spine and stomach alternatively. Traxam gel also applied three times during the day. Went early to bed with a hot bottle [F37].

Use of medication was the most recorded method of coping with the pain although there were many references to the use of TENS with half of the sample using a TENS machine on a regular basis, although all patients within the sample had originally been recommended a TENS and had tried the method with varying degrees of success.

Alternative methods of coping with the pain such as breathing exercises for relaxation purposes, back massages to ease muscle tension and the frequent use, by some, of hot water bottles, was also recorded within the diaries. Patients were very active in seeking strategies that eased their pain and partners/spouses were very evident in their support of this:

Long soak in the bath, then Ken massaged my back. I went to bed early – much too hot for the hot water bottle unfortunately!! [F58].

One of the requirements within the inclusion criteria was that patients had not attended a pain management programme. Pain management programmes teach coping strategies which can include one or more of the following techniques: relaxation, imaginative inattention, imaginative transformation of pain, imaginative transformation of context, attention diversion, pacing and somatization (Banks and Mackrodt, 2005:23). As no patient had attended such a programme (although it could not be guaranteed that they had not read self-help books) it was interesting to see how many strategies were used by the patients within their daily lives of living the chronic pain experience. The technique most used was that of pacing which involves planning activity and taking rests as required. All patients, bar one, recorded taking a rest or lying down during activities:

1.00pm had dinner and started painting our bedroom. Before starting I took two kapake. Had two or three breaks and stopped for tea at 5.00pm [M58].

5.5.2 Occasional coping

Within the transcripts there were frequent references to activities that were used to relieve pain on an occasional basis. Having a shower or bath was not always used as a coping strategy. Some detailed having a bath or shower as a matter of a daily, or a nightly routine. Others referred to having a bath as a means to use the heat from the water to help with the chronic pain, for one lady [F56] a shower was an “*hour of indulgence*”.

Other activities such as going to the cinema, theatre or circus caused an increase in pain or discomfort:

The circus was really very good but blimey were the bench seats uncomfortable!!! [F58].

In each case the patients recorded sitting caused the increase in discomfort but then used strategies to reduce the discomfort:

Went out to the theatre this evening wore TENS [F44].

Film wasn't bad, but seats weren't too comfortable and I could feel a draught – my back doesn't miss anything like that – ever!! Kids had a great time, Ken included! I wish I could sit comfortably in public places. I do quite often take a cushion, but it isn't really enough. I don't know what the answer is. If the seats are not very deep there is no room for a cushion or my knees are under my chin!! That isn't comfy either! [F58].

Sedentary activities such as reading, listening to music, driving, smoking and watching television were all used on occasion to distract from the pain. Distraction was an important strategy for all patients whilst living with chronic pain although all used distraction in various ways. For one patient just concentrating on a difficult task served as a distraction mechanism:

Spent some time dismantling the pump out of the pond to find out why it wasn't functioning properly. Managed to "forget" the pain because of the level of concentration needed [M74].

Another patient, recently engaged to be married, recorded:

Went to sleep in his loving arms – he just makes everything right in my world. He is the one person who can push the pain to the back of my mind. I hear people say that making love is too much of an effort and so they don't bother – I wish they would give it a try!! I'm sure there's no better way to relax – or not for me there isn't [F58].

5.6 Moods

There is a wealth of literature that details the effect of chronic pain upon negatives mood such as depression, anxiety states, short temperedness (Sofaer and Walker, 1994; Schaefer, 1995; Bowman, 1994a; Bowman 1994b) so this study can only confirm previous findings, however, there is very little that explores positive moods felt whilst

living the chronic pain experience. Moods, emotions and feelings were frequently revealed in the data gathered from the diaries and varied from guilt, frustration, and anger to depression although some patients still expressed periods of happiness and feeling lucky.

5.6.1 Negative mood experiences

All patients recorded the effect of the pain upon their mood and sense of general well being:

Bit ratty this evening, pain is horrible. I hate feeling like this. I'm not a moody person by nature [F58].

Some of the entries revealed that the patients had insight into the effect their negative mood had on others:

My friend came for coffee, it was hard to be jovial while I felt like this, but you can't be down and miserable or people will not want to visit [F56].

Whilst other entries were thought provoking and reflective:

One of the worst things I experience through this pain is guilt. I feel guilty when I don't interact with my family. I get on edge when the pain is bad and I just want to be left alone, I feel guilt when I lay down because it means I'm not doing housework which equates to me not pulling my weight around the house and since I gave my job up I'm not bringing any money into the house [F56].

Frustration was frequently expressed at inability to achieve tasks as quickly as previous:

I like doing DIY jobs but find it very frustrating that everything takes so long [M74].

And another extract illustrates how time is spent resting in order to manage the level of pain is also a cause for frustration:

Bed early – I think one of the most frustrating aspects of living with pain is the feeling of wasting precious time. I don't want to live my life having early nights with the hot water bottle!! [F58].

There is much debate within the literature about whether chronic pain increases or is a precursor to depression or whether there is a depressive element within the person's personality which exacerbates chronic pain (Sofaer and Walker, 1994; Turner *et al.*, 2004) whatever the case is there is no doubt that chronic pain and depression are interlinked. There were several references to feeling depressed or low in mood within the diaries, particularly when the pains appeared to be total body pain rather than just limited to one particular area:

It's really getting me down, aching from first thing in the morning to last thing at night, there's just no let up [M58].

Sorry but the only thing I can write is "HELP" because I am getting so depressed due to all my pains from the different parts of my body [F37].

This next extract offers insight into the physical and mental effects that chronic pain can exert over people's lives:

I don't like not doing anything because I think it's not helping my weight, which is making me feel down. I feel it's a vicious circle, my pain when it starts makes me want to lie down with hot water bottles, so I am not burning off the calories. When I feel depressed because of the pain, it's also my weight that adds to the depression. When I was working my weight kept steady, but since giving my job up, I've put on nearly two stone because it's easier now just to give in to the pain. But when I think of the times when I went to work in pain and how hard it was,

I'm glad I don't have that burden. It was like a weight around my neck. I often had to come home which used to make me feel like a terrible because I was very conscientiousness, and felt I was more of a burden than an asset to work. I feel that life has nothing to offer me anymore, I don't know if I feel like that because of my pain or because I'm getting older and maybe healthy people of my age feel like this [F56].

5.6.2 Elevated mood

The diaries, however, also gave accounts of happy times and feeling well, life was not always miserable and it was noticed that on those days when the pain was not as severe and a good night's sleep had been had, mood in general was elevated:

Good night's sleep, feeling great this morning, a bit stiff – but no pain [F44].

*Weather glorious, so very hot. Mike managed to get today off which was great, so this morning the four of us had a wander around Darlington then off to Whitby for the rest of the day. Fish and chips at Whitby, and home made ice cream!!
Lovely [F58].*

5.7 Discussion

This chapter had focused on the living experience of chronic pain through an analysis of the data provided within diaries written by the participants over a four week period. Previous studies that have explored the lived experience of chronic pain (Thomas, 2000; Soderberg *et al.*, 1999; Seers and Friedli, 1996) used interviews in order to explore the phenomenon. In each case the participant reflected on the experience. Through using diaries, although still reflective, the diaries recorded each day of living with chronic pain and therefore gave an essence of living in the present sense of the word rather than lived as in the past tense. This has given a different sense of the whole experience of living with chronic pain whereas the studies mentioned above only identified themes and furthered understanding relating to the negativity of the lived experience of chronic pain. Thomas' (2000) 'shrunken life world' and 'untamed monster' analogies, the adverse

affects as illustrated by Seers and Friedli (1996) and the struggle to gain dignity through loss of freedom and threat to personal integrity presented by Soderberg *et al.* (1999) all contribute to the meaning of chronic pain. However through an exploration of the diaries within this study there remained a sense of these patients actually having a life which despite the chronic pain still had some of the highs of the very essence of life itself.

The category simply labelled “activities” indicate that the patients in the study were able to participate in activities that could be considered normal such as shopping, doing their own or others’ housework, gardening and do-it yourself tasks. Some of the activities, such as gardening, increased pain levels whereas other activities, such as watching television or listening to music, soothed pain and were sometimes used as coping strategies by means of distraction. All the activities were interlinked in some way with the associated effect on mood whether it was to improve mood or to depress mood. Activities that once had been considered enjoyable such as do-it-yourself tasks were often the source of frustration, similarly activities that were considered to be in the domain of one particular gender (agreed within the individual roles of that particular family), such as housework frequently caused feelings of guilt if the patient felt unable to do properly (if at all) because of the pain.

Sleeping patterns were noted to be of great importance. All patients within their diaries had at least one entry reporting on how well, or how poorly, they had slept. Sleep and chronic pain are known to be closely related (Davis, 2003; Schaeffer, 1997) with an estimated 83% of people with chronic malignant pain and chronic non-malignant pain reporting poor sleep patterns (Wang *et al.*, 2007). Within this study all participants expressed disturbed sleeping patterns which they attributed to the pain. Sleepless or disturbed nights often cause the patients to report an increase in pain the following day which is verified by other studies (Davis, 2003; Reyes-Gibby *et al.*, 2003). Fatigue is a subjective phenomenon and can be experienced after physical activity although is not always related to activity (Jakobsson, 2006). Studies have shown that chronic pain is a variable of fatigue (Jakobsson, 2006) and yet within the patients’ diaries there was no record of fatigue or extreme tiredness. Patients stated that they needed to rest, but rest

was frequently associated with a need to get respite from pain caused by increases in activity such as gardening or housework.

The theme “pain won’t stop me” detailed the determination that patients put into their every day living to ensure that they had normality. Maintaining as near a normal life as possible was seen to be important and it was not being able to achieve what each considered to be their normal routine which frequently increased frustration, caused feelings of anger and lowered mood in general. This effect on mood, although not a new finding, confirms previous studies and contributes to the body of phenomenological knowledge surrounding the lived experience of chronic pain. Mood, however, was not consistently negative, and patients did detail periods of happiness, feeling positive and enjoying life in general. This finding is not one that has been documented previously in the literature as the literature focuses on the negative aspects of having chronic pain.

The use of coping strategies solely for the relief of pain or activities that could serve as coping strategies under certain circumstances gave an insight into the routines that patients practiced to relieve or limit pain. Medication was taken regularly and in most cases the diaries illustrated how important the analgesia was to each individual. Hot baths and showers or the frequent use of hot water bottles, massage and the use of breathing exercises for relaxation purposes demonstrated how patients were prepared to take an active role in the management of their pain. Distraction was perhaps the most used coping strategy although activities used to cause the distraction varied from passive activity such as reading or watching television to more vigorous activities such as gardening. It must be remembered that as part of the inclusion criteria none of the patients had attended a pain management programme, therefore any coping strategies used by them were developed intuitively or deliberately following the patient actively seeking advice and help from other sources such as self-help books. This shows that within this sample all patients had actively taken a role in managing their own pain outside of the analgesic regimen, acupuncture and TENS prescribed by the nursing and medical pain specialists within the pain clinic setting. Coping strategies can be divided into active or passive (Dysvik *et al.*, 2005). Passive includes attending pain clinics etc. for

‘something’ to be done to them such as acupuncture. Active strategies are those where the patient has to take a degree of responsibility for their own pain management. All patients within this study demonstrated some active coping strategies although some appeared to more active than others which supports theories that due to the subjective nature of the chronic pain experience the association between coping, beliefs and the patient’s own adjustment to pain as well as circumstance has to be taken into account (Jensen *et al.*, 2003).

Living with chronic pain does cause stress and this study confirms Dysvik’s *et al.* (2005) findings that the major stress caused by living with chronic pain is not health-related but the impact the effect of living with chronic pain has on social activities and family life. The exploration of the diaries written by the patients within this study has provided insight into the living experience of chronic pain. All the patients strive to manage a near normal life as possible and when unable to achieve this suffer from negative moods and emotions however the diaries also illustrate life to be still worth living, social activities still take place and positive emotions such as happiness and considering oneself fortunate are still experienced.

5.8 Conclusion

Findings from this study can be seen to add to the phenomenological literature that explores the human body and the nature of lived experience. This chapter explored what I considered to be ‘living’ experience. By providing the participants with diaries to detail their life with chronic pain - as it happened - insight into the daily routines concerned with managing chronic pain as well as the activities that were achievable whilst still experiencing chronic pain was explored. Highs and lows were experienced on a mood and emotion level with patients still able to express “feel good feelings” as well as negative moods. The ability to make the most of “pain-free moments” and the determination shown to continue as normal a life as possible through using various coping strategies illustrated that patients with chronic pain were not prepared to give into the chronic pain anymore than they had to. The living experience aspect of this chapter focused very much on the activities, the coping strategies used to achieve those activities

and the range of moods experienced during the four week period of maintaining the diary. The next chapter explores the lived experience of chronic pain and uses data obtained from the interviews with the eight participants. Although combining both interview and diaries in data collection has proven to be advantageous within this study (Clarke and Iphofen, 2006a) for the purpose of this chapter, and the following chapter, the data gathered from the two respective methods has been analysed separately.

Chapter Six

The lived experience of the perceived effect of chronic pain on relationships with families and friends

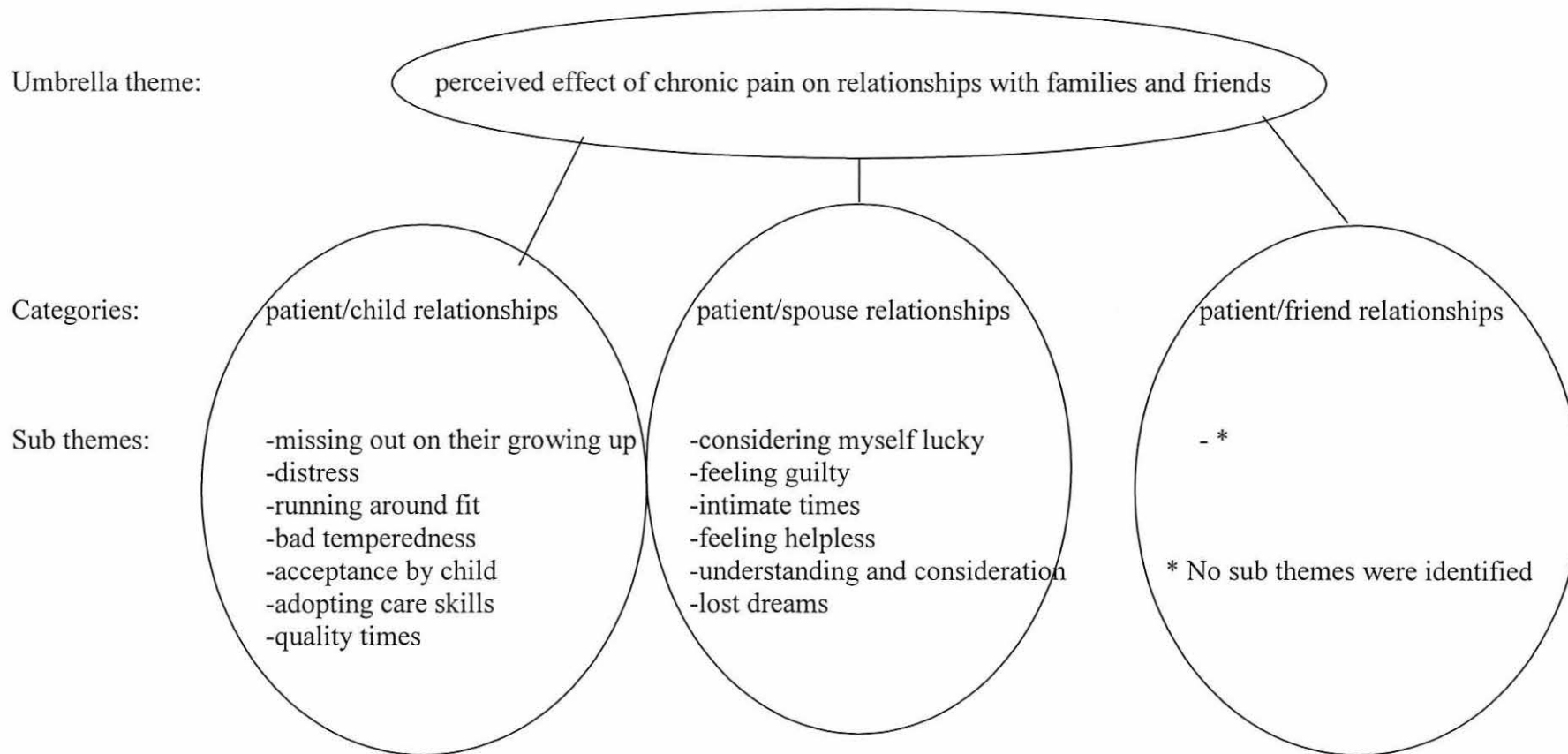
6.1 Introduction

The preceding chapter considered the living experience of chronic pain using data gathered from the patients' diaries. This chapter uses data from both the interviews and diaries and explores the effect that having chronic pain has on personal relationships. Within this chapter the theme focus initially identified was that of the family unit. All of the patients within the sample alluded to their family, on at least one occasion, and the effect chronic pain had on their individual family unit. Subsequent hermeneutic analysis exposed hidden meanings through a process of interpretation to provide further insight and a deeper understanding into the lived experience of the perceived effect of chronic pain upon the family unit. Further analysis of this identified theme exposed negative feelings of failure, guilt and frustration associated with functioning as a parent, partner, wage earner as well as more positive emotions of considering themselves lucky and appreciating their family members. This was then expanded to incorporate other relationships which included the role of grandparent and friends (see diagram 5).

6.2 Patient – child relationships

Within the sample two patients had children under the age of 18 years living at home, although others, whose children had since reached adulthood, still reflected upon the effect their chronic pain had potentially played within their own children's developing years. One patient had no children of his own but related to his 12 year old goddaughter. A further three patients had grandchildren, therefore, for the purpose of this section data was analysed from the interviews and diaries provided by six patients (three men and three women).

Diagram 5 – Diagrammatical representation of the findings of the perceived effect of chronic pain on relationships with families and friends.



6.2.1 Missing out on their growing up

Through the disabling effect of chronic pain parents were quite often unable to participate in family activities and this resulted in great distress and regret:

I even missed out on going to the local bonfire and fireworks display with my family. That saddens me as I seem to miss a lot of my children's activities and am so missing out on their growing up, which is irreplaceable [F37 diary].

This same patient whilst keeping her diary was unable to attend two separate family bonfire celebrations, the first detailed above, gave her a feeling of sadness, by the second occasion her mood had changed from sadness to a feeling of depression:

I couldn't even go to the bonfire display ...the back pain would not allow me to walk and stand for a few hours. So my husband and the boys went on their own and that made me feel depressed, knowing that I would miss out on quite a lot of family activities [F37 diary].

Everyday activities which most parents take for granted and perhaps even view as a chore became impossible to achieve and caused further upset:

It was hard because I wasn't able to do things like take them to school and I missed things like sports days and concerts and assemblies and that hurt [F58 interview].

6.2.2 Distress

This study was not designed to examine the effect on the child of having a parent with chronic pain; however, further research into this area would be beneficial. The perceived effect on the child, however, can be explored from the view point of the parent. Those who had children, of any age, frequently mentioned how they perceived that having a parent with chronic pain affected the child through causing the child distress:

Many a time he's cried (youngest son) when I've been in pain [F37 interview].

One patient had not realised for many years how difficult it was for her youngest daughter to leave the family home, leaving her mother to live by herself;

... but she now says the guilt she felt when she moved out has been dreadful, leaving me on my own. And I'm sorry about that because it isn't something I wanted her to feel and I hope it's not something I have made her feel [F58 interview].

Another patient discussed her inability to socialise with her family due to her pain:

And even when my daughter comes home from work, she picks her daughter up from nursery and she comes to our house for her lunch and sometimes the pain is so bad I can't speak to her (tearful) because I can't bear to talk to anybody I just want to be on my own. And then I feel so guilty that you know I'm not being a proper mother [F56 interview].

6.2.3 Running around fit

Regrets were expressed that children had never known their parent without chronic pain. In each instance the patient recalls a time when they considered themselves to be healthy and active:

Janet (daughter) never remembered me before all this happened. The other two do, kind of, she doesn't and that saddens me really because she never knew me running around fit [F58 interview].

Whereas Sam (youngest son) has been used to it, Jimmy (eldest son) has seen the good side and Sam has known no different but then again I feel awful for Sam he has missed out, where I used to play football and that with Jimmy and other games, other rough games, we used to play. I can't do those now. I can play

simple games with them but I can't toss them into the air like I used to [F37 interview].

Regret is an emotion which runs throughout the majority of the interviews and diaries, however, the regret at its most poignant when one patient refers to her children:

And the children are more worried than anything. I feel as if I am depriving them of a normal childhood. It's slipping away. It's not right for a five year old... [F37 interview].

6.2.4 Bad temperedness

In addition chronic pain adversely affects the level of patience parents had with their children. This was particularly noticeable when one particular patient was talking about his children:

That's why I'm, well, with all these pains, whatever, its not just a lame excuse but that's why I'm so terrible with the kids...It's when I get on my own I think about it, why, why am I so nasty with these children? [M58 interview].

This same patient continues to view his pain as being the sole reason for his impatience and bad temperedness with his children:

They're (children) just being normal, it's me that's not normal. It's all through pain [M58 interview].

His remorse and regret was obvious in his voice as he reflected on his relationship with his teenage children. The next extract taken from his interview was expressed with a lightening of his tone, was said almost apologetically and with a feeling of relief:

They don't deserve it and they still come back to me, normal, as if I hadn't given them a roastin' [M58 interview].

6.2.5 Acceptance by child

This ability of children to accept their parents' chronic pain, its disabilities and its impact upon mood and tolerance levels are reflected in the way that one of the patient's reports how considerate her son is:

My oldest boy was going to cancel a party he had been invited to so that he could look after me...– I made my son go to the party because he needs to lead a normal life and enjoy his childhood and not worry so much about me[F37 diary].

Another patient, a bachelor, spoke with fondness about his goddaughter, whom, he explained appreciates that the pain causes him to be irritable:

My godchild lives across the road, she's 12 now and she knows when I am in pain she says "leave him alone today, he's in a baaad mood". She's known me ever since she was 18 months old and she can tell straight away, to get out of the way or whatever, and her mam can [M48 interview].

Well she (godchild) knows me and I know her, the way she talks...when I'm in a bit of pain she knows to just keep away a bit [M48 interview].

6.2.6 Adopting care skills

The adaptability of children to be able to accommodate their parents' chronic pain and its restrictions is occasionally transferred into caring skills:

That is another thing I get unhappy about the fact that whenever I have a bath or shower I have to have either one of my sons or my husband in the room with me just to make sure I am safe and so once again my boys have to be grown up in that situation and I feel that I am depriving them of a typically normal childhood [F37 diary].

6.2.7 Quality time

Relationships with grandchildren were also adversely affected. Regret was expressed at not being able to spend quality time with grandchildren:

I don't think I am quite as ratty as I was last night! So it was better for me to just go to bed. What a waste of precious time with my lovely granddaughter [F58 diary].

One patient expressed relief when her two granddaughters went home, but this in itself causes added guilt and distress for the patient:

My daughter came with her two girls (half term) couldn't interact with them as I felt lousy, I stayed in the conservatory, granddad entertained them, glad when they left [F56 diary]

Another patient, whose granddaughter was still pre-school, laughed when he recalled how cross his young granddaughter had been when he fell asleep during their special playtime:

But if I've got a pretty bad day I go and lie down...I occasionally may doze off. When Sarah (granddaughter) was up here last time...I went to lie down, and then she said "I'll come and keep you company, Granddad". I knew what she wanted, to play polar bears, which is a game we play. I said "righto". We were doing all this and I had only been there 10 minutes and I was that tired and Sarah came downstairs and said: "can't you keep Granddad awake?" [M74 interview].

6.3 Discussion

Through the extracts from these interviews and diaries it is possible to view the lives of some of these children through the eyes of the person with chronic pain. There is no published literature which solely explores the effect that chronic pain has on a child, when it is the parent that suffers the chronic pain. There is, however, literature that

explores the effect of chronic pain when the child is the sufferer (Wahlstrom, 2004) and there is also literature that explores the effect of chronic pain on the parent when the child is the sufferer (Hentinen and Kyngas, 1998; Roy, 1989). This study has identified a need for further research into the effect of having a parent with chronic pain has on the child, which could be explored from both the parent's and child's perceptions.

Although having children was not a consideration within the inclusion criteria it can be seen that those who had close contact with children either in the parental role, as a grandparent or simply as friends felt that having chronic pain did adversely affect their relationship with that child and caused increased distress to the patient as well as the child. Distress for the child can be caused through seeing a loved adult family member in pain and therefore unable to participate in family activities, or increased distress could be caused through a simple similar response to the adult's expressed distress. Although this has developed through a wider remit of exploring the family unit important insight into patient/child relationships have been revealed, even when the child has grown into adulthood the parent still holds regrets. Consistent with other studies that explore the effect of living with chronic illness (Smith and Soliday, 2001; Gregory, 2005) as opposed to chronic pain these findings indicate that chronic pain affects the patient's perceived role as a parent, particularly noticeable within the perceived role of the mother.

Mothers and grandmothers reported regret and guilt at missing out on the normal family activities associated with having children whereas fathers tended to report their lack of patience and bad temperedness with children, which then brought about a feeling of shame, remorse and regret. All families have their own interpretation on what defines 'normal' family life. It is possible that when family life fails to live up to those expectations that negative emotions can take a hold. As expectations for family life are often set in anticipation of that life then the expectations are not always realistic and when coupled with the advent of chronic pain the expectations that initially defined family life become even more unrealistic and even less achievable adding to feelings of failure as parent, guilt and regret for what could have been. Snelling (1994) similarly identified a reduced level of parental tolerance within an English study which used a

grounded theory approach to examine the different effects a relative with chronic pain had on his/her partner and other members of the family.

A Dutch study (Kemler and Furnee, 2002) which investigated the impact of chronic pain on life in a household stated that chronic pain is likely to alter traditional family roles and create distress, not just for the person with the chronic pain, but also for other family members. This finding was reflected within this study which identified distress within the parent as well as the parents identifying distress in their children caused through the chronic pain experienced by the parent.

Emotions described by the patients experiencing the chronic pain expressed through the narratives include sadness, depression, hurt, guilt and regret. These could be termed negative emotions and are not commonly discussed when discussing bringing up children. This, however, does not imply that parents only feel these negative emotions if chronic pain is involved. It is possible that negative emotions associated with children are not discussed openly for fear of being considered a poor or inadequate parent. It could be argued that most parents at some time will experience guilt whether it be associated with being a working mother or earning too low an income to provide the latest toy or designer clothes. Living with chronic pain affects not just the sufferer but also impinges on what is considered to be normal family life (Seers and Friedli, 1996). Occasionally this was expressed as being a failure to parent correctly: *"I'm not being a proper mother"* although not all mention of children was negative. One patient, smiling affectionately at the memory, recalled a family caravanning holiday:

...there's a cricket pitch, and we walked around the edge of the pitch... after about four days I was saying "come on, kids!" ... I said, "what's keeping you, because they're that used to walking slow to keep up with me, they dawdle. I said "come on, what's keeping you?" [M58].

This extract illustrates a happy time and it must be emphasised that not all encounters with children caused distress to each party. The interviews focussed on living with

chronic pain and with this in mind it has to be acknowledged that each patient would potentially consider the abnormal and the inconvenience of chronic pain whilst giving their interviews or writing in their diaries, however, it is also a great privilege when patients share experiences which are particularly painful or cause them further regret or remorse.

6.4 Patient/spouse relationship

Relationships with partners and spouses was another area worthy of exploration. Out of the sample five patients were either married, lived with a partner or in the case of one patient was currently planning married life but was living apart from her partner whilst they combined households. For the remaining three patients, one lived alone whilst the other two resided with a parent or parents. The effect of chronic pain upon relationships within marriage caused the patients to experience a range of emotions ranging from considering themselves lucky to feeling guilty.

6.4.1 Considering myself lucky

Luck was often mentioned within the interviews when referring to partners. Although it sometimes appeared that the patient was trying to re-confirm to themselves that there was something good in their lives through repetition and emphasis:

But I am lucky. I know I'm lucky. You know, with my husband, I am so lucky. He's wonderful, he really is, he gets on my nerves at times but I probably get on his [F56 interview].

Another patient felt that her husband tolerated far more than he should have to when she considered the effect that chronic pain had upon their lives as a couple:

I'm lucky really. I mean most men of his age from having Sam (second child) would have done a runner. You know even my brothers have turned round and said if I was John (husband) I would have put you in a nursing home (laughs quietly, sadly) ... But yes he's been wonderful [F37 interview].

Sadness was often implied through tone of voice. This patient spoke wistfully and with gratitude as she reflected upon her husband and how he cared for her once her chronic back pain had become greatly exacerbated following the birth of their second child. From expressing luck at having such a “wonderful” husband she went onto to express regret and guilt at the fact that he no longer went to work as he had taken on the role of main carer for her chronic pain needs:

I feel awful because he's had to give up work now, feel like I've deprived him because he's always been a hard worker...never taken sick days at all and now he's permanently off working. I can see at times it gets to him, stuck in the house...I make sure he gets out but it's still not fair on him really [F37 interview].

The role of spouse as carer ranged for this particular patient [F37] from having help with activities of daily living such as “*had a bath but my husband had to help me to wash my hair*”, and “*My husband tries to make me eat*” to instructions on what to do “*he has told me not to get out of bed today*”. Dependence on spouses varied from patient to patient and many patients reported adapting their lives to accommodate their pain, in many instances this required slight role reversal and the use of other family members to ensure that jobs within the home were still accomplished:

We had done all that work because George (son) and Doris (wife) were barrowing all the soil. She's good with a wheelbarrow is Doris (both laugh). I offered to buy her one for Christmas but she wouldn't let me! [M74 interview].

There appears to be more of an acceptance of the role reversal depending upon the length of time of marriage and the age of the patient. This cannot be tested within this study as the sample is too small and the information required to explore this phenomenon was not included within the criteria, however, just from the data provided through the use of the interviews and diaries, it seems that the older the patient the easier the relationship, and the apparent lack of experienced guilt is expressed.

6.4.2 Feeling guilty

Feelings of guilt and frustration in fulfilling the role of wife/husband was frequently expressed by the patients when discussing their everyday lives. Guilt was expressed within the diaries by women who felt that housework was a part of the female role. This extract although illustrating the guilt she felt at apparent role reversal also highlights how the husband had taken on the responsibilities his wife had previously carried:

I am 37 years old and I should be the one doing housework, cooking etc and not my husband [F37 diary].

Another female patient also lamented about housework and how not doing it caused her feelings of guilt:

Feel guilty, didn't do any housework and quite a lot needs doing [F56 diary].

Feeling guilty because of an inability to perform housework appears to be a very superficial concern. Closer analysis of these expressions of guilt reveals that patients are unhappy and frustrated at how chronic pain prevents them from doing things that they consider “normal”. Associating housework with females can be considered to be stereotypically sexist; however, these are the patients’ own interpretations. The women did not directly discuss how housework was a female role, it was implied. Being “normal” and doing “normal” activities is an individual perception based on culture, relationships and personal boundaries. One female patient [F56] stated how she had “*lost interest*” in the housework because she no could longer maintain her own cleaning standards. Within the male patients guilt was not expressed when discussing their inability to fulfil their “role” instead it was expressed as frustration:

There are things you want to do at home and you think “Oh that shouldn't take me five minutes, but it does. Six little slabs to lay in the back garden the other day, it took me what? Three days... [M58 interview].

I like doing DIY jobs but find it very frustrating that everything takes me so long [M74 diary].

Carrying on with the building work, determined to push the aches and pains to the back of my mind. Just wish everything didn't take so long [M74 diary].

All of these extracts highlight that these patients are still able to do certain chores associated with gardening, do-it-yourself jobs and property maintenance. The latter extract showing that the patient is using physical activity and determination to distract himself from the pain. Frustration is caused by the length of time these jobs now take with the patient considering the length of time being taken has been extended because of chronic pain, age is not considered to be a factor. One male patient, who had taken three days to lay slabs, had had to curtail his activities due to chronic pain. This was expressed with quiet resignation and regret:

The jobs I'm not doing at home, I can't do them. I've always been a jack of all trades, doing electrics, plumbing, whatever, but I just can't do them [M58 interview].

This was emphasised at a later stage when he sighed and said: *"I'm becoming reliable on everybody else"* [M58 interview]. One patient had not minded role reversal when she felt she was contributing to the household:

I think it might be something to do with not bringing in the money because I've worked, well, all my life, and I only gave it up last September and I was contributing to the family home. You know, I was able to buy shares and make our life a little bit easier and then if he cooked the tea ... I didn't mind that because I felt equal but now that I'm not working I do feel guilty and not equal [F56 interview].

This feeling of inequality within the relationship is an interesting phenomenon. Relationships between husband and wife are, in today's culture, considered to be on equal terms. Role reversal was acceptable when she acknowledged her husband was cooking because she was out at work, once she left work, on ill-health grounds, the balance tipped and she saw it as a further loss of personal independence, she hadn't just given up work because of chronic pain, but she was unable to resume the role of cook within the family for the same reason. The chronic pain had affected both her working and home life.

One patient who had been divorced for many years reflected that the strain of looking after the house, bringing up three young children and working on her husband had been a major contributory factor in her divorce:

And with hindsight it's probably one of the reasons why my marriage broke up. I'm sure it must have been. I'm sure he just got sick of it [F58 interview].

Loss of independence, forced role reversal and inability to perform household chores to a previous standard all combine to increase the feelings of loss experienced through having chronic pain. One patient concluded her diary with the following summary:

One of the worse things I experience through this pain is guilt. I feel guilty when I don't interact with my family. I get on edge when the pain is bad and I just want to be left alone, I feel guilt when I lay down because it means I'm not doing any housework which equates to me not pulling my weight around the house and since I gave my job up I'm not bringing any money into the house [F56 diary].

6.4.3 Intimate times

Sexual relationships were discussed by two of the female patients, each in sharp contrast to the other. One patient had been married for many years and within her diary she revealed how de-feminised she felt when chronic pain forced her to abstain from sexual relations with her husband:

It's a pity we have no intimate times, since our sex life stopped when I was 37 or 38. I've missed those times, it used to be nice to look forward to going to bed together and for quite a few years I felt bitter that those times had gone. It was difficult when I was working and mixing with females when talk of that nature was mentioned. I had to pretend my life was full in every sense and it made me feel less of a woman. I felt I'd let my husband down and had a recurring dream he was leaving me because he was having an affair. I still have these dreams but not as often now [F56 diary].

For this extract it can be seen that she felt bitter at being unable to share a normal sex-life but it also spilled over into her working life where she felt she had to pretend that she had an active sex-life. The effect of chronic pain on both femininity and masculinity issues is another area of research that this study cannot address but would lend itself to future phenomenological exploration. In contrast the female patient who had just recently become engaged and was planning a second marriage spoke with joy during her interview of the physical side of her forthcoming marriage as well writing within her diary how much she enjoyed physical contact with her partner: “*Do so love having a cuddle at bed time*” [F58 diary]. Within the literature there is little research into effect of chronic pain upon sexual relationships. Again partners appear to become more tolerant the longer the marriage has lasted, however, this is an assumption based on very small numbers. Despite the small numbers though it has to be acknowledged that sexual activity is an issue for patients with chronic pain. Both these patients felt comfortable enough with the process of writing a diary to reveal a topic that even in today's enlightened culture patients and health professionals still find difficult to address without embarrassment. It is an issue that those working within chronic pain clinics need to be aware and consider addressing within pain assessment as routine practice. Notice that these comments were both taken from diaries where the patient felt comfortable enough to express these more emotional and personal issues.

6.4.4 Feeling helpless

There is an abundance of literature that examines the relationship between mood and chronic pain (Schaefer, 1995; Sofaer and Walker, 1994; Bowman, 1994a, Bowman, 1994b). Living in constant pain can cause a lowering of mood, irritability and a feeling of helplessness within couples. Through both the interviews and diaries patients often spoke of their partners getting upset because of feeling helpless in the face of chronic pain:

You know I've actually come down stairs when I've been really, really bad and I've actually caught John (husband) crying, because he feels useless [F37 interview].

This feeling of helplessness in partners can result in short temperedness and the same patient later describes how her husband becomes irritable. She feels this is as a direct result of her chronic pain and the way in which it has affected both their lives:

...but he loses his temper a lot and he bites quite easily, which is not him and I told him to ask someone to talk to but he says "no, no, I'm all right". But I think he does need to talk to somebody and when I try to talk to him he says "shut up, I'm all right" [F37 interview].

Being irritable and short tempered is a common feature within each of the patients' reflections of their chronic pain lived experience:

Unfortunately when the pain is this bad my mood goes like this and I also tend to get angry at everyone and when anger sets in I am better off where I am now (in bed) an' the children away from me as I tend to shout at them for no reason at all [F37 diary].

And then, well, you're bound to have off days aren't you? So I just stay in the house so nobody sees me cranky [M48 interview].

This one particular morning I had had enough. She (wife) said “there’s your tablets” and she didn’t mean anything, and she said “there’s your tablets” and I just grabbed them and threw them across the room...Of course Sharon just walks away. I think she counts to ten in the other room, but ...no matter what I say to her, she just takes it, water off a duck’s back, which is good [M58 interview].

6.4.5 Understanding and consideration

‘Understanding’ that patients perceive their partners as demonstrating is illustrated within these extracts. Patients are allowed to remove themselves away from the family unit where their bad temper may cause further distress to the family. Despite apparent violent reactions to frustrations caused by chronic pain partners understand and “put up” with bad temper, irrational behaviour and rudeness.

A sense of understanding from partners is clearly in evidence within both diaries and interviews. It is possible that the understanding received from the partner is returned in the form of consideration from the chronic pain patient. Consideration for partners is shown in many ways too. One patient whose sleep pattern was greatly affected by his pain spent long periods of the night downstairs to ensure that he didn’t disturb his wife:

Go to bed, lie on one side, lie on my back, oh that’s no better, but I try and stick it for a bit, the only alternative is to turn on this side, which is the bad side and I now if I turn on that side, the pain’s there, but I try and stick it out. But no, it’s no good, and all of this is keeping Sharon awake [M58 interview].

Within the diaries and interviews are patients’ narratives not just detailing life with chronic pain but great love stories which show compassion, care and understanding. The strength of this love is illustrated in the following extract which shows that life, despite pain, can still raise a smile:

...my husband and I have a really good laugh. We laugh at ourselves. When we get up in the mornings and he says “how are you?” and I say “fine, how are

you?” “Great” and he’ll say “just been round for a jog”. And I’ll say “didn’t you wait for me?” “No. I didn’t think you would be up for it this morning”. You know. A load of cods wallop! [F56 interview].

6.4.6 Lost dreams

One single man, during his closure interview, showed photographs of his sister’s children and spoke wistfully of what his hopes and dreams once had been:

I would like to have hoped I was in a steady job, my own little house, perhaps married, and perhaps children, like my sister ... Yes, I think that’s what’s missing in my life [M37 interview].

6.5 Discussion

The seven dominant themes identified through an analysis of the effect of chronic pain on relationships with spouses or partners revealed varying behaviours and emotions and provided a glimpse into the effect that living with chronic pain has on relationships with spouses/partners. The themes identified were labelled: “considering myself lucky”, “feeling guilty”, “intimate times”, “feeling helpless”, “understanding and consideration” and “lost dreams” and explored the effect of chronic pain on relationships with partners as perceived by the patient and recorded either in their diary or recorded at interview. There is literature which explores family relationships and chronic pain (Kemler and Furnee, 2002; Snelling, 1994) and also literature which examines relationships within families when affected by a chronic illness (Yun *et al.*, 2006; Fiese and Wamboldt, 2003) which could be considered transferable as chronic pain is a condition which people have to learn to adapt to, as well as more specific studies which consider family relationships and intimacy of women with chronic pain (Smith, 2003) and living with a person who has chronic pain (Rowat and Knafl, 1985). A more recent study (Newton-John and Williams, 2006) investigated patient-spouse interactions in chronic pain using both quantitative and qualitative methods and concluded that although their study has advanced understanding of patient-spouse interactions it also under-represents the complexity of those same interactions. This study had not aimed to explore the relationships between spouses but

within the analysis of the lived experience of chronic pain it became obvious that relationships were affected both positively and negatively by the phenomenon.

Positive emotions and behaviours within the relationships were labelled within the category “considering myself lucky” and “understanding and consideration”. Partners were frequently supportive, helping with household chores, looking after the children and helping with activities of daily living such as hygiene needs. It was for these reasons that the female participants often considered themselves lucky whereas the male participants did not speak of luck but felt frustrated by not being able to fulfil their perceived role.

Understanding and consideration was a common theme throughout the interviews and diaries. Patients spoke only well of their spouses, with one patient, newly engaged to be married, although expressing deep love for her partner also concerned that he would be able to “cope” with her chronic pain. Coping with pain appears to be not an individual concept limited to just the chronic pain sufferer but spouses were also seen to be using coping strategies. One patient [F37] ensured her husband went out for a drink with friends at least once a fortnight; this coping strategy was enforced by the patient onto the husband to give him breathing space and time away from being main carer to both herself and their children.

This form of dependence and role reversal became the reason for lowered mood incorporating feelings of helplessness, guilt, frustration and anger. Frustration was linked very much to not being able to fulfil their perceived role within the marriage. Women felt guilt at not being able to do the housework adequately, if at all, whereas the male participants expressed frustration and anger at not being able to perform do-it-yourself tasks which they felt was their domain. Role reversal was only acceptable if there was a “trade-off” so when one female patient was still working it was acceptable for her husband to prepare her evening meal, once she retired from working because of her chronic pain problem she felt guilty that he still needed to cook for her. Interestingly there was no single comment that partners felt frustrated or angry that the partner with chronic pain was not fulfilling their role, there was no evidence of disharmony either

within the diary contents or the interviews despite there being evidence in the literature to demonstrate that marital discord is positively linked with chronic pain (Cano *et al*, 2004). Each patient seemed to be in a stable caring relationship, although this study did not incorporate interviews with family members, so this could not be verified independently of the respondents' accounts.

Sexual relationships were only alluded to by two of the patients, both female, although it is possible that perhaps if the male participants had been interviewed by a male researcher they may have felt more comfortable at discussing this topic. As illustrated in the analysis it was two extremes: one patient abstained from sexual relations because having intercourse increased her pain, the other patient found her new sexual relationship both comforting and relaxing. Smith (2003) in her study interviewed 25 women and some of their family members, including spouses, using a narrative ethnographic qualitative research design identified three patterns of behaviour, one of which was labelled "loss of sexual intimacy". The loss of sexual closeness results in a physical as well as an emotional distancing and further increases feelings of isolation and guilt.

The final theme in this section is an extract from a single man, which appears wrongly placed but this young man feels that having chronic pain has prevented him from finding a wife and therefore his chronic pain had destroyed his hopes and dreams of being happily married with a home and family of his own. Lost dreams and regrets become part of the negativity of living with chronic pain whether patients are yearning for times past and activities that were once easily achieved to hopes that they once held but can no longer have as they cannot see how those hopes and dreams could fit into a life with chronic pain.

6.6 Patient/friend relationships

Friendships were not reflected on in much detail in any of the transcripts however where there was mention of friendship or of spending time with friends it was enlightening but although each extract is unique it cannot be considered to be thematic.

Having friends visit caused a variety of responses, some patients were pleased to see their friends: “*Seen Brian it was good to see him*” [M48 diary] whereas for one female patient the unexpected arrival of friends was not welcomed:

Unfortunately a couple of our friends arrived but I just had to stay in the conservatory until the pain eased, they didn't stay long [F56 diary].

In sharp contrast another male patient recorded in his diary how he used his friends to distract him from the pain:

Friends visited with whom I watched the snooker final which proved to be a good pain distractor [M74 diary].

Whilst another patient utilised her friendship to occupy her time and give her a reason for going out:

Up early to take Rhian to Prestatyn market to set up her stall – Posh Wash Soaps. It looks really good. She has been doing this for a month now. I will help her occasionally – will do me good to get out! [F58 diary].

Another very descriptive and reflective account taken from one female patient's interview highlighted how chronic pain can prevent socialising with friends and then cause feelings of guilt:

Well one of my friends, well actually she's my best friend, she was going to come round last Thursday but I rang her and said I'm going to Amy's – that's my daughter, I said I wanted to clean cos I can't go on Friday, she said okay and I said will you be in this afternoon, and she said yes and I said I don't know how I'm going to feel but regards the pain – she does understand – and I said but when I come home, I said, if I feel okay, I will give you a ring and you can come round for coffee. Well when I got home from Amy's I was in terrible pain so I just

didn't ring her. And I feel so guilty, cos she's just found out she's going to be a grandmother and I knew she wanted to bring the photograph round of the scan ...and I wanted to see it and I couldn't, can't, I just can't be bothered to listen to anyone talk when I'm in that kind of pain [F56 interview].

This final extract taken from a patient's diary illustrates how one patient compared her life of chronic pain to the "normal" life her friend enjoyed and found her own life wanting:

My friend came for coffee and I wasn't in pain!! She went to Alton towers last Monday. Last night she went to the theatre. She's off to have lunch out today, out tonight and off to a late afternoon wedding tomorrow...Hearing of my friend's social life makes me realise what a normal life must be. I'm a little jealous [F56 diary].

6.7 Discussion

Friendship and the social activities that are frequently associated with it are important entities in anyone's life. Human beings are social creatures and isolation is sought by only a few. For these patients friends are either welcomed as a distraction or considered an intrusion when pain is severe. The latter has the potential to alienate friends and produce an isolating effect which adds to the negative experience of living with chronic pain and gives the patient a further cause for guilt.

Avoiding friends or having to change social arrangements because the patient was having a "bad" day also adds to the frustration of living with chronic pain. This study does not consider the impact of changing social arrangements on other people involved in that same arrangement such as a partner or child although there are studies that do (Cano *et al.*, 2004) and conclude that the adverse effect on others can lead to stressful marital interactions and poor family functioning, which in turn increase psychological distress.

Comparing one's own life to someone else's is not always a good thing. The old adage "the grass is greener on the other side" serves as a warning that what we see is not always what it seems. Within this study the one reflective diary account where a patient compares her own social life with that of her friends brings an admission of envy. Although she tempers the word jealous with the prefix "little" it is a poignant reminder that chronic pain affects all areas of her life.

6.8 Conclusion

This chapter has explored the lived experience of chronic pain through an examination and analysis of the relationships enjoyed by the patients in their everyday lives. Relationships whether with children, grandchildren, spouses, partners or friends are all affected through the experience of living with chronic pain. The disabling effects of chronic pain appear to influence relationships with children preventing parents from enjoying what is considered to be normal activities such as attending a firework display. Being unable to partake and enjoy social engagements whether with friends or family has an isolating effect which leaves patients feeling sad, angry and depressed as well as guilty. Having regrets for lost dreams and hopes as well as regretting how the pain limits physical activity contributes to a feeling of hopelessness and helplessness. Despite all of the negative emotions expressed by the patients through their interviews and diaries there were also examples of positive emotions. Some patients considered themselves lucky in their choice of spouse as the spouse had taken on role of carer without complaint. Role reversal was a common occurrence amongst couples which although frustrating for the patient and often causing more feelings of guilt illustrated the supportive and caring relationship within marriage. The role of carer was not limited to spouses alone; there were examples of children performing caring acts to support a mother with chronic pain although this was more apparent in one patient's data than in any others (see chapter 7 for case study).

The diaries and interviews also revealed how living with chronic pain affected spouses and children. Children would get upset because parents were unable to join in family activities whereas spouses could become bad tempered or frustrated at being unable to do

anything to help their spouse in managing the pain. Further research into living with a family member would be beneficial in identifying how partners could work together to develop joint coping strategies.

Chapter Seven

The lived experience of the perceived effect of chronic pain on one family: a case study

7.1 Introduction

The previous chapter explored the patient's perceived effect that chronic pain had on their relationships with families and friends. This chapter explores just one patient's interviews and diary to illustrate how living with chronic pain can adversely affect relationships within families through the changing of "normal" roles to accommodate the pain experience.

7.2 Social history

Within the sample, one patient [F37] suffered back pain and although had experienced some form of back pain since childhood, it had been exacerbated through suffering a separation of the symphysis pubis during the late stages of pregnancy with her youngest son some five years previously. This lady first came to the attention of the hospital's Pain Service nurses whilst she was an inpatient on the antenatal ward, where she had been admitted for treatment of the acute pain caused by the separation of the symphysis pubis. Following delivery of her son she continued to experience pain which became chronic by definition, she was then followed up within the Consultant pain clinic before having her care transferred to the nurse-led clinic initially for pain management using TENS.

For the purpose of this chapter this patient's personal circumstances need to be described. This lady had been married for several years and lived with her husband, two sons, aged five and nine years respectively and also her husband's step-grandfather. Her own family lived in Yorkshire and although there was contact it was not on a daily basis. Neither she nor her husband worked, and the grandfather contributed to the financial cost of running the home.

The first interview took place in a private room within the ward which had been utilised by the orthopaedic multidisciplinary team to see outpatients. Each single room served as

a clinic room with a desk, chairs and an examination couch. The desk was positioned at an angle against the wall and the two chairs were positioned at an angle facing each other, by the corner of the desk. This allowed space for tissues, a jug of water and glasses and the tape recorder to be placed on the desk. The tape recorder was plugged into the mains electricity- ensuring battery failure was not a concern.

The interview commenced with pleasantries and chit-chat, with the two of us discussing the School of Nursing and my new role within the school. We were provided with a hot drink by the muscular skeletal multidisciplinary team coordinator and the interview commenced with me asking her how she felt following her last clinic appointment when she had told the clinical nurse specialist that she was not feeling very well. Her current complaint was of pain in the abdomen for which her GP had prescribed antibiotics which had then resulted in her developing vaginal thrush. When asked directly about when her back pain had first started she gave details of her difficult pregnancy with her second son:

Well, er, I've had it on and off all my life but I just put it down to lifting wrong and then when I got pregnant with Sam, from seven weeks in I was in horrendous pain, constantly, then at 33 weeks they brought me in cos my blood pressure was high, well at least that's what the midwife said but I think she just wanted me in because of the pain really. Mr. Woods (obstetrician) thought it was a pelvic something or other separating of the symphysis in other words and he said it would go after your baby is born but it just got worse and worse...

7.3 Relationship with husband

Throughout the first interview it became clear that her husband had taken on the role of main carer for both the children and F37. He had finished work to enable him to take on the caring role:

But yes he's been wonderful (silence) but I feel awful because he's had to give up work now, feel like I've deprived him because he's always been a hard worker, never taken sick days at all and now he's permanently off working.

Her concern for her husband was further reflected when she described how she felt it was important for him to go out and have something of a social life:

I can see at times it gets to him, stuck in the house, and he's stuck in constantly, I kick him out at least once a week to his friends, and he goes, once a fortnight, he takes the oldest to dancing competitions. I make sure he gets out but it's still not fair on him really. No, but he says "you don't have to worry about me, it's you you should be worried about but I say "no".

The relationship with employment and chronic pain has been the subject of many debates and poorly managed chronic pain accounts for 208 million days lost from work within the United Kingdom (British Pain Society, 2004b). Secondary gain is often referred to within chronic pain management and alludes to the issues that some patients may actually gain from suffering from chronic pain for example if a patient is in a low paid, thankless, job, then being retired from work on ill health grounds (i.e. chronic pain) and being able to claim benefits that still allow the patient to live in similar circumstances, than there is potentially no good reason to return to paid employment. Similarly if a woman feels starved of affection/attention and it is then given because she complains of pain then there is potentially no reason for the pain to resolve. Although secondary gain within a chronic pain context is a well documented phenomenon (Main and Spanswick, 2000:68) what is not well researched, and would be an area for further investigation, is whether sufferers' spouses achieve secondary gain.

John, F37's husband, had resigned from his job in order to care for his wife and young family. The change in his role is clearly shown within both initial interview and diary:

Kath: Who does the cooking at home?

F37: John. I haven't cooked since Christmas. I was cooking at Christmas and I was taking the turkey out of the oven and I passed out. And luckily, I don't know how, I went one way and the turkey and tray and all the oils went the other.

Kath: Who does the housework?

F37: er John does it now. I do the odd dusting and that. I used to love me Sundays, I'd save the ironing and do two or three hours of me ironing but I can't even stand five minutes of ironing now, even sat down I can't. So now it's a case of iron when we want... But I do potter about. Things he won't do, like the bathroom. He won't – I don't think men know what cleaning the bathroom is anyway, they make the worse mess in the bathroom specially with toilets. You know, I clean that every night, even if I'm in severe agony I manage to get the disinfection wipes and wipe it round and brush it down and that.

This change in the traditional role of husband from going out to work to being a “house-husband” who cooks and cleans takes on a further dimension as he looks after his wife and assists her with activities of daily living:

I have to rely on others to help me to do things – like my husband had to help me undress [diary]

Took morning medication and with the help of my husband I managed to get out of bed and into the sitting room [diary]

Had a shower to try and ease the pain but unfortunately I passed out in the shower. Luckily my husband was in the bathroom with me [diary].

Taking on the role of carer, house husband as well as husband is a difficult role to adapt to. Within her interview and diary transcripts F37 shows insight into understanding how this change in role is affecting her husband:

He is slowly losing his temper...

Despite all, however, her husband understands and believes her pain and distress:

And John knows if I cry then it's real bad [interview]

Dependence upon spouses is not unusual within relationships. Dependence can be seen as a woman expecting her husband to be the person responsible for changing an electric plug or washing the windows, whereas the husband may expect his wife to do the ironing. Household tasks, roles and duties are assigned within a relationship during its early phase and adaptations are made as time passes and the strengths and weaknesses within that task allocation becomes more obvious and as the relationship develops. The arrival of children alter a relationship from that of husband and wife to that of parents and the shared work that arises from the birth of offspring will similarly alter roles and responsibilities within a marriage. Chronic pain, however, can alter relationships quite profoundly. Within her interview F37 expresses how her husband limits her independence, through his concern for her, which then has the effect of forcing her to become more and more dependent on him:

F37: And he won't let me drive just in case I pass out, even though Dr Knowles (Pain Consultant) says it's okay to drive as long as I'm supervised, but its been three years, got myself a new car and not driven it. I miss the independence of that, not being able to jump in the car and go. Like through the summer I can't see the harm in driving to the local shop but he won't let me. Well, he's got my best interests at heart, I suppose (pause). I know....But I can't stay mollycoddled all the time. I keep telling him but he won't listen.

Kath: Do you feel as if he's overprotective?

F37: In a way, yes, yes

Kath: Does that make things easier for you or worse?

F37: (sighs) When the pains really bad it's easier but when I feel like I want to get up and about then it makes it worse cos he'll be saying "well, sit down, relax, sit down", you know. Like last week I started to feel a little better towards the end but he still wouldn't let me out of bed until Monday, you know, every time I got out of bed he'd say "where are you going?" "Just to the toilet". "Go and then get back in bed". You know I think, well, enough is enough, you know"

The strain of living with a spouse with chronic pain is illustrated by the following excerpt, taken from the interview transcription:

You know I've actually come downstairs when I've been really really bad and I've actually caught John crying, because he feels useless and the Granddad whenever I come in the Granddads crying even if I've just been in casualty for two hours, he's crying his heart out cos they've got to a point where they're frustrated now because of the pain [interview].

This clearly shows that not just the husband was affected by his wife's pain but her repeated admissions to the casualty department also affected her husband's grandfather. The grandfather had also taken on some of the role of carer within the household as is illustrated by F37's reflection on the reasons why her husband had resigned from work:

It's unfortunate him having to be off work but its not right but his old place were getting a little funny and the doctor suggested, my GP suggested, you know enough's enough, you know, you can't carry on like this and the granddad can't carry on coping anymore cos he's, what, seventy six now [interview].

7.4 Relationship with children

Following the delivery of her second child the acute pain within the symphysis pubis did eventually resolve however her back pain became more chronic in nature. The fact that she felt all her problems stemmed for the birth of her youngest child was highlighted in her first interview:

Dr. Manning thinks that were down to the amitriptyline I were on so I still notice its (pulse rate) still fast even though I'm on alderlone, I'm on the 25 milligram strength, and the atenolol, but I haven't mentioned it to my doctors that its still fast, I mean my pulse, probably I take it two or three times a week and its still over 120 on average and that's if I've just walked down the stairs or even got out

of bed (laughs). I notice it more. And that could be to do with the dizzy spells I don't know and the passing out and that. So – (pause) all this from having a child [interview].

As the interview progressed it became more and more obvious that she felt her back problems and ill health stemmed from the birth of her son. She began to recount how she was saddened by the fact that her youngest child had not known her active and in good health (see chapter six) and then the conversation focussed on her youngest son:

...a child has started to bully Sam as well. Turned round to him and said "my mummy told me that you caused your mummy's problems, that's why your mummy's so poorly". And I think that's horrendous. If I find out which mother it's off I'll kill her. I will because she has no right to say stuff like that. She was probably talking to her husband really and didn't know the child was around but she still has no right. Not in front of the child or she actually should say "well but don't say anything to Sam". Because that's going to make him, or if this carries on, God knows what effect it's going to have on him [interview].

Although F37 questions what effect this is going to have on her youngest son, she actually answers her own query later in the interview:

Many a time he's cried when I've been in pain and he said "I'm sorry for doing this to you mummy". I said "you've done nothing to me darling, it's something what happened to my body not your body. You didn't do anything. It happened just as I was carrying you. Not your fault. I wanted you. It's not your fault". But he's still "I'm sorry mummy" [interview].

This heart rending excerpt was made all the more powerful by the apparent lack of insight F37 appeared to show into the devastating effect this was having on her five year old son. For a child to feel he is possibly to blame for a parent's illness or condition caused me to have a judgement reaction and it is possible that this "blame" that Sam is

already expressing will have far reaching effect into later childhood and possibly adulthood (Koutantji and Pearce, 1998).

The adverse effects of having a mother with chronic pain were not just limited to the youngest son:

F37: He's (oldest son) very affected by my condition. He goes; - I don't know whether you've heard of it? - to the young carers group

Kath: Yes

F37: Yes, he goes there now and they have done wonders for him. Since he's done dance lessons and gone into competitions his confidence has come back up. His first words when his dad picks him up from school is "how's me mum and has she been in hospital today?"

This child was nine years old at the time of this interview and from this extract it can be illustrated that his primary concern was focused on whether his mother would be at home or not, although F37 considers that this is partly to do with the fact that her son is aware that she has tried to take her own life:

But then again he's seen the suicide attempts as well so that plays on his mind as well [interview]

The effect of chronic pain on mood is well documented (Sofaer and Walker, 1994) and F37 was aware that her mood was lowered and adversely affected by exacerbations of the chronic pain. She acknowledged this within her diary:

Unfortunately when the pain is this bad my mood goes like this and I also tend to get angry at everyone and when the anger sets in I am better off where I am now (in bed) and the children away from me as I tend to shout at them for no reason [diary].

Regrets were clearly demonstrated within the interview and diary, particularly regrets about being unable to enjoy family life as she felt it should be. Attending firework displays through an exacerbation of her pain had to be cancelled and the children went with their father instead:

I even missed out on going to the local bonfire and fireworks display with my family that saddens me as I seem to miss a lot of my children's activities and am missing out on their growing up, which is irreplaceable [diary].

Having health professionals believe a chronic pain narrative is discussed in depth in chapter ten, however, the effect of belief is further expounded when the effect of 'faking' chronic pain or its associated problems on the family unit is considered by F37 within her interview. She clearly questions why anyone could believe she was faking a faint, caused through severe pain, when it had such devastating effect upon her children and husband:

Because that's how they make me feel at times, like I'm faking, and I think why would I fake? Why would I make myself pass out? Why would I do that to my children, my husband, my family?

The notion that a health professional can infer that a patient is 'faking' chronic pain illustrates that the health professional is querying whether the patient is telling the truth. The truth with chronic pain is quite simply it is "what the patient says it is" (McCaffery, 1968:95) however the second aim of this thesis explores the effect that health professionals can exert over patients with chronic pain if they feel that their pain experience is not believed and this idea of feeling disbelieved is explored in the next three chapters.

Through focussing on one patient's narrative of her chronic pain experience and the effect she feels it has on her husband and children it can be seen that the uniqueness of an experience must be taken into account when caring for these patients. Human experience cannot be categorised and each person will cope with life experiences in their own way,

often utilising skills and strategies learned through their own childhood. The effect of living with a mother with chronic pain is an area for further research and through the powerful images provided through the interviews and diary of this young mother and wife it would be interesting to be able to interview these children when they reach adulthood to determine if the effect is as great as this chapter purports. In addition to this, research into how children of parents with chronic pain cope themselves with pain would also be a further area for future research.

7.5 Conclusion

Chronic pain, as illustrated within this case study, has far reaching effects, which affect not just the sufferer, but the entire family. It can steal from a person roles and responsibilities that are often taken for granted; the ability to play with young children, partaking in family activities and functioning as a wife, mother and housewife whilst allocating those roles and responsibilities to others, a child as carer, a husband as househusband and a wife who feels *"like a burden"*.

I cannot stop my thoughts from wondering what a better life my family would have if they did not have to take care of me [diary].

Section 3: Examination of the effect of ‘being believed’ by the health professional on the patient with chronic pain

Incorporating

- Chapter Eight: The language of pain: the rhetoric
- Chapter Nine: Living with unseen pain
- Chapter Ten: Believing the patient with chronic pain

Chapter Eight

The language of pain: the rhetoric.

8.1 Introduction

The second aim of this study was to examine the effect on the chronic pain patient of 'being believed' by health professionals. This was approached through an exploration of the mechanisms by which the patient achieved some measure of credibility about their claimed pain experience. Being given credibility appeared to be of great significance to the patient and feeling that they were not believed increased frustration and in some instances appeared to be a barrier to pain management (see chapters ten and eleven). The interviews and diaries provided a wealth of thick description which through analysis provided an insight into the lives of eight people living with chronic pain whilst ultimately deepening our understanding of the experience and how gaining credibility for that experience was accomplished. Whilst reading and re-reading the transcripts of the interviews and diaries and repeatedly listening to the audio-tapes lead to the inference that there was a barely conscious "pain language" employed by the patients to describe their pain but that it was also used to give emphasis to their pain experience and potentially increase credibility. It was this use of pain language by the entire sample that created the discussion within this chapter and the following research questions were generated:

- How do the patients in the study describe their pain?
- What rhetorical devices do they use and to what effect?

Without subjecting the transcripts to advanced linguistic analysis the hermeneutic focus of this thesis is maintained where rhetorical devices are considered in more detail.

Through the method of hermeneutics it was possible to explore the "beingness" of the human chronic pain experience through exposing hidden meanings, a technique with which to explore lived experience whilst concentrating on ordinary language. This then is based on the assumption that for humans the world is primarily experienced through language and that language is a vehicle for understanding and knowledge (Byrne, 2001a).

8.2 Language

Language is defined as a system of sounds and symbols which is used for communicating thought, and is particular to a nation or people (Collins, 2005: 331). Words are the primary medium used for communication within language and can be either conveyed through sound or graphic symbols (Corbett and Connors, 1999:337). Within a study of rhetoric, words have more importance than grammar. The English language is a composite or hybrid tongue based on groups of vocabularies, with each group reflecting great historic change in the life of the English-speaking peoples (Davidson, 1968: 242). The English language, therefore, draws on Celtic, Latin and Anglo-Saxon origins. Pain language perhaps would be better phrased as the language of pain – there is no separate language as such that communicates pain but the use of language in such a way can express pain in a way that is common to its sufferers.

Within the mechanics of language there are many linguistic devices which are used to create effect, invoke atmosphere, gain sympathy and understanding whilst fulfilling the basic objective of language: communication. The pain language employed by the patients within this study used a variety of linguistic tools which together formed the powerful rhetoric that was found within the data.

8.3 Rhetoric

Rhetoric is conventionally understood as the art of speaking or writing and is used to give persuasion and effectiveness to whatever form of communication in which it is employed (Davidson, 1968: 2). Although rhetorical style might employ logical argument it is frequently designed to appeal more to the emotions than to reason (Wyld, 1958: 1015). Rhetorical styles are routinely employed to persuade and convince hearers of the speaker's legitimacy to make certain claims and perhaps this is why it has been employed so successfully by the patients within this study. Rhetoric is used to inform, persuade or motivate an audience (Corbett and Connors, 1999: 1). The audience in the context of this study being the interviewer, however, as the patient was fully aware that the interviews and diary were being used for research purposes the audience could be construed as being

those that would be party to the research. Frequently, patients consented to participate in the research because they hoped that the research could in some way help others. This potentially widens the 'audience' to any output for the dissemination of the research. Within the analysis of the transcripts generated from the patients' interviews and diaries the use of language and rhetoric could be seen to be a powerful tool which the patients used routinely to add emphasis to their experience as described. Given the length of this experience of chronic pain it could be argued that such language had become habituated and so employed regularly to communicate the experience to wider audiences – friends, family and health professionals in this therapeutic domain.

There are four forms of discourse: argumentative, exposition, description and narration. The patients used description and narration in their interviews and diaries. One presupposition is that as the patients knew me as their pain nurse and as I had invited them to participate in the study, they would have assumed that I already believed their pain experience, and therefore I did not need convincing of the pain experience through argumentative discourse. Description and narration, however, is still used to persuade others, and the means by which this is done is through *logos* (by appeal to reason), *pathos* (by appeal to emotions) and *ethos* (by the appeal of personality or character) although whether one of these means is used or all three is very dependent upon the circumstance and the audience (Corbett and Connors, 1999:32).

Figures of speech are used to give style to discourse either through clarity, through appealing to the emotions or through providing imagery for the imagination to develop. Corbett and Connors (1999: 378) state: "...figures can render our thoughts vividly concrete, they help us to communicate with our audience clearly and effectively; because they stir emotional responses, they can carry truth...; and because they elicit admiration for the eloquence of the speaker or writer, they can exert a powerful ethical appeal". It is the figures of speech which are used by the patients as they describe their pain and the effect it seeks to achieve which will now be discussed.

8.4 Metaphors and similes

A metaphor is defined as an implied comparison between two things of unlike nature that yet have something in common (Corbett and Connors, 1999: 396) whereas a simile is an explicit comparison between two things of unlike nature. Within this study there were many examples of both metaphors and similes which patients used to give strength to their descriptions of the chronic pain experience whilst seeking to develop credibility with health professionals. Given the unique and subjective nature of the pain experience metaphor may seem an intuitively apt linguistic device for “sharing” the experience by means of comparison.

Metaphors are an effective and powerful use of language adopted to convey meaning (Kangas *et al.* 1998) and although they do not add facts to a description they add depth of meaning to the understanding of a phenomenon, through the use of imagery. Imagery within language utilises words to conjure up pictures, thoughts and feelings by association or comparison with something else and is defined as a figure of speech (Collins, 2005:398) and is often used to gain understanding through appealing to other senses, emotional, sensory and imaginative. The phenomenon being described becomes the context for the metaphor and, as it is the chronic pain experience that is being described, the influence of culture and beliefs have to be considered. One of the advantages of having selected a convenience sample from a nurse-led pain clinic, based within a District General Hospital within Wales, is that it provided some definition to the culture of the participating patients: all were white, of the Christian faith and had lived in Wales for at least three years. Culture is primarily transmitted through language (Waddie, 1996) and De Saussure (1959:7) states that speech is more important than anything else in establishing a generic culture.

There were many examples of the use of metaphors and similes throughout the transcripts from the interviews and diaries. The initial coding used in the analysis was simply “pain descriptors” and each time any reference was made to the type or severity of pain it was allocated to this code. This resulted in many single word descriptions, such as

“horrendous”, “excruciating”, “pounding” or “throbbing” as well as more detailed descriptions:

I'm just getting deeper and deeper at the moment. You know – deep into pain [M58].

Using *NVivo* it was possible to generate reports from the allocated codes. In this first stage a report was generated which provides the allocated patient identification, the number of passages relevant to that code and the number of characters used within the passages. From this report, further exploration was needed as it could be seen that patients used similar language with varying themes to describe their pain experience. This is not unusual and was used to great effect by Melzack (1975) in the development of the McGill pain questionnaire. Each of these pain descriptors were then coded into themes which depicted the imagery used. In addition the transcripts were analysed line by line for any use of rhetorical figures of speech.

Metaphors are figures of speech which give depth and power to descriptions and are pervasive in daily living, in language, as well as thought and action (Lakoff and Johnson, 1980:3). Within the textual analysis many powerful images were used to describe the pain experience. Wiklund *et al.* (2002) state that by searching for deep structures in the form of metaphors and similes it is possible to arrive at a deeper understanding of the world of the text and subsequently the world of the human being. The metaphors used to describe the pain experience ranged from imagery associated with fire and violence to religion.

8.4.1 Fire

Two patients used imagery of fire to give clarity to their description of pain. In each case the metaphors were used to describe the pain sensation. A female patient with chronic back pain [F37] described the pain which “radiated” from her back to her hip as being “...like a burning sensation” whilst another female patient who had experienced chronic bladder pain [F56] for many years said: “*The fire from the pain was burning into me*” to

describe the pain she experienced on a daily basis. The visual imagery of fire is used to emphasise the physical sensation of burning which was not literally acquired from a burn injury.

In several instances the word “flare” was used to describe the onset of increased pain. Fire and burning are associated with pain and the patients were using the intense imagery of fire and burning to emphasise the degree of the pain they experienced. Describing pain is notoriously difficult (Main and Spanswick, 2000: 166) over time pain clinicians have been able to categorise certain descriptions to mean certain types of pain. A burning pain is often associated with neurogenic pain (Banks and Mackrodt, 2005: 65) and it is very possible that the patients were indeed literally describing, in their experiential terms, a nerve-type pain.

8.4.2 Religion

Within the metaphors used by the patients to emphasise what it was like to live with chronic pain were metaphors associated with religious belief. Indeed expletives such as “God”, “Christ” and “Duw” (Welsh word for God) were used frequently throughout the transcribed narratives. One patient [M58] said “...*honest to God, the pain is terrible*” where he used an oath to convince the listener that he was not lying about the strength of his pain. The more powerful metaphors were used by one patient [M37] when he described his pain as being “*crucifying*” and then further clarifying it by saying: “*It’s quite soul destroying, really*”. Religious metaphors were used by another patient as he described a pain which “...*throbbed like hell*”. Hell was a commonly used metaphor and another patient summed his pain description by giving a long sigh and then saying “...*well really it hurts like hell*”. This was made more powerful by the sad manner in which it was delivered. The patient appeared resigned and it was the way in which it was uttered as well as the substantive content of the language that gave the words their power. Rhetorical effect relies on the style of delivery as much as the content of the communication for its effect. The metaphor “like hell” is not an unusual utterance within the English language and is often used to emphasise something such as “he ran like hell”

whereas in the context of this patient's chronic pain, you could accept the idiom that he felt his pain experience was like living in hell.

8.4.3 Violence

One patient [M37] used several violence-related metaphors to describe his pain:

But I'm having pain now, it's like a stabbing pain in the stomach

Today I had nasty pain whilst passing water. There is a funny stabbing pain in the end of the penis

Another patient, who had a long history of back pain, described his pain in equally violent terms:

I could feel it ...can't say a knife, a grating thing, a cheese grater – just felt like that...[M74]

Two more patients used the imagery of being kicked to describe how the onset of pain felt with both patients using exactly the same phrase:

*My normal day is I get up about, well, I wake somewhere around half past five, and it's six o'clock when **the pain kicks in**. [M48]*

*And I said I don't use it (wheelchair) much but through the winter I do because I know I can't walk very far because **the pain kicks in**. [F37]*

And a further patient [F58] described the back pain that disturbed her sleep at night as “...a sudden kick of pains”. It is interesting to note that within the Short Form McGill Pain Questionnaire (Melzack, 1987) that “kicking” is not one of the adjectives used to indicate the type of pain experienced whereas both “burning” and “stabbing” are. Language is constantly developing and over generations adaptations will need to be made

to this assessment tool to maintain its resonance within the English language framework and the culture it represents.

8.4.4 Toothache

Several patients compared their pain to the pain of toothache. This is used to great comparative effect as many people will have experienced toothache and therefore it is a means of gaining empathic understanding. However, consider the following quote taken from a patient with chronic foot pain:

It's like hurting now but it's just like a long distance toothache. You know you get one that's just niggling, well that's how it is [M48].

In this example the patient is requesting confirmation of understanding a toothache experience whilst clarifying it by adding the phrase “long distance”. Another female patient with chronic back pain also used toothache imagery:

Pain is just grinding away like nagging toothache [F58].

Note however the accompanying adjectives of “grinding”. This adjective conjures up an image of a relentless onslaught of pain and coupled with “nagging toothache” aims to amplify the effect and gain empathic understanding from the listener. The simile is consistent with the notion that ‘grinding teeth’ stands as a familiar pain-related action but there may be an element of “mixed metaphor” which suggests that compound metaphors can be employed to amplify the perceived effects. “Grinding” analogises a mechanical view of the structure of the body and how it might be experienced.

8.4.5 Building

Initially the following quotes were assigned to a code labelled “growth” but, as a deeper understanding of the language began to develop, growth did not seem to be an adequate description of the patients’ experiences and eventually the code was re-labelled to incorporate the following quotes where patients used the metaphors and associated

imagery of actually building as a verb, rather than a noun. Two of the patients used very similar language to demonstrate how the pain increases and increases: “...and then it would build up and really build up and really build up”, whilst the second patient clarified his building metaphor to compare it to a nightmare: “The pain was building up, building up and it’s like a nightmare,” once again appealing for empathic understanding through the use of a commonly understood phenomenon. Another patient [M37] used imagery from childhood games to demonstrate how his pain builds up until the force of the pain is that great that it becomes destructive: “it’s like a house of cards or a domino theory”. This is a very interesting use of rhetoric as most can visualise the development of a house of cards or a wall of dominoes which then finally collapses, giving an imagery of a crashing crescendo.

8.5 Alliteration

Alliteration is the repetition of initial or medial consonants in two or more adjacent words (Corbett and Connors, 1999: 388) and is frequently used within advertising slogans. Bearing in mind that the patients were using alliteration unconsciously there were examples to be found within the transcripts. One patient [F56] “had pressure pains” whereas another lady [F37] in her diary recorded “getting severe stomach cramps”. The first example gives a better description of the pain with the second only describing the intensity. Repeating words to emphasise the intensity of pain was used in particular by two patients:

...because it’s like nerves tish, tish, tish all in your legs [M74]

...bump, bump, bump, it’s like something pumping the pain in [M48]

The second description is qualified with a simile which also uses alliteration to further increase the effect of increasing pain.

8.6 Hyperbole

Deliberate overstatement or the use of exaggerated terms for the purpose of heightened effect or emphasis is termed hyperbole (Corbett and Connors, 1999: 403; Davidson, 1968: 283). Within the transcripts of both interviews and diaries patients used the word “kill” to give more emphasis to the pain being experienced:

My hip and back are killing [M58].

I'm not going to touch them (crutches) today cos they're going to kill me [M48].

My back's killing me [F44].

Whereas hyperbole was used to great effect within an initial interview when a patient described his foot pain:

...and then some days it's really bad and you think well I'm not going anywhere today, cos it feels as if you're foot's going to jump off [M48].

Of course this is gross over exaggeration as feet do not “jump off” however this use of hyperbole summons up the intense feeling experienced by the patient, the need to rest to ensure that movement does not further increase the pain and also visually conjures up the image of a traumatic auto-amputation. Conversely, however, taken out of context of the interview, the image of a foot “jumping off” can give a humorous image and it serves as a reminder that all language must be experienced within its full context to enable true understanding.

8.7 Personification

Davidson (1968: 285) defines personification as being a figure of speech that places an inanimate object or abstraction with human qualities. Although there were no true examples of this within the transcripts one patient [F56] did address her pain as if it was an individual, almost a separate entity from herself: “...and the pain was going mad” and

also the “*pain went chronic*”. This had the effect of depersonalising the pain as she had not said “I was going mad with pain”. It has the effect of distancing herself from it as if to emphasise that she had no personal control over the pain experience.

8.8 Rhetorical examples

So far the use of metaphors, similes, alliteration, hyperbole and personification has been discussed with examples from the transcripts of the patients’ interviews and diaries. These figures of speech all combine with others, such as assonance, irony and onomatopoeia, to provide language with persuasive, engaging, humorous and emotional qualities. Through the hermeneutic analysis of the language of pain, sentences and phrases have been extracted to illustrate effect, however, the conversations taken from the interviews and the prose within the diaries also provides powerful rhetoric which is also illuminating.

I was also breathless and my heart rate increased and I could feel it pounding in my chest and also my head [F37].

This was a description supplied within the diary where the patient described the onset of an episode of pain and the physiological effect it had. The repeated use of the word “and” gives the reader the feeling of being breathless as well as a feeling of horror.

I’ve always thought it the worse pain possible, cystitis type pain; when you want to bang your head against a brick wall with cystitis. Dreadful. Dreadful. And this is sort of doubly worse because it’s so more acute and it’s there all the time because with cystitis it’s painful but then you have to go for a wee and that’s when it really hurts [F56].

Within verbal rating pain assessment tools patients are often asked to score their pain on a scale of zero to ten, with ten being the worst pain imaginable. The above extract, taken from an interview, shows that for some patients, they are able to classify their pain in this way, having already given their pain experience some thought. This description of pain

also gives an impression of deep frustration through the repetition of the word “dreadful” and the use of the phrase “bang your head against a brick wall”. The length of the sentence also contrives to show how the patient is trying to convince that cystitis is the worst pain possible by explaining that it is a continuous chronic pain which is acutely exacerbated by urinating, however as this was taken from an interview the placing of the punctuation marks were done by myself as I undertook the transcribing of the tapes. Punctuation marks were, however, placed where the patient took a breath or naturally placed a pause which could be verified by listening to the audio tape to ensure that the transcript read as closely as possible to the spoken word or by asking an independent person to read the transcript out loud to allow comparison with the audio tape.

8.9 Stream of consciousness

Stream of consciousness is a writing style used to create the impression that the reader is a “fly on the wall” and is party to the characters’ thoughts or interior monologue. The extracts below were taken from an initial interview with one patient who had chronic phantom and stump pain following amputation after failed bypass surgery:

If it was just this (points to stump), before I knew I had anything wrong (coughs) I could carry on, but it's not that easy, I just can't carry on, it's the pain isn't it? I can't do things I want to do, or even do as quick as I want to. Like decorating at home, something that's got to be done and look at that wall! I could knock a room out in a day one time, you know, and I used to help out with my mate, move furniture, Look do us a favour mate, what are you doing tonight? Do a room for us. Yes, no problem. Next thing I would have a room done out, but now, how am I going to get to that bit, how am I? Stretching, bending, standing. You know it's really depressing like. The jobs I'm not doing at home, I can't do them. I've always been a jack of all trades, doing electrics, plumbing whatever but I just can't do 'em Kath you know. Like if something needs doing on the floor I have to get down, sit on the floor, lean on one hand and do things one handed... You know something drops on the floor. Sharon, can't bend down [M58].

This extract, taken from the initial interview, although not describing the pain directly employs a stream of consciousness technique to give a window into this man's life with chronic pain. The frustration that this patient feels is illustrated through a comparison of what he was once able to do to his present ability. He personalises the conversation by appealing to me directly by name "but I just can't do 'em Kath you know" for understanding whilst almost acting out the scene from the past and the present day. He uses this technique, also with great effect, to illustrate how the pain affects his sleeping:

...but you can't explain to people what the pain is. To me it's this hip now, never mind, I take two kapake before I go to bed now, make sure I keep two back before I go to bed. Have a cup of tea. Half an hour and they've started working. Go to bed, lie on one side, lie on my back, oh that's no better, but I try and stick it for a bit, the only alternative is to turn on this side, which is the bad side and I know if I turn on that side the pains there but I try and stick it out, but no it's no good, and all of this is keeping Sharon awake. I keep trying different ways, turning over; honest to God the pain is terrible. I sit on the side of the bed in the end, I sit there in the dark and I've sat there for over an hour sometimes at the side of the bed. You know. I know Sharon's awake and I say oh well I'll try again. So I get back in, and I say if it doesn't work this time I'm going back downstairs and that's what I do. Back down stairs again, get the crossword, turn the telly on, for the sake of turning it on, which is company, isn't it? Not even watching it half the time, get the crossword out, cryptic, get the brain working, try and really tire yourself out that much, but there's been times I've done that, gone back to bed and been in the same boat again. Because the more you try to get to sleep, the more you can't get to sleep. What shall I think about now? What shall I do tomorrow? Sharon, what's on the agenda for tomorrow? (laughs) you know, well we've got to go here. It's pain again you see. I'm not getting the sleep; I'm really not getting the sleep.

Again he makes use of the stream of consciousness method to bring life to his words. The short, staccato-like sentences used in the first part of the extract give the impression of

someone tossing and turning in bed. There is pathos in the image of the man sitting in the dark because pain will not let him sleep and even humour when he contemplates what he and his wife are going to do tomorrow – the humour is not obvious in this extract, but taken within the context of the whole interview, it has an ironic humour to it as he considers his life to be quite mundane and although he states “*home is wonderful*” he also says that “*it can close you in*”.

8.10 Discussion

The rhetoric used by the participants incorporated various figures of speech: metaphors, similes, alliteration, hyperbole, personification and also a stream of consciousness approach to narrative style. Exploring the relationship between expressing pain and various descriptors is not new and many researchers have published papers on varying descriptors (Gartrell, 2005; Closs and Briggs, 2002), application to people from different backgrounds and cultures (Bates *et al.*, 1997; Bates and Rankin-Hill, 1994) and transferability of validity and reliability across different age ranges (Schuler *et al.*, 2004; Franck *et al.*, 2002) and various conditions (Bergh *et al.*, 2005; Jaraith, 1999).

Melzack (1975) developed the McGill pain questionnaire (MPQ) for use in the assessment of chronic pain which incorporated various descriptors such as “hot-burning”, “stabbing” and “throbbing” all of which were similarly used by the participants within this study, however, other descriptors such as “kicking” were used which is not in the MPQ and therefore demonstrates that any assessment tool which relies on verbal descriptors has to be kept up to date with current use of language and its relevant applicability to certain conditions, experiences and circumstances. Some patients were unable to describe their pain experience simply using terms like “*horrendous*”, “*horrible*” and phrases like “*the pain was killing me*” this apparent inability to be able to verbalise pain is not uncommon (Miller and Newton, 2006; Archibald, 2003) although whether it is the patient’s linguistic skills which are compromised or whether the experience defies accurate description is not known.

Exploring the use of rhetoric within the language of pain and its effect has not been previously explored within the literature, this chapter therefore adds to the body of knowledge that explores language. Language is used to convey meaning, so within that context the patients within this study are using rhetoric to illustrate, convince and portray what the meaning of pain is to them within their own personal lived experience. Pain, it is said, has many meanings to different people depending on their culture and reaction to pain is learned from birth (Gartrell, 2005). To one patient [M48] pain meant life: *“if I didn’t have pain there would be something drastically wrong or I’d be dead wouldn’t I?”* whereas another felt there was religious meaning to her pain experience [F56] *“but I know that God understands the pain and if He hasn’t taken it from me there’s a reason why I’ve got it”*. These two different perspectives of the pain experience can only be shared with another through the use of language.

The invisibility of pain is discussed in the following chapter but this chapter shows how patients use rhetoric and metaphorical language not just to convey meaning but to gain credibility for their pain experience by making the pain visible. Similar findings have been illuminated in men’s descriptions of their experience of fibromyalgia type pain (Paulson *et al.*, 2001) and also women’s (Soderberg *et al.*, 1999). Through using metaphorical language the patients are verbalising their meaning of the chronic pain experience in order to enhance the understanding for the listener. It could be debated whether or not this use of language is purposive/intentional or whether it has been learned as a part of linguistic socialisation. It could be said that language is being learned from within the womb and beliefs and values of particular cultures are embedded into the use of that language. Responses to pain and ill health are examples of vicarious learning and pain behaviour can be acquired through observation of other people’s reaction to pain (Koutantji and Pearce, 1998). Understanding of the pain experience is gained through employing a variety of rhetorical devices with the intent to persuade others of the credibility of the phenomenon. These devices can be employed deliberately to achieve affect or effect but potentially are used almost sub-consciously as a part of linguistic socialisation that has been learned or acquired as a component of each individual’s socio-cultural background. Within a chronic pain context it could be argued that the patients

employ pain language on two planes, firstly as a learned response to pain and its meaning to that individual and secondly, particularly when having to describe their pain to a 'disbelieving' health professional, with a conscious effort to achieve effect and affect through having to persuade individuals that their pain is genuine.

Although only drawing upon small samples phenomenology allows for the exploration of how unique phenomena and the individual experience can be collectively appreciated. It is one of those areas of explanation in which the need for the balance between the idiographic and nomothetic can be understood. It is through the use of rhetoric that the unique qualities of the pain experience can be revealed to others.

8.11 Conclusion

Jairath (1999) states that meaning is embedded in metaphorical language and this can be clearly demonstrated through the language used by the patients within this study who were living with chronic pain. Chronic pain is less likely to be a universal experience unlike its acute counterpart. All people have experienced acute pain and, therefore, empathy for acute pain is perhaps more easily achieved. Patients attempt to describe their pain in terms that will find empathic understanding from others such as likening it to toothache or the pain from a burn which most people have usually experienced.

Metaphors only work when hearers can assume commonality of experience. Patients with chronic pain appear to have an inherent need to have their pain experience accepted as being credible (Clarke and Iphofen, 2005) and through the use of metaphors the patient is attempting to provide the means by which the experience can at the very least be understood. Gartrell (2005) states that verbal communication is a feature of pain expression that allows others to develop understanding; however, as the pain experience is purely subjective patients have to use metaphorical language to offer an alternative interpretation into their own phenomenal world (Czechmeister, 1994). It is only in this way that hearers can "share" the depth of the experience.

There are many papers that examine the language of pain (Waddie, 1996; Sist *et al.*, 1998) and also the varying descriptors that patients use to describe the pain experience

(Closs and Briggs, 2002; Wilkie *et al.*, 2001), these descriptors often being compared to those used within pain assessment tools (Franck *et al.*, 2002) to ensure that there is still some degree of validity and reliability. This chapter has used a different approach and has examined the rhetoric used by patients to describe their chronic pain experience. By applying the principles of classical rhetoric it can be shown that patients used their ‘instinctive’ rhetorical prowess, more than likely subconsciously, to describe in emotive and vivid terms their own pain experience in order to develop credibility, gain sympathy and even therapeutic outcomes whilst trying to make their pain more visible to the audience.

Pain is a highly complex concept with many factors, which have to be understood in their sociocultural contexts, combining to make the perception of the pain experience unique for each individual. Exploring the rhetoric adopted within the language of pain used by patients, with chronic pain, through a hermeneutic approach provides further insight and an even deeper understanding into the struggle that patients must engage with whilst trying to articulate their pain experience. The management of chronic pain remains a challenge for all nursing staff. Patients with chronic pain, however, are presenting nurses with a unique opportunity to share their lived experience by describing their pain through universally understood metaphorical language providing as nurses we are prepared to listen carefully because if as Frantsve and Kerns (2007) suggest that patients believe that good relationships with health professionals are instrumental in their treatment regardless of the aetiology of their pain condition and that patients do report high levels of satisfaction with pain treatments despite unresolved pain then it is a simple and inexpensive method to use – listening.

Chapter Nine

Living with unseen chronic pain

9.1 Introduction

This chapter contributes to the second aim of the study: the effect of “being believed”. One of the themes identified through hermeneutic analysis was “the unseen pain” and this chapter develops that theme using extracts from the patients’ diaries and interviews, supported by relevant literature, to illustrate the everyday challenges and feelings experienced by patients with chronic pain. This chapter demonstrates that the patients within this study were well aware that their pain experience could not be supported through clinical investigations, objective measurements or public visibility which added to the negativity of the chronic pain experience consequently for the nature and existence of their experience of chronic pain to be believed it had to be made more ‘visible’. There were four dominant sub themes which emerged from this analysis: “isolation”, “needing to prove the existence of chronic pain”, “in their head” and “depression” (see diagram 6).

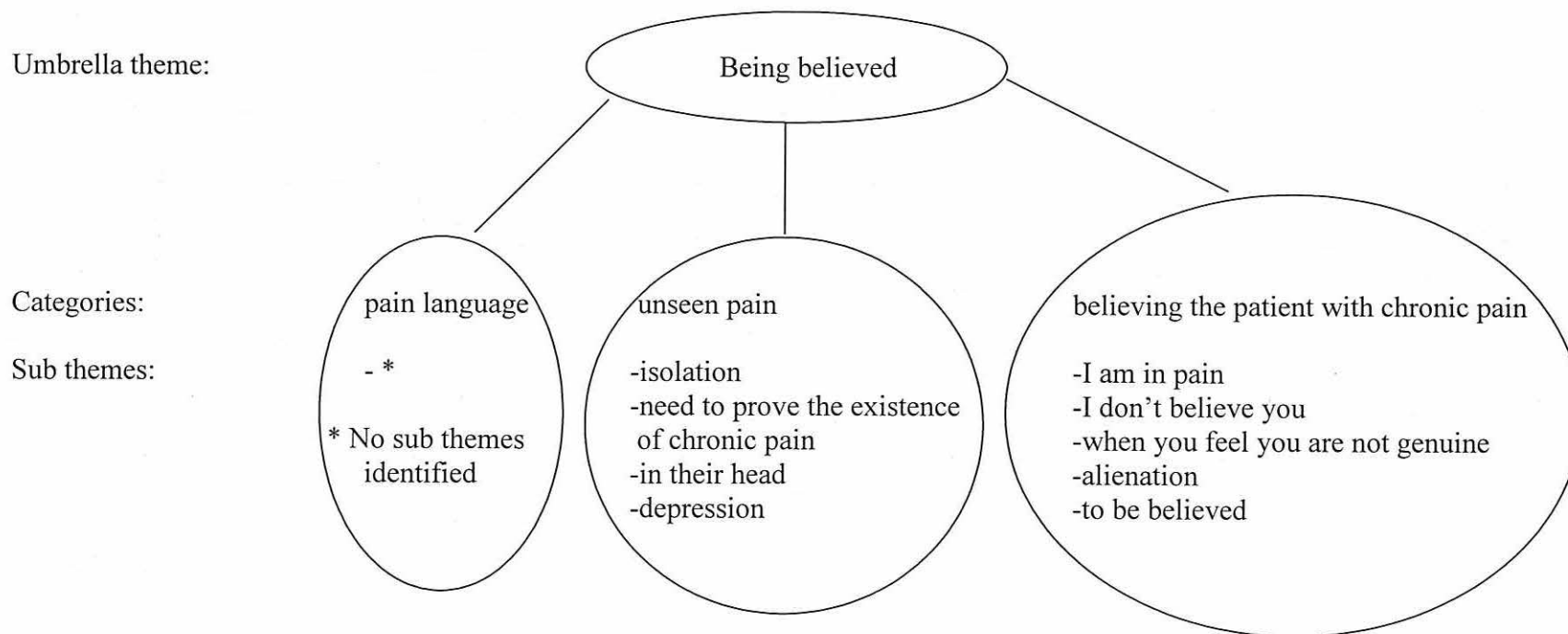
9.2 The unseen pain

The initial coding generated from the textual data gave rise to the category of “the unseen pain” to identify when patients made reference to chronic pain as an “unseen” or “invisible” phenomenon, but further hermeneutic analysis highlights that this invisibility of the pain experience affects many different aspects of life. Further analysis of the texts obtained from both interviews and diaries allocated to this coding revealed further deeper meaning associated with this initial theme of unseen pain.

9.2.1 Isolation

I still have a bit of pride in myself and if I go to church and people have been praying for me and they look at me – I look fine. And I feel a fraud... Please don't say I'm ill because I am not ill, I'm just in pain. And there's a big difference ...so people expect me to be ill so when I walk to church and I look you know good ... I can imagine people looking and thinking "I thought she wasn't very well". It's a problem ... I don't want people to think I'm lying. [F56]

Diagram 6 – Diagrammatical representation of the findings of the effect of ‘being believed’ by the health professional on the patient with chronic pain



This was taken from a first interview with a lady who experienced chronic bladder pain. She had been a regular church-attende and her religion was an important part of her life. Her parish priest had added her name to the prayer list for the sick which although initially giving her support eventually isolated her from the church. The extract illustrates how the invisibility of the chronic pain experience makes her “feel a fraud” and because she does not want to be thought to be lying she no longer attends church. This, therefore, has an isolating effect upon her life and through living with chronic pain she denies herself an activity that she is able to achieve and enjoys but no longer feels comfortable in doing because she looks “good”. Rose (1994b) describes feelings of isolation in chronic pain to be a common factor within her study of patients (n=22) with pain. She states that pain and its effects constitute a totality that invades all aspects of the patients’ lives.

9.2.2 Needing to prove the existence of chronic pain

Thomas (2000) in her phenomenological study of chronic pain identified “the invisibility of pain” as one of her figural themes. Similar to the narratives analysed within her study some patients within this study wished for signs of obvious disability to provide greater credibility:

Needed the loo while I was out and I find it difficult to wait in a queue, if I looked disabled it would be easier and I could use the disabled toilets, but other people are not aware of the need I feel. [F56]

Whereas another patient who outwardly looked very athletic stated: “*I think my appearance deceives people sometimes*” [M37]. A “badge of illness” is not required by all, but it does provide a form of confirming a pain experience albeit not a constructive means. Freund and McGuire (1995:156) state that people in chronic pain frequently receive invalidating responses if an organic basis for the pain is not apparent. This is common to many illness experiences in which credibility is linked to the visibility of the source of ‘dis-ease’ and the sufferer caught in an identity management dilemma (see for

example Iphofen, 1990). This need to appear credible in the eyes of others uses identity management and emotional resources that the patient with chronic pain would be better off using to manage their pain condition (Werner and Malterud, 2003). For there to be a broader acceptance of pain as it is recounted by the sufferer there would need to be greater public understanding that chronic pain is not life threatening despite the inability of the medical profession to find a cure for it. Until then patients with chronic pain will have to continue to “work hard” to develop credibility.

A qualitative study, in which women with fibromyalgia, living in Sweden and the USA, were interviewed, found that the patients' perception of their illness and the lack of objective findings caused deep distress. This was mainly due to the lack of a label for their ill health and fatigue and the physicians' inability to diagnose compounded this and as a result the women felt disbelieved and as such were unable to deal with their situation constructively (Henriksson, 1995a). The disbelief they felt was founded on the fact that there were no outward signs of illness. Similar results were found by Steihaug *et al.* (2002) in a Norwegian study where data was drawn from an action research project examining treatment groups for women with chronic muscular pain. The women again expressed the importance of being listened to, understood and believed.

Understanding and being listened to are frequently referred to within the literature and are associated with being believed (Hwang *et al.*, 2004; Blomqvist and Edberg, 2002; Smith and Friedemann, 1999). Many patients through analysis of their individual interviews have expressed the feeling that others do not understand them, often because they haven't had similar chronic pain experiences. The invisibility of the chronic pain experience was also associated with not being believed and added to the feeling of not being understood (Lillrank, 2003; Soderberg *et al.*, 1999). This relationship between being believed and unseen pain appears to be a common association:

...sometimes she will ask me to do something and then she'll say oh I forgot it's your back isn't it? Because it's not an open wound, something they can't see you know... and I look well, I look too well [F44 interview].

9.2.3 “In their head”

Given the invisible nature of chronic pain there were several references from patients who felt that health professionals thought that their pain was imaginary or “in their head”. The literature reports similar findings with some patients feeling that the doctor was implying insanity (Lillrank 2003). These two extracts are both taken from a first interview with a young woman whose pain often caused her to faint and was consequently frequently admitted to casualty:

So it's down in my notes that they're psychosomatic so whenever I've ended up in casualty I've been laid on the bed for half an hour and sent home and I felt like some doctors have just treated me like a waste of space really, I've taken up their time...[F37 interview].

One of the doctors said “well I've just read F37's notes she can go”, and she hadn't even been in and seen me and my husband went out and said” how can you base that?”, and she goes “well I've just read her notes and it's just in her head” ...[F37 interview].

This feeling of implied insanity was echoed by one patient herself when investigations failed to reveal a cause for her chronic pain:

You think you're going mad because you know there's something wrong with me, why can't they find something? [F56 interview]

The lack of clear explanations and potential diagnosis is all too often a reason for why patients with chronic pain are unable to move from seeking a cure to adapting to living with and managing chronic pain. Within Western culture pain is considered to be indicative of ill-health or tissue damage (Banks and Mackrodt 2005: 156), therefore it is not surprising that patients seek many opinions on the cause of their chronic pain. The lack of “hard evidence” to support patients' claims lead to a vicious circle of feeling

disbelieved and trying to develop credibility for their pain narrative instead of focusing on how to manage the chronic pain. Appropriate explanations of the chronic pain process can confer positive confirmation of the chronic pain experience without reinforcing illness behaviour (Clarke and Iphofen, 2005):

...but then nobody explained to me about how pain works, the pain stays in my body, no one can see it...[M74 interview]

9.2.4 Depression

The lack of explanation, the absence of physical signs to prove the pain narrative and the feelings of being disbelieved by the health professional caused great distress to the patients within this study. Several of the patients referred to feeling depressed:

I can tell I'm depressed [M58 interview]

...there are days when I do feel a bit low, there are, yes, there are. Thankfully they are not that often. It's when the pain is really bad, when it makes me weepy I'm really not coping with it very well and that is depressing...[F58 interview]

or to having had suicidal thoughts:

The pain depresses me but the suicidal thoughts are more to do with the people not believing the intensity of the pain as if you're trying to make it all up and that makes me feel that I'm wasting their time...[F37 interview]

Chronic pain is often associated with depression (Elliott *et al.*, 2003; Grey, 2001; Linton, 2000) and there are many arguments surrounding whether the pain brings on the depression or whether there was a depressive element prior to the onset of pain (Ho and Biskupiak, 2004; Ciccone *et al.*, 2000). One patient blamed the chronic pain experience entirely for feeling so low:

F56: *And I know I've got high blood pressure which they haven't put me on medication for but to be honest with you I don't care. It would be a relief. If that something – I had a heart attack or something (blows nose) at least I'd be out of it.*

Kath: *is that just the way you're feeling today, now, because I'm exposing...?*

F56: *I've been feeling this for a while. If I do get chest pains or anything like that I go, ... I don't really mean it, God, you know, cos I'm frightened – I'm not frightened of what comes after cos I know I'm all right there. I'm frightened of leaving my husband and children (silence). Suicide does cross my mind...but when you're in pain and you don't have pain relief it's the only way out when the pain's that bad.*

Not all of the patients associated their chronic pain with depression, one patient considered it to be no more than a bad mood:

There's no point going out and well, you know, you're gonna annoy people proper if you're in pain and in a bad mood, so you just keep yourself to yourself and hope for the best that's its better tomorrow and then get out and go where you want to don't you? [M48 interview].

9.3 Discussion

The invisible nature of chronic pain is not a new observation and many studies have reported on this dimension (Werner and Malterud, 2003; Thomas, 2000), however, there is very little literature which has focused solely on the effects of “unseen pain” on the chronic pain patient. This study has identified “unseen pain” as an umbrella theme and then explored the effect of living with unseen pain on the chronic pain patient. The subsequent categories of “isolation”, “needing to prove the existence of chronic pain”, “in their head” and “depression” are all themes that illuminate the plight of people with chronic pain and the nature of its' invisibility.

The isolating nature of chronic pain is not a new finding and many previous studies have reported the same (Rose, 1994a; Bowman, 1994a; Bowman, 1994b). Within this study the patient who would not go to church because of “feeling a fraud” because she looked so well actively brought about her own isolation. Isolation was not brought about by being physically unable to attend church but occurred as a result of a decision taken deliberately because of the perceived views and comments of others. The priest had simply included her name on the prayer list for the sick would she have been able to continue going to church if the priest had been able to clarify this by stating she was experiencing unremitting pain, thereby placing the “sickness” in context. Looking well and therefore having invisible pain is an issue which causes problems for chronic pain patients and yet all pain is invisible. Acute pain can be empathised with more often because there are often physical signs to validate the experiencing persons report. For example a patient complaining of pain in a limb which is oedematous, hot and inflamed is more likely to get sympathy than someone complaining of pain in a limb which looks healthy and normal. Outward physical signs can be important to gain other’s sympathy and therefore validation of the pain experience. There is, however, another facet to this observation: from personal experience whilst undergoing treatment for breast cancer I was always delighted when people told me how well I looked, this confirmed to me that the disease was not taking a hold of my body and that I looked healthy, yet I had sympathy, kindness and consideration in abundance despite ‘looking well’. The difference being that I had a diagnosis, and even worse, a cancer diagnosis. This lack of diagnosis or label for the chronic pain patient becomes the cloak of invisibility that hides chronic pain from the outside world.

Metaphorically this ‘cloak’ can be said to be designed with several linings: lack of label or diagnosis, non-presence of evident tissue damage and the difficulty experienced in communicating this pain to others. This design ensures that this cloak of invisibility is so thick that it becomes very difficult to remove and to reveal the chronic pain within.

Having a diagnosis or label, therefore, should remove the invisible nature of chronic pain and confer validation of the chronic pain experience. The need to prove the existence of

chronic pain through repeated consultations with physicians of varying specialities is a common feature of life with chronic pain. Being given an inappropriate label or explanation can often further expound the chronic pain experience. For example a patient who is told that their back pain is due to a “slipped disc” or a “crumbling spine” is unlikely to maintain activity levels for worrying about the risk of further slipping or crumbling and similarly a patient who is told there is nothing physical to be found to account for their pain can be led to believe that the pain is a mental problem, thereby adding to depression, or it has the effect of forcing patients to seek a diagnosis to validate and confirm their pain experience, through increasing number of consultations.

The invisibility of the pain experience leads patients to begin to believe that their pain problem is that of mental ill health. Patients complaining of chronic pain are frequently treated by health professionals as if they were suffering mental illness (Lillrank, 2003) and within this study one patient had been told that her pain was “psychosomatic”. This leads to the assumption by others and potentially even by the patient that the pain is somehow ‘not real’. This has a profound effect on patients who begin to lose faith in the health service feeling that they have been let down by the inability of the health professionals to explain why they have pain. It is therefore not surprising that chronic pain has a strong relationship with depression.

Thoughts of suicide are not uncommon within the chronic pain population (De Vlieger *et al.*, 2006) and attempted suicide as well as completed suicide is not unheard of (Fishbain, 1999; Fishbain *et al.*, 1991) and although chronic pain is a given reason for people taking their own lives the National Office of Statistics does not hold data on the incidence of suicide within the United Kingdom associated with chronic pain. The relationship between chronic pain and depression is a much discussed issue and within this study six of the eight patients mention low or depressed mood associated with their chronic pain. Depression, therefore, must not be seen as a co-morbid condition but needs to be seen in conjunction with chronic pain as the subtle interaction between the two has the potential to increase morbidity and mortality. Neglecting to consider depression whilst assessing chronic pain can result in the patients becoming suicidal and in a now dated study by

Fishbain *et al.* (1991) it was reported that patients with chronic pain completed suicide at two to three times the rate of that seen in the general population. Patient F37 is currently receiving professional help for her chronic pain associated depression.

Labelling patients with chronic pain as depressive is also not helpful. It pre-disposes the patient to think that their pain is “in their head”. The use of tri-cyclic antidepressants for adjuvant pain relief such as amitriptyline can also compound patients’ distress that they are being treated for a mental disorder unless careful explanation of the pharmacology is given. A diagnosis of depression independent of the chronic pain experience increases the unseen nature of the pain phenomenon.

The effect of “needing to prove the existence of chronic pain” results in patients feeling disillusioned with the health professionals and yet they still have a need to seek confirmation of that experience by those professionals. Werner and Malterud’s (2003) study illustrated the extent to which women with chronic pain went to in order to gain credibility from their doctors. Strategies such as surrendering, appropriate assertiveness and appearance were utilised, in order to convince their doctors of their pain existence and its devastating effect on their lives. Certainly the concern about appearance and “looking well” was similarly found in this study.

9.4 Conclusion

The unseen nature of the chronic pain phenomenon causes further distress to patients through its potential to isolate, predispose to depressive episodes and perhaps, more importantly, it causes patients to feel disbelieved by other members of society as well as by health professionals. This has a profound effect on patients with chronic pain who then channel valuable psychological resources into appearing credible to both society as a whole and health professionals in particular.

Chapter Ten

Believing the patient with chronic pain

10.1 Introduction

The previous chapters looked at the impact of having pain that could not be supported through clinical investigations, objective measurements or public visibility. This appears to have a cumulative effect on patients which contributes to the negativity of the chronic pain experience. There also appears to be a 'pain language' which is employed by the patients to give emphasis and increase credibility for their pain experience. This chapter further develops the examination of the effect on the chronic pain patient of 'being believed' by health professionals through hermeneutic analysis of the umbrella theme 'being believed' and its associated questions whilst exploring why it is so important to patients, with chronic pain, to feel that they are being treated as being credible patients.

In the interviews the patients were allowed to relate their own chronic pain lived experience and in most cases the patients spoke about the effect of being disbelieved without any probe questions being asked. This in itself adds power to the evident negative effect that these patients experienced through feeling disbelieved. In some instances there were some probing questions asked in order to clarify the effect on the patients and within this chapter I aim to enhance the transparency of this probing process.

The second aim of this study was developed from personal observation that many patients attending a chronic pain clinic often expressed relief that they had been believed. For some it was a cathartic moment and it was not unusual to assess a patient's chronic pain for the first time and for the patient to become very emotional. Often simply listening to the pain history would evoke the comment "thank you for believing me". Over time I became increasingly interested in the issues surrounding health professionals believing a patient's pain experience particularly as I became aware that the comment about being believed was not an isolated incident but was generalised across my sample and the chronic pain population according to the literature. The literature review revealed that although no single paper examines the effect of being disbelieved many papers do

refer to the negative effect on the patient if the patient feels disbelieved (see chapter two). The literature review pertaining to the issues of believing the chronic pain patient has since been published (Clarke and Iphofen, 2005) and preliminary findings presented at a national nursing conference (Chief Nursing Officer of Wales' Showcase Conference, Llandudno, 2004).

10.2 Belief

Belief is often associated with values (O'Hara, 1996:52) and every human will have his/her own individual beliefs and values which will form a social and cultural code which they often subconsciously or consciously follow. Some beliefs and values relate to religious systems of thought. There are many different religions throughout the world which all have their own code of behaviour and which can influence peoples' values and beliefs significantly. Values and beliefs can then be applied to other human phenomena. The way in which grief is expressed varies from country to country with the British still showing a "stiff upper lip" whereas Asian communities frequently showing a public outpouring of grief. These cultural differences within a chronic pain context have been the subject of many papers (Kvaren and Johansson, 2004; Risdon *et al.*, 2003; Clark, 1999; Kodiath, 1998) and illustrate that even a universal experience such as pain can hold different values and beliefs for individuals with varying cultural backgrounds. For the purpose of this study cultural differences were not considered initially and it was simply by coincidence that the small sample within the study contained the following cultural characteristics: white, Christian, and lived in Wales, although this was not considered within the inclusion criteria. This was not difficult to achieve however as the population in general who attend the pain clinic within the hospital fit these criteria.

This study, however, does not focus on cultural beliefs or even personal beliefs surrounding the pain experience, its focus is on 'being believed' or having the pain account treated as being 'credible' by health professionals. Through analysis of the data gathered from the interviews and diaries the issues surrounding being believed are explored.

10.3 Findings

Six from the eight patients reported incidents indicating their pain account was not believed and this section uses data from those interviews and diaries for analysis and discussion. Perhaps inevitably the two patients who did not have an issue with being believed both had a long term physical disability. One [M74] used a wheelchair periodically because he had contracted poliomyelitis at the age of 17 years and the second patient [M48] was born with spina bifida and used a wheelchair most days. Linking to the chapter on unseen pain (chapter nine) it is possible to assume that their chronic pain accounts were always accepted as being credible because they had a physical disability that to health professionals and others made their chronic pain appear more visible.

Through the reading and re-reading of the transcripts a sense of the emotions associated with feeling disbelieved was revealed. In addition the reasons why patients felt they were not believed were also highlighted. The effect that feeling disbelieved has on the patient can be far reaching, it does not just affect the patient emotionally but can lead the patient to contemplate suicide. The sub theme identified within the category and umbrella theme “being believed” were labelled as “I am in pain”, “I don’t believe you”, “when you feel that you are not genuine”, “alienation” and “being believed” (see diagram 6).

10.3.1 “I am in pain”

Throughout the interviews and diaries there were several reasons given for patients feeling disbelieved. The withholding of analgesia figured strongly in two transcripts, although in one instance it was an episode of acute on chronic pain, which had warranted admission to hospital that had prompted the request for further analgesia:

I think it's partly my own anxiety which is convincing myself that some of the nurses don't believe that I'm that bad. That I'm just having the pain relief or the pethidine just for the sake of it. I am not a drug addict. I don't get a kick out of people giving me opiates or anything. I associate the word pethidine with relief, I've never been tempted to look for opiates on the street at all. Yeah I really don't think some of the nurses actually realise what the pain entails [M37 interview].

Another patient recalled being prescribed pethidine for chronic pain and then having her GP shout at her for taking more pethidine than had been prescribed:

I wasn't coping at all well and I went back to my own doctor and she didn't half shout at me. She had given me pethidine, give her her due, she had done and I know that they have got to be careful. But I went back to see her before I came into hospital and she went nuts about the use of pethidine. She said "I've warned you about this, you shouldn't take it" but I was in pain [F56 interview].

10.3.2 "I don't believe you"

The attitudes of health professionals shown to patients experiencing chronic pain vary from those who demonstrate empathy and understanding to those staff who are extremely disbelieving to the point of appearing rude. The health professionals, who showed poor manners, appeared to be unfriendly or actually told the patient that they didn't believe their pain story which further compounded the feeling of being disbelieved.

He (GP) was another one who blatantly said to me "I do not believe you are in pain" and he went to walk out the house – he wouldn't give me pain relief [F56 interview].

Consider the following extract taken from an interview:

F56: I think that's because of the way I've been treated in the past by doctors who haven't believed what I've said and who have said to me I don't believe you

Kath: they have actually said that?

F56: Yes. Yes. Not all of them. Just a few of them have said it

Kath: Just in relation to the pain?

F56: Yes.

Kath: Nothing else?

F56: No, just in relation to the pain. I got struck off by one set of doctors (pause) because they didn't believe me.

One patient recalled feeling that the nurses caring for him whilst an inpatient was unfriendly towards to him:

12.45pm I have seen Aled from the pain team – we are sticking with the same oxy pain tablets. I suffer from anxiety - but I feel that some of the nurses are unfriendly. Do they not believe you are in pain? [M37 diary].

10.3.3 When you feel that you are not genuine

Patients expressed various emotions at how feeling disbelieved made them feel. This ranged from anger, frustration and sadness to thoughts of suicide:

F37: They're the only two who I think don't really believe me.

Kath: And how does that make you feel?

F37: Angry. And of course some of the doctors in A & E. It makes me feel angry, very angry, that they are not taking me seriously.

Another patient expressed frustration at being made to feel not genuine, whilst emphasising how hard the effort needed to achieve normality was:

It does bother me because I work very hard to cope with it and when people make you feel that you are not genuine it's frustrating. It's very frustrating because they will never know how much effort goes into putting on a smile and getting out of the house some days [F58 interview].

And finally, one patient acknowledges how her pain causes her feelings of depression but it is the feeling of being unbelieved that causes her to contemplate suicide:

The pain depresses me but the suicidal thoughts are more to do with the people not believing the intensity of the pain, as if you're trying to make it all up and that makes me feel that I'm wasting their time [F37 interview].

10.3.4 Alienation

Feeling disbelieved has a negative effect on the patients, apart from feelings of frustration, anger and depression as well as the more sinister thoughts of suicide it has the effect of alienating the patient from the health professionals who are there to help them manage their pain:

You think you're going mad because you know there's something wrong – why can't they find something? [F56 interview].

Some patients felt that they could no longer ask for help from health professionals because they were made to feel as if they were making a nuisance of themselves:

And you didn't like to make a nuisance of yourself [F44 interview].

Another patient felt that her pain caused the nursing staff additional work:

F37: He (husband) says "I know you're in pain but you're not letting staff know it" and I'm afraid I hold my hands to that, I don't like putting them out.

Kath: Why?

F37: (Silence) I feel like I'm a burden

The patients within this study recall a variety of different health professionals who they consider do not believe their chronic pain story. It is not restricted to a particular profession and although this chapter focuses on the patients experiences of not being believed and therefore illustrates the negative aspect of a caring relationship within the interviews and diaries there are also examples of empathic and understanding relationships.

M37: ...but coming into hospital and he'll (doctor) say "oh what brings you into hospital this time?" you know

Kath: You feel (pause then hesitantly) patronised?

M37: *Yes. And my own sort of anxiety I feel as if no one believes me you know*

I was unsure as to whether by saying “patronised” I was leading the patient, hence my hesitancy in introducing the word, however, it was the patient’s tone of voice which prompted me to use the word because it was the way he spoke the consultant’s words. I did not, however, expect the patient to clarify his affirmation of ‘feeling patronised’ by saying “*I feel as if no one believes me...*”

Not all patients felt that they were patronised, one patient struggled to explain the difficulties he experienced in expressing his pain:

I know that the girls (physiotherapists) here are great and they will help you all they can but ...she thinks it's all muscular you see, so she gave me these exercises, and I'm doing 'em, doing all these exercises faithfully and yet I'm still getting worse not better. And how do you explain to people what pain is? Or the extent of the pain? Like my one to ten might be different from his one to ten, and you can't explain pain can you?... And it's getting worse. I think these girls are great, they're smashing they are, but you can't explain to people what the pain is [M58 interview].

It is not just health professionals who are guilty of displaying disbelieving attitudes to patients with chronic pain. One patient recalls a work colleague who showed lack of concern for her back pain:

I've had a bit of a do with this teacher I'm working with. She wanted me to climb up to do some displays on the wall but I said “if you don't mind, I prefer not to do it”. She wasn't very happy...sometimes she will ask me to do something and then she'll say “oh I forgot it's your back isn't it?” because it's not an open wound something they can't see you know [F44 interview].

Another patient is greatly affected by the invisibility of the chronic pain experience and although this has been explored in chapter nine it warrants further exploration as she does not want her personal integrity to be questioned:

Please don't say I'm ill, cos I'm not ill I'm just in pain. And there is a big difference, so people expect me to be ill so when I walk up to church and I look you know, good, ...I can imagine people looking and thinking "I thought she wasn't very well". It's a problem that is. I know it sounds stupid but it is. It's not that I want sympathy off anyone I don't but I don't want people to think I'm lying [F56 interview].

This is a very subtle inference, F56 does not want to be seen as ill, but needs to have her pain acknowledged and it is her pain alone which limits activities in her life whilst having a negative effect on her mood. Conversely another patient [M37] does link his pain to ill health; his pain is a direct consequence of Crohn's disease. It is perhaps worthy of noting that for some 'being in pain' is not 'being ill', whilst for others being in pain means you are ill and equally people can be ill and yet have no pain.

10.3.5 To be believed

Not all recollections are negative, however, one patient recalled her first appointment to the nurse led pain clinic where she had been referred for instruction in the use of a TENS machine:

And it was such a new experience, to be believed...[F56 interview].

Another patient spoke with gratitude when she spoke about a previous hospital admission:

I mean the nurses are lovely... and they said "oh you are in pain, we can see the pain in your face..." they are very nice and understanding [F37 interview].

10.4 Discussion

The sub themes identified within the analysis of the umbrella theme and category “being believed” are labelled with powerful expressions taken from the patients’ own interviews. The need of the patient to emphasise their pain experience to try to gain credibility despite the fact that the action of others, such as withholding analgesia, is actually seen by the patient as confirming the feeling that they are not believed illustrates how much effort has to go into convincing staff of a need for pain relief. Through analysis of the diaries to explore the living experience of chronic pain (chapter 5) medication was documented by each of the sample demonstrating that analgesia was an important part of their life in managing their pain.

Successful pain management is dependant upon accurate pain assessment (Plaisance and Logan, 2006). It is not possible to provide appropriate treatment or management options if an accurate appraisal of the current situation has been undertaken. Pain assessment is often seen as the cornerstone of acute pain management and nurses are still taught McCaffery’s (1968:95) famed definition of pain: “*pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does*”. This definition of pain immediately acknowledges the subjectivity of the pain process and places the onus of the pain intensity into the patient’s domain. In other words, the health professional is obliged to accept the patient’s report of pain because there is no objective way of determining whether pain does or does not exist. This, however, is the point at which pain assessment frequently fails. Health professionals through attitude or actions, such as withholding analgesia, demonstrate that they are not accepting the patient’s report of pain.

Chronic pain has further assessment difficulties. Acute pain is often accompanied with physiological signs such as tachycardia, sweating, hypertension or tachypnoea whereas chronic pain frequently has no signs or symptoms other than the patient’s self report. This further compounds the invisible nature of the chronic pain experience. McCaffery and Beebe (1989: 7) state that health professionals have a professional responsibility to either believe the patient’s report of pain or to give the benefit of the doubt. They continue to

say that each professional is entitled to his/her own personal opinion about the credibility of the patient's account however it is a professional responsibility to accept the patient's report and to help the patient by adopting a positive and responsive manner. Person centred counselling based on Rogers' philosophy provides three core conditions essential to the process: unconditional positive regard, congruence and empathy (Mearns and Thorne, 1988:15). If these conditions were applied to chronic pain then believing the patient's pain experience without prejudice becomes more possible. It could be argued that poor pain assessment is the result of not believing the patient's self report of pain. The link between accurate pain assessment and believing the patient is not a new finding. Jacques (1992) examined the interactions between nurses and patients during pain assessment and reasoned that if each patient was treated individually and holistically it would allow for the subjectivity of the individual pain experience. Her conclusion was simple in the extreme and she stated that "*accurate pain assessment is dependent upon the patient feeling that they are believed by health professionals*".

Under-administration of analgesia is frequently associated with poor pain assessment (Salmon and Manyande, 1996). Within this study the under-administration or withholding of analgesia is perceived by the patients as being evidence that health professionals do not believe their pain account. Waterhouse (1996) claims that pain relief should be a two way process between the nurse and the patient and that believing the patient is the initial step in this process. Waterhouse (1996) is making a clear link between believing the patient and successful pain relief/management. It would appear that as health professionals if the patient is not believed then pain assessment and the management that should follow will fail.

The attitudes that health professionals display towards patients has a far reaching effect. Those patients who meet health professionals who have caring, empathic and friendly attitudes will be remembered and recalled in a positive manner while those professionals who are rude, abrupt in manner and do not appear to listen reinforce the negativity of the pain experience and supports the patients' feelings that they are being disbelieved. Listening is an action which takes very little physical effort on part of the health

professional and yet appears to be one of the skills most under used by health professionals. It must be acknowledged that the attitudes of health professionals are those as perceived by the patient with chronic pain. This study does not examine the attitudes of health professionals per se and therefore this study cannot be taken as evidence that health professionals do act in any way that could be interpreted as being uncaring or negligent. It could be suggested, however, that health professionals need to develop skills that demonstrate to patients that they are listening. Further work would need to be done to establish what patients are looking for in their professionals, which confirm that they are being listened to.

Feeling unbelieved contributes to the negativity of the pain experience by increasing the negative emotions that are already recognised as being synonymous with chronic pain. These emotions of anger, depression and frustration have already been explored within this study (see chapter five) but in relation to living with chronic pain. The patients within this study are stating that these emotions are further compounded through the attitudes of the health professionals which force them to use strategies to develop credibility whilst preserving their own personal integrity. Werner and Malterud (2003) similarly found that women with chronic pain through feeling unbelieved by the health professional put a lot of effort and work into appearing to be a credible patient and concluded that the same effort would be better placed into managing the pain experience.

Feeling as if they are not being genuine questions patients' personal integrity. The patient does not want to appear as if they are lying and the effect on not appearing that they are speaking the truth can lead to patients to isolate themselves from situations or activities even though they might have previously enjoyed that activity such as attendance at church. Isolation can then exacerbate depression which is frequently associated with the presence of chronic pain. Depression in itself can have far reaching devastating consequences on the sufferer as well as the family and there are arguments as to whether the depression increases the pain experience or whether the pain is the trigger factor for the onset of depression (Ho and Biskupiak, 2004; Ciccone *et al.*, 2000). Depression can lead patients to consider suicide (Fisher *et al.*, 2001; Fishbain, 1999; Fishbain *et al.*,

1991) and within this study one patient [F37] directly attributes her thoughts of suicide with “*people not believing the intensity of the pain*”. If the effect of feeling that health professionals do not believe a patients chronic pain account can then lead a patient to contemplate suicide then as health professionals we need to explore ways in which we can confirm the chronic pain experience without reinforcing illness behaviour or disempowering the patient.

Throughout this chapter I have used the term health professional to encompass not just doctors and nurses but physiotherapists which are those professionals named by the patients within the study. Through an exploration of available literature it can be seen that patients feel that there are other professionals such as occupational therapists who similarly can display attitudes that the patients perceive to be that of demonstrating disbelief (Brown, 2003). Add to that the invisibility of chronic pain and the effort that patients feel that they have to go to in order to convince health professionals of their pain experience as well as the emotional toll involved and the increasing negativity of the pain experience can be appreciated. It is not just health professionals though who demonstrate disbelief in pain accounts; family members, employers, and friends can be similarly charged with the same crime.

A further negative effect of not being believed is the damage that it can cause to the patient/health professional relationship. Patients begin to feel alienated from those who they expect to help them and this can cause them to seek alternative help and support from other sources compounding the constant fruitless search for a cure. Watt-Watson (2002) considers this to be a trust issue rather than a belief issue. He states that unrelieved pain is often the result of the health professionals not trusting the pain experiences of patients, although it could be argued that not trusting a patient is very similar to that of not believing a patient. Interestingly he concluded that physicians actively resist entrusting themselves to the vulnerability of the patients’ pain, this suggests that health professionals are in someway intimidated, embarrassed or even frightened of witnessing a patient in pain. Thomas (2000) suggests that nurses who have experienced pain are more empathic to patients that are in pain, although this appears to say that nurses that have

had a similar pain experience have greater insight perhaps the insight and understanding stems from issues of not feeling vulnerable.

This discussion focuses very much on the effect that disbelieving patients' chronic pain experience has on patients but it needs also to consider why the patients need to feel believed. Personal integrity does appear to be a key feature. One patient [F56] within this study stated she did not want to be thought of as a "liar" but it could be argued that it is more than this. The relationship between health professional and patient is based on trust – the patient trusts the health professional to listen and to respond to their needs and for most health concerns this is usually the accepted practice however with the health professional continually failing to "cure" the pain the patient can be seen as a "heart sink" patient from the health professionals perspective. Frantsve and Kerns (2007) concluded in their literature review that many health professionals fail to provide adequate treatment for chronic pain which could be related to the differing expectations of both patients and health professionals as well as inability of the health professional in accurately predicting patient outcomes.

Having differing expectations may be the result of poor communication and lack of understanding on the part of either the patient or the health professional. Expectations frequently determine outcome and it is necessary for a patient to have the expectation that pain is not imaginary but is real and can be managed successfully. If patients with chronic pain do not understand the "science" behind chronic pain then it is possible that they may never feel that their pain experience has been legitimised, confirmed or believed. Equally if the health professional fails to understand the spiralling negative effects of the chronic pain experience such as depression, anxiety, necessary changes on life style and effect on family relationships and the inherent need for the patient to feel believed then the relationship may be irretrievably damaged.

This chapter focuses on the negative effect on the patient of feeling that the health professional does not believe their chronic pain experience what has not been explored in any depth is the effect on the patient when they feel believed by the health professional.

This is because overall it was not an issue that was reflected upon in any detail by any of the participants. It could be argued that the converse happens when a patient feels believed. Trust is mutual, the patient / health professional relationship is therapeutic, the patient would feel supported and respected and the effort put into trying to gain credibility would be used to manage pain more effectively. The positive effects of believing patients' accounts has not previously been studied and would be an area for future research.

10.5 Conclusion

In conclusion the effect that believing a patient's account of a chronic pain experience cannot be under estimated. Within even this small study the patients express gratitude, relief and even surprise when they find their pain experiences are accepted at face value without having to 'prove' the existence of their pain. The two preceding chapters examining the unseen nature of chronic pain, coupled with the rhetoric employed by patients in order to convince people of their pain experience and this chapter on believing the patient with chronic pain illustrates how powerful the relationship between health professional and patient can be. Providing this relationship is based on trust, the patient is reassured through simple acts of being listened to, it is possible for the health professional to empower the patient to accept the massive life style changes that are necessary to adapt and manage chronic pain. Having health professionals believe the chronic pain experience as recounted by the experiencing patient assists in alleviating the negativity of the chronic pain experience through enabling and empowering the patient to move forward with managing their pain rather than endlessly seeking a pain cure which can be viewed as alternatively seeking confirmation of their experience.

Section 4:

Development of an understanding of why some patients are able to successfully move from seeking a pain cure to accepting pain management

Incorporating

- Chapter Eleven: Accepting pain management, seeking pain cure – an exploration of patients' attitudes to chronic pain.
- Chapter Twelve: Accepting pain management, seeking pain cure – an exploration of one patient's attitude to chronic pain: a two-faceted approach

Chapter Eleven

Accepting pain management, seeking pain cure – an exploration of patients' attitudes to chronic pain

11.1 Introduction

This chapter explores the different attitudes to managing chronic pain shown by the patients within this study. Due to the subjectivity of the pain experience in general individuals react to living with chronic pain in varying ways. Some patients are able to successfully manage their chronic pain whilst others continue to seek a pain cure. Within this chapter a comparison between those who were perceived to have accepted pain management against those who were still seeking a pain cure was attempted. This chapter addresses the third and final aim of the study: developing an understanding of why some patients appear to be able to successfully move from seeking a pain cure to accepting pain management.

Within the methodology of the study a measurement instrument was devised to enable identification of those patients who were perceived to have accepted pain management rather than still seeking a pain cure (appendix 6). The instrument was used by a panel of clinical nurse specialists in pain management (n=3) within the hospital's Pain Service. Each nurse was asked to individually consider named patients from their clinics and categorise them accordingly. To increase reliability in the sample allocation a rating scale was used. The objective was to identify two men and two women who the nurses considered managed pain for one group and two men and two women who were still seeking pain cure for the comparative group. The rating scale utilised a six-centimetre line, scored from one to six and ranged from accepting pain management (score = 1) to seeking pain cure (score = 6). I was interested in those patients who scored at either extreme of the scale i.e. either scored a 1 or a 6 from each panel member, which collectively gave a score of either 3 or 18. Once patients had been categorised in this manner they were then approached to participate in the study, ensuring that each group was considered by the specialist panel to be a fair representation of patients accepting pain management versus seeking pain cure.

This method of categorising patients was dependent upon the professionally acquired but still personal views of the specialist panel. By ensuring that each panel member assessed each patient individually, without discussion, it was hoped that some reliability could be obtained. Interestingly upon analysis of the interviews the categorisation used by the nurses was borne out but on analysis of the diaries it could be seen that one of those patients who were considered to be seeking a pain cure was clearly managing their pain very well indeed. This supports theories that as health professionals we may only see what the patient wants us to see (Gross, 1992: 898). The use of the diaries genuinely allowed a glimpse into the patients' personal lives and how living with chronic pain affected their daily lives.

The data were analysed and the interpreted meaning of the individual's experience was extracted. In analysing the data, themes were identified which emerged after repeated reading and grouping of data. The sub themes that emerged from the designated pain management group were labelled "rules for living", "pain = life", and "acceptance"; whereas the themes from those seeking a cure were labelled "pillar to post", "self-fulfilling prophecy", and "mood". There were also some shared themes common to both groups, these were categorised as "family" and "coping strategies" (see diagram 7).

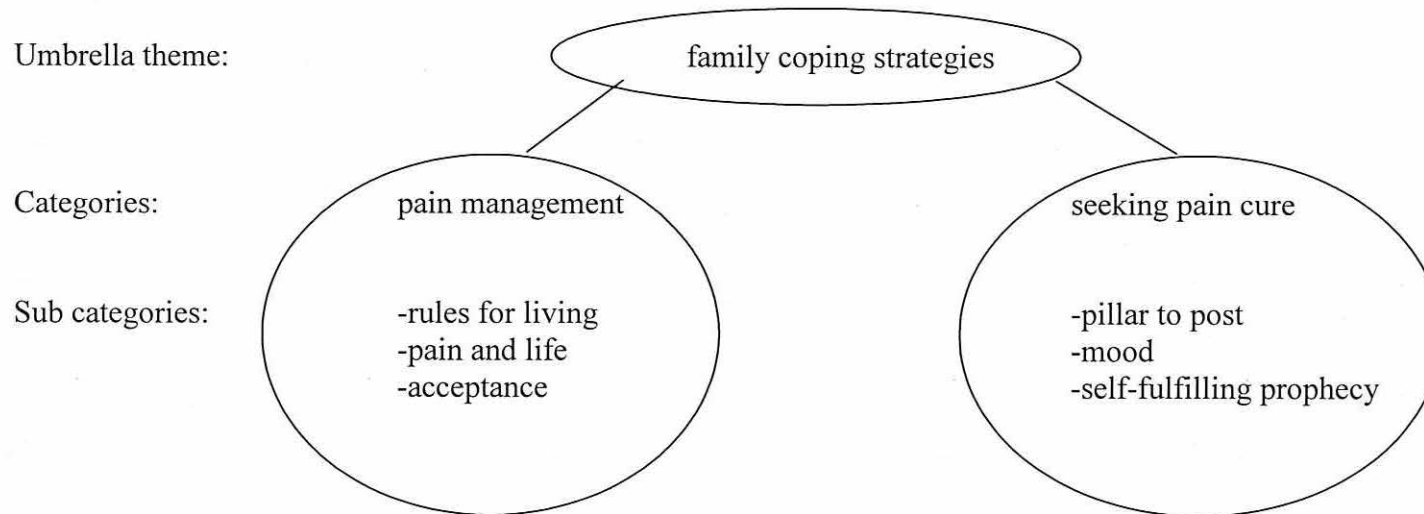
11.2 Pain management themes

11.2.1 Rules for living

All four within this group reported giving themselves goals that had to be achieved despite their pain. These varied from doing household tasks, going to work or just going to the local shop to buy a newspaper. This extract is taken from an interview with a patient who has been disabled from birth but has chronic pain in his foot:

I always go down for my paper by quarter past nine. I make a point, doesn't matter how much pain I'm in ... I think if I've got to do that, I've got to work for that, because I think if you don't do that, you'll miss one day and you think to hell with it I missed it yesterday so I won't bother today. That's my rule [M48].

Diagram 7 – Diagrammatical representation of the findings from the exploration of patients attitudes to chronic pain towards accepting pain management or seeking pain cure



Another patient recorded in his diary: "*Mind over matter works well for me*" [M74] as he described how he sets tasks for himself when the pain is particularly troublesome.

Goal setting is an inherent part of pain management (Main and Spanswick, 2000:289). However none of the sample had attended pain management programmes, this form of goal setting has been developed intuitively by the patients themselves to assist them in controlling the pain situation and enabling them to retain some independence.

11.2.2 Pain = life

This theme demonstrated that these patients had been living with chronic pain for so long that they could no longer envisage life without pain. Unlike in acute pain events where pain equates to recent evident harm, chronic pain actually signified life. This is very similar to reports from some cancer patients who seem to embrace pain as a reminder that they are still alive:

Well people say to me "how do you put up with the pain?" but I say if you're in pain you're alive aren't you? [M48 interview].

This comment reflected a common view from those patients who appear to manage their pain and cope well with life. They embraced life and saw their chronic pain as a nuisance but not as an insurmountable burden.

11.2.3 Acceptance

The ability to try to lead a normal life despite their chronic pain was another theme that emerged from those patients perceived as able to manage their pain. These patients had a life outside of their pain, whether social, through employment or family.

I just get on with things...[F44]

...is a direct quote from three different patients' interviews. It is this acceptance of the chronic pain that appears to be a cornerstone of pain management (Bowman, 1994).

11.3 Seeking pain cure themes

11.3.1 Pillar to post

This theme emerged from those patients who were still perceived as seeking a pain cure. They could all recall many visits to different hospitals and varying specialities including surgeons, physiotherapists, general practitioners and pain specialists. One young woman in her interview said that, on presenting herself to the Accident and Emergency department, “...one of the doctors actually turned to me and said do you realise in the last six months you’ve been in this hospital 26 times”[F37]. This highlights the desperation felt by some patients and also illustrates the frustration felt by some doctors as they feel ill equipped to manage chronic pain episodes (Seers and Friedli, 1996). Moore *et al.* (2003) stated that patients with intractable pain are chronic consumers of health care and that behavioural management is often the most cost-effective and efficient form of pain management.

It’s been trying to prove all along that I’ve got something wrong.

You think you’re going mad because you know there’s something wrong with me why can’t they find something? You try to prove to them [F56 interview].

Rose (1994b) in her study examining the feelings of isolation felt by elderly patients with chronic pain found that many of the patients within her research project were making a “virtual career” out of seeking a cure and going from one doctor and speciality to another.

So in a way I am looking for a cure [F56 interview].

11.3.2 Mood

In the group still seeking a pain cure the interview and diary transcripts contained many references to mood. Bad days caused a low mood, or feelings of depression, although Wells and Nown (1996) state that when a patient with long term pain feels depressed or unable to cope the pain itself can increase despite there being no further aggravation of the initial injury or illness.

Did not get any sleep due to pain. Had to have oramorph in the night, feeling in a low mood due to the back, hip and stomach pains [F37 diary].

Another patient stated “suicide does cross my mind” [F56 interview] whereas another patient said: “the pain depresses me but the suicidal thoughts are more to do with the people not believing the intensity of the pain...” [F37 interview].

11.3.3 Self-fulfilling prophecy

A self-fulfilling prophecy is described as holding a particular belief about another person, and then behaving towards that person in such a way that the initial expectancy is confirmed or fulfilled. The self-fulfilling prophecy theory argues that predictions made about the future of individuals will tend to come true because the prediction has been made (Haralambos and Holborn, 1995). This can be seen to be occurring in the patients that are still seeking pain cure:

They (orthopaedic surgeons) saw me twice and said unfortunately there is nothing we can do; we can't offer you an operation or nothing. He said if we did operate you would end up in your wheelchair straight away [F37 interview].

This young woman now uses a wheelchair to assist with her mobility.

11.4 Shared themes

11.4.1 Family

Family was very important to both groups, although there were identifiable differences. Individuals in the “managed pain” category spoke of the support their family offered:

He (partner) was so understanding [F58 interview].

Even when they were acknowledging that pain was causing a problem in that particular instance, the family served to give practical help as well as moral support without burdening the patient with feelings of guilt:

She's (sister) so good with me, she knows when I can't carry on [F44 interview]

Whereas those in the group who were perceived to still be seeking a pain cure felt guilty, sad or worried about their family. The impact upon family life in this group was very obvious and compounded the distress caused by the chronic pain:

Yes, he's (husband) been wonderful. But I feel awful because he's had to give up work now, I feel like I've deprived him, because he's always been a hard worker, never taken sick days at all and now he's permanently off work. I can see at times it gets to him, being stuck in the house... I make sure he gets out but it's still not fair on him really [F37 interview].

One diary extract, from a woman with young children describes the effect on her family life:

My oldest boy was also angry and cried because he (like my husband) feels frustrated with me. My oldest boy was going to cancel a party he had been invited to so he could look after me – I made my son go to the party because he needs to lead a normal life and enjoy his childhood and not worry so much about me. ... I must admit that when I get like this my mood turns to sadness and I wonder why anyone, especially my family, stays around [F37diary].

Montes-Sandoval (1999) in her paper which presented an analysis of the concept of pain discussed the merits of pain as a function and considered it a form of communication. She stated that the expression of pain can draw sympathy and attention and could be seen as a request for comfort, although it is possible it is also an indication of a problem within a relationship. Within the interviews and diaries there was no evidence of current

relationship problems what was expressed was gratitude that the partner/spouse had remained within that relationship and in all cases was the corner stone of the relationship and quite often the primary carer. The importance of family life cannot be underestimated. It is a necessary part of living and one which is often taken for granted until something happens to threaten it, although it must be acknowledged that not all people have families, however, within this study all participants had family. Pain is seen to be an isolating phenomenon (Rose, 1994b) as the patient's ability to work and/or socialise normally decreases with the onset and continuation of chronic pain, isolation develops. This isolation can serve to cut patients off from family, friends and colleagues:

I feel guilty when I don't interact with my family. I get on edge when the pain is bad and I just want to be left alone [F56 interview].

11.4.2 Coping strategies

All of the patients within the sample, whether perceived to be managing their pain or still seeking a pain cure, had developed individual coping strategies. Some were very simple: *I do like a soak in the bath and I like heat [F58 interview]*; whereas others involved the use of analgesia, the application of TENS, exercise or goal setting. The complexities involved within the use of coping strategies for pain needs to be further researched as it appears the more complex the strategies used the more likely the patient was to be still seeking a cure.

11.5 Discussion

In this chapter the third aim of the study, to develop an understanding of why some people are able to successfully move from seeking a pain cure to accepting pain management, is explored. Understanding is defined as the ability to learn, judge or make decisions and can be used adjectively to mean kind, sympathetic or tolerant towards people (Collins, 1999:918). For the purpose of this study understanding is taken to mean to learn and to be tolerant towards people. Pain is a unique experience and as such every individual's experiences should be considered. Pigeon-holing people's experiences can provide the basis for care pathways as they can give a framework for being the accepted

norm, however the unusual to that norm should not be overlooked just because they do not conform. Unfortunately it could be considered that by categorising the sample into two groups that was exactly what I was trying to do – pigeon-hole experiences. However, through identifying these two groups it was possible to cluster themes that were relevant to only one or other group and yet also to identify what was shared. Accepting pain management is considered to be the way forward and yet it is the health professional who decides how well a patient is managing his/her pain. This is discussed in detail in the next chapter where one patient's diary and interviews illustrate how to health professionals he was thought to be still seeking a pain cure, however, within his diary he shows a different side to his chronic pain lived experience and does indeed appear to be managing his pain quite effectively.

Telford *et al.* (2006) through an exploration of the terms acceptance and denial in a chronic illness context report on how the use of acceptance and denial labels may impact negatively on the experience of chronic illness as health professionals who adopt the theory of acceptance and denial may not listen to patients who attempt to tell their own stories of living with chronic illness. If this is transferred to the sphere of chronic pain management is it possible that health professionals are negatively using labels that may impact adversely on the patients we aim to help. Accepting pain management possibly could be viewed as acceptance of the chronic pain state, but can denial be seen as denying the pain state, in which case it could have positive effects by encouraging the patient to pursue a normal life even if that means still actively seeking a pain cure.

In a research paper by Nicholas and Asghari (2006) it was questioned whether acceptance in adjustment to chronic pain is broader than first thought. Although using a quantitative approach and using data gathered from the administration of the Chronic Pain Acceptance Questionnaire (CPAQ) they discussed issues relating to how much chronic pain patients were able to engage in normal activities in spite of the chronic pain experience. McCracken and Eccleston (2005) define acceptance of chronic pain as engaging in normal activities regardless of their pain related experiences to that activity, acceptance therefore involves a “disengagement from struggling with pain, a realistic

approach to pain and pain-related circumstances, and an engagement in positive every day activities” (McCracken and Eccleston, 2003).

Acceptance of chronic pain, coping with chronic pain, managing chronic pain successfully and accommodating chronic pain are all terms used throughout the literature to describe persons who live a fulfilled life in spite of or despite having chronic pain although each term has its own respective explanation (see box 2). The sample used in this study comprised patients who were attending a nurse-led pain clinic and had been doing so for at least three years; McCracken (1998) claimed that the fact that people are attending pain clinics for treatment implies that there is a certain level of unacceptance of chronic pain amongst those patients. Another factor in deciding whether a patient is accepting of pain has to be function, activity and quality-of-life related. Those patients that suffer with less pain, associated disability and distress and have a more functional life may be more accepting of pain as a result (McCracken, 1998), however, the subjectivity of the pain experience remains an individual experience and there is no measure available to identify that one patient’s pain hurts more than another’s. This again leaves researchers to focus on those factors that can be identified in the pain management strategies employed by individuals with chronic pain.

Each individual will have his/her own perspective on what a fulfilled or functional life is. Within the sample and in the category of managing pain is M48. This patient uses a wheelchair, outside of the home, because of a congenital disability. His chronic pain is in his foot and was caused initially through a long term chronic bone infection. His life comprises playing whist, swimming, playing computer chess and visiting friends and relations. Housework is divided between himself and his father. He does not work but this is not because of his pain. His life is functional and he employs a realistic approach to pain and engagement in positive every day activities through his own use of goal setting and his rules for living.

Box 2 Explanation of terms

Term	Explanation of term	Source
Acceptance of chronic pain	“Acknowledging that one has pain, giving up unproductive attempts to control pain, acting as if pain does not necessarily imply disability, and being able to commit one’s efforts toward a satisfying life despite pain”.	McCracken, 1998
Coping with chronic pain	The purposeful effort to attempt to adapt to pain, or to manage one’s personal negative response to pain.	Keefe <i>et al.</i> , 1992
Chronic pain management	To reduce the disability and distress caused by chronic pain by teaching patients physical, psychological and practical techniques to improve quality of life.	Pain Society, 1997
Accommodating chronic pain	Substituting more achievable goals or modifying unachievable goals.	McCracken and Eccleston, 2003

Seeking a pain cure is a characteristic of most chronic pain patients (McCracken, 1998) particularly in the initial stages of the pain affecting their lives. Patients will begin to avoid activities that cause increased pain and thereby begin to limit their function ability. This then leads to frustration, mood swings, particularly a lowering of mood and depression, (Dewar *et al.*, 2003) which can ultimately lead to thoughts of suicide or even an actual attempt on their own lives.

The labelling of patients is not new in nursing and on a busy ward with a quick turn over of patients it is not unheard of for a nurse to refer to patients by the diagnosis and bed number such as “the appendix in bed 4”. This impersonal and unacceptable form of address is mirrored throughout health care and the labelling of patients is particularly

endemic within chronic pain. Patients can often be termed as “whingers”, “moaners” or even “liars” which only adds to the frustration felt by patients experiencing the chronic pain. This inappropriate labelling can also be seen in relation to the diagnoses and explanations that patients are often given by health professionals. Being told that back pain is potentially attributable to a “crumbling spine” does not encourage a patient to exercise, in fact, quite the reverse, it encourages a sedentary life to prevent further damage. Furthermore predicting the future for a patient with chronic pain if not handled sensitively and in a positive manner can become the basis of a negative self-fulfilling prophecy. Gross (1992:487) states that individuals’ expectations of others, particularly in respect to their personalities or capabilities, may influence the way we actually treat them, which in turn may influence their behaviour in such a way that our expectation is confirmed. The reaction of others can become part of a persons own self-concept, which is then reflected in our actual behaviour. Apply this theory to a patient with chronic pain and if, as health professionals, we give the impression that their pain experience is not believed, they are wasting time and there is nothing that can be done to improve their lot, then the patient is less likely to be able to manage their chronic pain and continue to seek help from many different sources (McCracken, 1998).

The shared theme of “family” is discussed in more detail in chapters six and seven where both the perceived effect of chronic pain upon the family unit and also the patients’ perceptions of the perceived effects of chronic pain upon their children are explored in depth.

Employing coping strategies to manage chronic pain and in fact life itself was a theme common to both groups. This should not be surprising as all human beings employ coping strategies in everyday life even if it is just a strategy employed to juggle the demands of family life whilst working full time. Coping strategies can take various forms and in reality patients will employ a range of range of both coping styles and strategies to assist them in limiting their pain (Main and Spanswick, 2000: 37) although within this analysis coping strategies are explored rather than coping styles.

Coping strategies have, in the past, been divided into active and passive strategies. Active strategies were defined as those strategies where the patient had to take responsibility for pain management such as taking exercise whereas a passive strategy could be considered to be resting or relying on others to take the lead in the management, for example, repeated visits to a clinician (Brown and Nicassio, 1987). Within the interviews and diaries there were numerous references to how different people approached their pain management, however, it has to be noted that they each employed a mixture of passive and active strategies. It could not be shown that those who were still seeking a pain cure purely employed passive strategies. All patients within the sample employed rest as a passive strategy although all also had active strategies (for example: swimming, housework, holidays, cooking) and it was through the appropriate use of resting that these active strategies could then be carried out. This technique is often termed “pacing” and involves the patient planning their day to ensure that there is equal levels of activity each day rather than peaks or troughs where the patient literally overdoes activity on days where they feel less pain (Banks and Mackrodt, 2005). Keefe *et al.* (1992) argues that all coping strategies are active as having to comply with any routine that was not previously considered the norm to that individual becomes an active strategy in its own right. Even complying with a medication regime takes a degree of active responsibility. Perhaps it is the concept responsibility that requires further exploration.

Responsibility is defined as being accountable for one’s actions (Collins, 1999:72) and perhaps a better measure of how patients respond to pain management would be to examine the degree of responsibility that they are prepared to accept for their chronic pain. Compliance is defined as a tendency to do as others want (Collins, 1999:159) and is seen as being a positive trait from a health viewpoint. Advice and treatment is offered to patients and it is always hoped that patients will comply with this advice/ treatment. If patients do not comply with offered advice they are seen as not being compliant and can be seen as being obstructive, however, if patients actively make a choice not to do something or conversely to do something are they not taking responsibility for that decision?

11.6 Conclusion

The highly subjective nature of the chronic pain experience particularly lends itself to a phenomenological research approach. It is vital that the health professional as researcher allows the patients' perspectives to emerge authentically and strives not to impose their own expectations and conceptual categories. Given the designated focus of the present study the dichotomy between 'pain management' and 'seeking cure', based on professional observation and experience seems allowable. Thereafter the dual method approach of interview and diary produced a degree of methodological triangulation which elicited distinct and separate categories for the two groups and some degree of commonality. The pain management group, in "accepting" their pain, treated the experience as "part of life" and so established rules by which that life of pain could be lived. Ironically those still seeking a cure seemed more fatalistic in their perspectives with a view of the inevitability of outcome betrayed by a "self-fulfilling" attitude. It was as if they were subjected to forces outside of their control – being moved from "pillar to post". Perhaps necessarily they were more subject to fluctuations in mood. Both groups talked equally of the role of family and the need to develop coping strategies. Those who demonstrated an ability to accept pain management were overall positive in their outlook on life, showed less psychological distress, and were able to set goals to motivate and move forward. Those patients who were still seeking a pain cure were more distressed, felt guilt towards their families and used a huge variety of coping strategies whilst still seeking help from a variety of health professionals.

Further research is needed in this field to understand why some patients with chronic pain are able to successfully accept pain management whilst others still relentlessly seek a cure which is almost certainly not possible. The crude dichotomy characterising the patient groups was chosen for pragmatic reasons and, with greater numbers of patients interviewed, it is possible that more subtle variations between the categories could emerge.

It is vital not to make the assumption that any one strategy is the correct route to dealing with the pain experience. The evocation of a pain management approach might conceal a

deep-seated malaise not revealed in ordinary encounters with health professionals and/or researchers. Similarly those not “accepting” their fate may be more psychologically stabilised by their “mission” to seek a cure. There is no doubt that further research, on a larger scale, is needed into discovering why some patients are able to move successfully from seeking a pain cure to accepting pain management within the chronic pain experience.

Chapter Twelve

Accepting pain management, seeking pain cure – an exploration of one patient's attitudes to chronic pain: a two-faceted approach

12.1 Introduction

The previous chapter explored the similarities and differences between two groups of patients with chronic pain, one group who were considered to manage their pain, the other group who was still seeking a pain cure. The means of categorising patients has been previously explained but although on analysis of the interviews the categories in which the patients had been placed appeared appropriate, the analysis of one diary appeared to contradict this perspective. In simple terms, the interviews supported the view that the patient was still seeking pain cure but the diary showed a completely different picture and clearly demonstrated that the patient was successfully managing his pain.

The diaries provided, in some instances, a deeper insight into living with chronic pain and the subtle characteristics of living with pain and its management or otherwise became more apparent within the data provided through the diaries. As stated earlier the patients were assigned to either the “managing pain” group or the “seeking cure” group on the assessment and consideration by the specialist panel comprising pain nurses. It has been acknowledged that the panel had professional knowledge and insight into the patients considered, rather than personal knowledge. Some of the patients included in the study had been inpatients either through an exacerbation of their chronic pain or through other ill health. This previous inpatient hospital experience may also have provided insight into how the panel viewed and categorised the patients. This knowledge of the patients, albeit from a professional perspective, was used to great benefit within the study to ensure that a relationship based on professional trust existed. The existence of this trust was used to great advantage by myself within my role of nurse-as-researcher and although the diaries and some of the interviews demonstrated that the panels categorisation of the patients, in some instances, was inaccurate, it was only through using this trust was I able to gain

such detailed, personal data from the patient's two interviews and four weeks of diary-keeping.

This conflict with categorising this one particular patient raises several questions. Phenomenology seeks to explore lived experience but the unique experience is as of equal value as shared experiences. To this effect this chapter focuses solely on this one patient's interviews and diary in an effort to further explore the two-faceted approach that this patient adopted for his chronic pain.

12.2 Background

Within the sample, one patient, M37, suffered chronic abdominal pain as a result of having Crohn's disease. This gentleman was well known to the Pain Service having had repeated admissions for both conservative and surgical management of his disease. His disease caused chronic pain as well as having acute on chronic exacerbations when the Crohn's disease was active. His rating by the specialist nurse panel scored him as 18, which placed him in the "seeking pain cure" category. This opinion would have been based on the knowledge the panel had of this patient both as a surgical inpatient and as a chronic pain clinic outpatient attendee.

The contrast between his first and last interview and also the developing story contained within the diary illustrates quite clearly how this patient reveals one side of his life to health professionals and yet there is another life kept hidden from those same professionals. M37 was interviewed initially whilst an inpatient. He had been approached about participating in the study at an outpatient appointment as were all the patients within the sample. Due to an exacerbation of his Crohn's disease he was admitted to a surgical ward and it was whilst he was on the ward he was seen by the Pain Service and he requested that his first research interview took place whilst an inpatient.

The interview took place in a quiet room on the ward, two chairs were placed at an angle to each other and the tape recorder was placed on a low table between the chairs. This first interview was one of the worst that I recorded. The patient moved his chair to ensure

that he was facing the tape recorder and he proceeded to address the tape recorder rather than myself: “it’s a bit daunting when you’re looking down there”. Despite trying to put him at his ease and using distraction questions to divert him from the presence of the tape recorder, he proceeded to address the tape recorder. His initial conversation revolved around Crohn’s disease:

I average about three hospital visits a year with the Crohn’s disease, and on a couple of occasions I’ve had to have a couple of units of blood, because my blood count has been quite low.

This discussion about Crohn’s disease then began to take on documentary-like perspective:

Basically the only form of treatment for a Crohn’s patient when he comes in is pain relief and surgery and steroids and antibiotics. Sometimes you can have all four of these things, I’ve just described, at once. It really is a horrible disease which leaves the patient feeling not very well at all and psychologically the actual manner of the disease as well, what with going to the loo, it’s very, very wearing. Very wearing.

The insight the patient has into the disease is obvious as he recounted possible treatments available. He was also able to give very detailed explanations of the process required to heal the many anal fistulae he had suffered from in the past:

These fistulas are like, er, what I can describe as a cone and they don’t really want it to heal over the top of the cone and leave like a cavity behind, they just want it to heal from the inside. So what they use is a, it’s actually seaweed, it’s called sorbisan and this sorbisan is packed into the wound and it gradually heals from the inside and just as the doctors hopefully want it.

Having knowledge of a disease process from which a patient personally suffers from can be viewed as a form of empowerment. Patients today are encouraged to ask questions

about their health, well being and any disease processes which may have direct relevance to them. The use of the internet and the World Wide Web has now provided a vast on-line medical dictionary and encyclopaedia which the majority of people within the United Kingdom now have access to whether it is direct or indirect via family or friends.

Focusing on a disease state can, however, be counter productive. Imagination is very powerful and psychologically it is possible to imagine certain symptoms should one consider them for too long. The right mind-set is required to be able to read, digest information and retrieve what is applicable to that individual. This is not as easy as it sounds and when feeling vulnerable it is possible to let the imagination run away with one.

The patient continued to describe the debilitation, frustration and embarrassment caused by having to live with Crohn's disease, these graphic descriptions recounted in the initial stages of the interview only contained brief references to the pain experienced: "*at the moment I'm getting a lot of pain in the abdominal area...*" and then immediately refers back to the Crohn's disease: "*what I find is very, very frustrating is the fact I go to the path lab or have a blood test and my blood test will come back as showing little or no activity of the Crohn's disease.*"

This focusing on the disease process prompted the following question from me: "*what do you yourself consider the worse, the Crohn's or the pain that you have with it?*" the patient did not pause before answering: "*I think the Crohn's would be easier to live with really.*" This surprised me at this stage as the focus had been solely on the Crohn's disease and it is now, on analysis, that I question whether the patient gave me an answer that he thought I was looking for. After all, he had been asked to participate in a study researching the chronic pain experience, not the experience of living with Crohn's disease. Had my question refocused his thoughts and direction unfairly and had I inadvertently introduced bias into the interview? However, Crohn's disease is synonymous with pain, so perhaps the experiences of both living with the disease and the chronic pain experience are inextricably linked.

This was then supported as the interview proceeded and the patient began to illustrate quite graphically how painful going to the toilet to have his bowels opened was. Interestingly at this stage he compared his own experiences with a stomach upset experienced by someone on holiday abroad and said that the going to the toilet was the same but he additionally experienced severe pain, which people with so-called “holiday tummy” did not.

This first interview confirmed to me that this patient did not appear to actively manage his pain, and he had been appropriately categorised by the specialist nurse panel. He appeared very much “hospitalised” and was familiar with systems and processes known to those who had repeated hospital visits and frequent hospital admissions.

His second interview conducted exactly four weeks later took place in his home. He lived with his parents and the interview took place in the living room. A coffee table was used to place the tape recorder on and we sat at a diagonal to each other, I sat on a chair, whilst the patient sat on the sofa. After initial pleasantries were exchanged, the tape recorder set up and a cup of tea accepted the interview proper commenced. This time although his hospital admission was mentioned the focus was on his recovery and how he no longer required analgesia: *“I brought home some MST 60mgs, which I’m off completely, which I have been for the last week or ten days...I’m not taking no pain relief at the moment”*.

He then proceeded to reflect on his hospital admissions:

Looking back on these hospital admissions, it’s a nightmare, it really is. It seems like a dream now at the moment, it really does. You go in, I mean before hand you have so much pain and you just can’t take any more you now and, er, you don’t care what they do to you in hospital as long as they can sort of help the pain...

Living with pain was the focus of this interview and following the format for phenomenological interviews I asked only questions to encourage his narrative rather

than to guide it in any particular direction. He was recounting his visit to Australia when the Crohn's disease had first started when he suddenly said:

I would like to have hoped I was in a steady job, my own little house, perhaps married, and perhaps children like my sister. You know you can see the photographs ...of my niece. Yes, I think that's what's missing in my life.

These flashes of insight into people's most personal lives vindicate the inclusion criterion of attending pain clinic for at least three years. Would such personal information have been divulged if a trust basis had not previously been established?

The second interview was used as a 'debriefing' interview, the prime aim to ensure that the patient had not been left feeling vulnerable following the keeping of a diary for four weeks. In all second interviews the content was less focussed on the pain and more on the patient and how they had coped with the diary keeping. In this instance, the patient's debriefing interview was of better quality in the data provided than the first, remembering that the first interview read like a text book or a radio documentary. I was reluctant to call a premature halt to this interview so allowed the patient to talk, what I didn't realise at this time was that this second interview was almost a continuation/companion guide to the diary that he gave to me on the conclusion of the interview.

The diary was extremely detailed. He had written an entry for every day, although the length of the entry did depend upon how well he felt that day. The initial entries during his hospital admission were timed entries and some days had more entries than just a single summary of the day:

5.45pm I had a new pain killer (oxynorm – that's how it's pronounced). Unfortunately I am having some very nasty spasms and pain. My feet are beginning to sweat due to the pain.

8.00pm *I have just been given an extra pain killer – they don't seem to be working.*

11.00pm *I can't seem to do anything right sometimes. I have a consultant who is not "human" and I seem to have some nurses having-a-go at me.*

The content of the diary during the period of hospitalisation was very much that of a pain diary. Times that analgesia was due and the time that analgesia was actually administered was documented. The different attitudes of staff towards his pain control were also clearly illustrated through his account of his hospital stay:

I was due a pain killer at 9.00pm and even asked a nurse for it. I never got it and had to wait until 10.40pm when the "sweet trolley" came round. As the nurse left the room I politely asked if she was coming back with my tablet – I couldn't wait any longer. She snapped at me sarcastically saying: "I have to wait for someone to check the drug blah blah blah". I explained that I didn't get a tablet back at 9.00pm... Sometimes you wonder if they are in the right job? When you are in pain you are desperate!!

Young *et al.* (2006) examined nursing attitudes and beliefs in pain assessment and management and concluded that if nurses are given the appropriate education in pain management it can have an effect on their attitudes (increase positive attitudes) whilst improving pain management. The negative effect of this particular attitude as perceived by this particular patient is illuminating and illustrates that nurses attitudes are still an issue within pain management and perhaps the standard and provision of pain education at both pre and post registration level needs to be examined.

Compare then the previous extract from his diary to one written four days previously:

I had my pain killer at 9.00pm. I caught one of the new shift staff for a pain killer bang on when it was due before the medication is handed out.

The patient is now 'hospitalised', has recognised nursing staff that will listen to his requests for analgesia and has identified that staff new to the ward are more likely to administer his prescribed analgesia. It is well documented that the more experienced nurses are likely to score pain lower and therefore give less analgesia than less experienced nurses (Nagy, 1999) but it is interesting to note that in this instance the patient is perhaps subconsciously aware of this and uses it as a strategy for ensuring he gets his prescribed medication. How common an occurrence is this on busy surgical wards? And can the ward being busy be used as a justification for withholding analgesia? In the late 1960s a study was undertaken which examined the nature of nurse-patient relationships. The findings were published in an account of that study called "The Unpopular Patient" (Stockwell, 1972; Stockwell, 1984). It is possible that M37 had fallen into this category. Stockwell (1984) examined the behaviour of the 'least' popular patients and within this category fell patients who the nurses felt demanded unnecessary attention, and were grumblers or moaners. Today the popular professional phrase for this is "heart sink" patients and patients with chronic pain often fall into this category (Coren, 2002). Blomqvist (2003) in his study investigating the perceptions and pain management of nursing and paramedical staff towards older people with persistent pain found that older people who were perceived as exaggerating their pain, or those with care-related pain or those with self-caused pain induced feelings of frustration in the staff caring for them. Although at the age of 37 years this patient does not fall into the category of an "older person" it is possible that Blomqvist's (2003) findings are applicable to the chronic pain population as a whole irrespective of age.

The unpopularity of this patient is described within his diary and he details how unsympathetic the nursing staff were to his chronic pain:

I suffer from anxiety – but I feel that the nurses are unfriendly. Do they not believe that you are in pain?

Morgan (2006) in her study which explored hospitalized substance abuser's perspectives about getting their pain appropriately managed in the hospital setting discovered that patients felt that nursing staff had a lack of respect for them because of their history of illegal drug taking. It is possible that chronic pain patients, who require poly pharmacology, including the use of strong opioids, are considered by nursing staff to be addicted to their analgesia (Kemp, 1995).

The change in this patient becomes apparent once he is discharged from hospital nearly two weeks later. The entries just after discharge document a slow recovery but within two days of being at home he is beginning to set goals for himself: *I am now trying to set myself a target for getting back in the gym*” and *“walking the dog”*. Within a week of discharge he is going to the gym, driving his car, consciously improved his diet, walking the dog and working on his own web site. Analgesia is gradually reduced until by the time I visit for the debriefing interview he is no longer taking analgesia but managing his pain through distraction and pacing methods.

This caused me some concern that the panel of specialist nurses had all identified this patient as being within the “seeking cure” category, which his interviews appeared to support and yet within the pages of his diary it could be seen that he was goal setting, using his own personal coping strategies and actively managing his pain as well as his disease process.

This section has solely concentrated on the data provided by one patient and yet it shows quite graphically how wrong the panel was in categorising this patient into the “seeking cure” category. This patient was extremely well known to the hospital's Pain Service and had been attending pain clinic for six years as well as having numerous hospital admissions spanning over a decade. If this patient, who as a Pain Service we all felt we knew extremely well, could offer one facet of himself in behaviour and yet within his

diary reveals himself to be a man who goes to the gym, swims and walks his dog when he is well enough to actively manage his pain. Further research is required to ascertain whether as nurses we are doing an injustice to these patients through forcing them into “unpopular” behaviour in an attempt to emphasise their chronic pain and gain credibility and empathy. Is this patient’s behaviour a strategy he employs to try to appear credible to nursing staff in the face of their unsympathetic attitude to him? It also has to be acknowledged that when this patient is admitted to the ward it is usually because of an exacerbation of his Crohn’s disease which causes an acute flare up on top of his chronic pain. This patient is then systemically unwell and this is the face he portrays to the health professionals caring for him at the time. This is a possible explanation for the two different faces that have been seen in regard to his chronic pain experience: one face of the acute on chronic pain episode whilst unwell and the second face of the chronic pain patient whose disease state is quiescent. This explanation does not however provide reasons why the pain nurses had not seen the pain manager face of this patient. He had been attending pain clinic for six years and not all of his visits were when he was systemically unwell. It was only through his diary and perhaps seeing him in his own home environment that I felt that this patient had some aspects that could place him in either category.

12.3 Conclusion

This case study serves as a warning that within research particularly that of a phenomenological nature where the patients’ lived experience is at the core people cannot be simply categorised. As human beings we have individual personalities, thought processes and beliefs which are subject to the influences of family, culture and religion. Experiences that are unique and do not appear to conform to health professionals’ views of an accepted norm should not be dismissed but should be recognised as providing further insight into a phenomenon that sits purely within the human domain.

Section 5:

Concluding chapters

Incorporating

- Chapter Thirteen: Reflections from the research diary
- Chapter Fourteen: Discussion and conclusions
- Appendices
- References
- Bibliography

Chapter Thirteen

Reflections from the research diary

13.1 Introduction

It was always my intention to keep my own diary during the period of the study and as such was included in the research proposal. Koch (1994) recommends the use of a field diary to help in establishing rigour in qualitative research and it can also be used to help clarify thoughts and feelings. My research diary was commenced at the same time as I registered for my PhD and was entitled “PhD ramblings” and for the first few months it was no more than this. I jotted down ideas, wrote down questions for my supervisor and compiled lists of tasks to be achieved. Gradually it took shape and as my writing developed I began to use it for more reflective thoughts, particularly, I noticed, when I needed some form of self encouragement.

It was on reading past entries in my own diary that I realised it was an excellent way to capture personal information if the writer wanted to impart it. At this early stage I decided to incorporate the diary as a means of collecting data for the phenomenon under study. Once this had been decided and still appreciating the value of my own diary I added the research diary as an element of the research process feeling that if I wrote reflectively at the end of each interview it could only enhance insight and develop understanding. It could also be used as an *aide-memoire* when recalling the atmosphere of the interviews, the attitudes of the patients and any problems I encountered along the way.

All the diary entries following the interviews were written within two hours of the conclusion of the interview and followed the reflective framework I had developed using Maslow’s hierarchy of needs (Clarke, 2004). This simple framework was developed following an incident at home when my young son had a respiratory cardiac arrest. Years later when reflecting on this terrifying moment with a group of college students studying first aid I realised that despite an appalling technique I had managed to successfully resuscitate my baby and the relief and pride I still feel at recalling the moment when he

took a breath and screamed is indeed a moment of self actualisation. It was from here that I knew that self actualisation can happen at any time within our lives and that self actualisation is a pinnacle which can be achieved at the most negative of moments. Reflection was becoming very much a 'buzz' word within nursing and was often used as a means of learning after a critical incident. This disturbed me as reflection was becoming associated with learning from a negative incident. Having a dual role as clinical nurse specialist and lecturer practitioner, my own personal reflection became more based on acknowledging the negative but celebrating the positive and recognising future improvements. Reflection for me was no longer a means of scourging myself but became a means of recognising good practice under difficult circumstances without being an excuse for poor care.

This chapter uses excerpts from my own research diary and from some of the patients' transcripts generated from their interviews and diaries to illustrate my own personal research journey, my thoughts and feelings and how I developed as a phenomenologically-orientated nurse researcher.

13.2 Nurse-as-research interviewer

The role of nurse-as-researcher was a role I had taken on previously, once through using questionnaires to generate data for my Master's degree and latterly within work acting as a research nurse to gather data for clinical trials for drug companies. Overall I felt comfortable with the role of nurse-as-researcher however this research demanded low structured highly focused interviews and in my naivety I had decided I would undertake the interviewing of the patients myself. Of course I had my reasons for this which has been included in the methodology (see chapter three) but my research diary has been invaluable in allowing me to reflect on my own journey as interviewer.

Through my diary entries I can see how I grew in confidence and skill at being the interviewer. The first interview [F56] on reflection I saw as a great success and the excitement I felt on completing this first interview and the story it contained is reflected in the diary entry:

I had to be very careful whilst listening to her story. On occasion I wanted to shout “yes!” I was so excited at what she was telling me.

Not all of the interviews were as successful. In particular the interview with M37 was, I described as, “*disastrous*”. This was the only time I conducted two interviews on the same day, one in the morning [M48] and another the same afternoon [M37]. Again two reflective accounts were kept and the contrast between the two accounts is remarkable:

What a lovely interview! He [M48] made me laugh so much – I’m not sure if I should laugh whilst interviewing but it was his expressions, almost his innocence – and when I asked him about a life without pain and he said he’d think he was dead, well the two of us laughed so much. I’ve had such a lovely morning.

Disastrous. Absolutely disastrous! He spent the entire length of the interview looking at the tape recorder – he even turned his chair so he could speak to the recorder and not me! I laughed at one stage at something he said and then realised that it was totally inappropriate. The interview was like a text book monologue about Crohn’s disease. What a disaster.

Even now I still want to laugh when I recall my inappropriate laughter. The patient was telling me how going to the gym was the mainstay of his social life and then he began to talk about his consultant surgeon:

...unfortunately I don’t find he has a very good bedside manner. I will use the word unfortunate again; unfortunately he seems to go to every gym I join you know

It was at this stage I laughed and I’m still not quite sure what provokes this laughter, whether it’s the image of the consultant surgeon in the gym, or whether it’s the image of the surgeon and the patient discussing the intricacies of Crohn’s disease whilst using a

weights machine, however I did realise it was inappropriate at the time and apologised immediately to my patient. I did wonder whether after having such a lovely interview in the morning where laughter was a frequent element within that interview had given me a sense that this interview should follow the same course, in which case I had failed to suspend judgements and I had not given M37 the same amount of respect that each of my patients deserved. It was a lesson learned and I did not conduct two interviews on the same day again.

Of course now I realise that the interview was not disastrous and still provided insight into the lived experience of chronic pain, however, the diary that M37 kept was extremely detailed and provided a very personal glimpse into the lived experience of chronic pain. The relief I felt on reading his diary was also recorded:

I am so glad I decided to use both interviews and diaries as a means of capturing data. M37's diary is incredible, so detailed, so powerful and in places, so very sad. I feel privileged to be given access to this man's innermost thoughts and feelings.

My own emotion of feeling privileged continued throughout the course of all the interviews and the reading of the diaries and indeed is a feeling I still hold today. Interviews and diaries alike provided me with information that was extremely personal and gave me an insight not just into the lived experience of chronic pain but into the lives of their families, their employment and social lives as well as some of their innermost thoughts, feelings and concerns.

I did not expect to achieve self actualisation within my role as interviewer but my last two interviews were conducted at a time of great stress in my own personal life. I had been diagnosed with breast cancer in September 2004 and this had great implications for my research and was reflected in my diary:

Feel so cheated. My life now on hold whilst I wait results of biopsies - decisions almost taken out of my hands. A rollercoaster of emotions. Am so drained, and yet so full of nervous energy. I telephoned my supervisor this afternoon, from home - couldn't get hold of him at first and left frantic messages on his voice-mail for him to contact me urgently. Fair play - one returned call later - and he has agreed that a sample of eight will be okay (am not sure but even think this could be called emotional blackmail!!). Have interviews seven and eight booked, one tomorrow and one next week - won't be able to do the closure interviews because will be having surgery and whatever comes after that. What a bloody awful way of getting the time to become a full time PhD student...

I conducted both these interviews with the knowledge that I had breast cancer, knowing full well that I would be unable to conduct the closure interviews and yet I was able to still give my patients their diaries and arrange for the closure interviews. I was concerned that I would bias the interviews by revealing too much of myself but on reflecting after each interview I honestly felt that I had achieved two interviews that were equally comparable with the previous 12 that had already been completed. A moment of self actualisation but not appreciated until later. I wrote to my last two participants and explained that I would have to cancel their closure interviews with me whilst providing them with clinic dates to ensure that any unresolved issues raised from the diary keeping could be addressed by my colleagues within the Pain Service. I requested that the diaries be returned in stamped addressed envelopes to me at home which gave these two patients my home address. Both of these patients complied allowing me to conclude the research element of the study and commence the lengthy process of hermeneutic analysis. Later following my surgery I received cards off both, I wrote in my diary following receipt of one card:

Received a lovely card off M74 and his wife today. Wishing me well and stating how shocked they were to hear about my diagnosis. They even wrote in my card "when we received your letter cancelling the interview we had no idea how ill you

were... ” – just shows my manic behaviour at time of diagnosis wasn't that manic that I didn't appear normal- my interview skills must be better than I thought!

13.3 Nurse-as-analyst

Hermeneutic analysis was a skill I had to learn. I had no previous experience of conducting hermeneutic analysis and on occasions it was a daunting task. To assist with data management I had planned to use the *NVivo* computer programme. I had started to use *NVivo* prior to September 2004 and all my transcripts were stored within my *NVivo* project and I had begun to generate codes and explore the nodes within it. Unfortunately ill health stopped this progress. I did not have remote access to the programme from home and during my treatment, although I felt very well, because of the neutropenic aspects and associated fatigue of my chemotherapy treatment I was limited to where I went at certain periods within the treatment regime. This caused me great frustration and it was at one of these times that my diary served as an outlet for anger; fortunately it also allows you to time to think, to consider and eventually to seek an alternative. The alternative was a manual analysis, involved highlighter pens, several copies of the transcripts, envelopes and scissors:

What a productive day. I have had great fun, reading, highlighting and cutting and placing excerpts in lots of different envelopes all marked with the appropriate category.

Although a time consuming way of analysing data it provided me with an opportunity for reading and re-reading the data and developing an intimacy that might not have been achieved otherwise.

13.4 Unique experiences

It was during this period of intense analysis that I became aware of the unique occurrences. Rolfe and Gardner (2005) describe a “*nursing science of the unique*” which is concerned with the individual and they propose that nursing is a series of individual and unique experiences which defies description using a science of large numbers.

Phenomenology is concerned with peoples' lived experience and yet still attempts to identify trends, although sample sizes are often small. Within all the transcripts were examples of unique occurrences which could not be grouped, themed or coded and yet these incidents had the potential to be powerful in the extreme and had a great impact upon my reflective diary keeping. One such incident was horrifying in its honesty. F44 described her father dying suddenly whilst at home:

...and he literally came off the bed that much (indicates 15 centimetres) and died in front of us, lifted himself up, must have had a massive heart attack. I just went down to the phone and the emergency services said "can you drag him on the floor?" "No" I said "I can't I'm sorry". And I just couldn't think. Not only dragging my own father on the floor off the bed, but the weight of him, I just couldn't [F44 interview].

This was a powerful description and the memory upset her, so much so that the tape was paused for a while to allow her to compose herself. Once the interview was completed F44 began to reminisce about her father's death again, this time expressing regret and guilt at being unable to get him onto the floor in order to commence cardio pulmonary resuscitation:

If I was well and it wasn't dad, I should have done it, or could have done it but I couldn't do that to my dad and also I was worried about my back [F44 interview].

My own diary reflected how the memory of needing to resuscitate a family member had struck a chord in me and I could empathise with the horror of the situation and the feeling of panic and helplessness whilst watching a loved one potentially die in front of you. Of course my own story ended happily and my son is a healthy fourteen years old, for F44 her father died and she was obviously struggling with guilt at not being able to get him onto the floor to instigate effective cardio pulmonary resuscitation. It was the latter that caused me to reflect quite emotionally:

I couldn't quite come to grips with it at first – worrying about her back when her dad was dying in front of her and yet she was so upset. What would it have been like if I couldn't have resuscitated Jack? How would I feel today if he had died in front of me because I couldn't resuscitate him? Oh God I can't bear the thought - and then of course she felt she couldn't pull her dad onto the floor because he was her dad – I suppose it does sound disrespectful and the thought of pulling my dad from bed to floor, with the potential of his head thudding on the floor brings a knot to my stomach – whereas Jack was only weeks old, so easy to handle, so terrifying...

It is quite clear from my diary that the revelation of the effect of chronic back pain upon her ability to help her father had a profound emotional effect upon me. Part of me felt she should have done all she could despite her back pain to resuscitate her father and I had to “bracket” my own thoughts and feelings. Up until this stage in my interviewing bracketing had not really been an issue, I had no personal experience of chronic pain and therefore I was looking to develop my understanding and deepen insight whereas when suddenly and very unexpectedly F44 had described a situation I related to, as the researcher I saw how important bracketing was:

No one told me how difficult it would be to bracket! I am quite happy that F44 didn't realise what a barrage of emotions she had raised in me, so that was okay, but now writing this diary of my own, well, how do I separate my own experience with hers. No wonder Husserl advocated it – I wonder what made him realise it would be so important to the research methodology – perhaps during the course of piloting the phenomenology methodology he had a similar Eureka moment!!

Although within the literature the financial aspects of chronic pain are often a theme (for example see Walker *et al.*, 1990) within my own study there was little reference to the financial impact of living with chronic pain, except for one patient [F37] and I instigated the topic when she had told me that her husband had given up work to care for her and their children and his grandfather, who lived with them:

We had one big loan then we had another one on the car but the people on the car have been right nasty. I mean the bigger loan we're paying less on, but the one for the car they took him to court and everything. So he's got CCJs (pause) but the granddad helps out – a lot – but we don't tell people that ... well we don't mind telling people, it's the family, it's the family. They would ask "why are you taking money off him" but then again he's lived with us since, well we had only been married nine months when he moved in with us so we've had him for ten years, no eleven years we've had him. So I mean we never charged him anything, so it's his board and lodgings he's paying for in a way. So, and as he says "it's only going to go to waste" ...and he says "if there's anything you want for the house or for the boys" - he gets it on credit and he says "when I die it dies with me" (laughs) [F37].

Although I wanted to laugh at this last comment I also inwardly cringed. Immediately after this comment I tried to qualify the health state of her husband's grandfather: "*But he's relatively fit and well isn't he?*" To which the reply was "*yes, he's just got this aneurysm at the moment*". My diary helped to clarify my own thoughts as I reflected on why I had found it funny whilst also being uncomfortable with the nature of the comment:

I wonder how fraudulent it is to spend on a credit card knowing you've a life threatening condition. Perhaps the granddad doesn't realise his aneurysm is life threatening, perhaps F37 doesn't realise either: she did say "he's just got this aneurysm" bit like saying "he's just got a headache". I felt quite uncomfortable when she was discussing her finances particularly when she was talking about the granddad's credit card, but why was I so uncomfortable? I think perhaps because it was something I wouldn't do- spend on someone else's credit card. Perhaps this is a question of integrity and I felt that in some way my own integrity was being questioned or a question of values. It certainly shows how her values are different to mine but then again her life is so very different to mine. Perhaps I even felt that

she was trying to get me to approve her and the granddad's actions with the use of the credit card and yet I also felt sorry for her, it must be terrible to be that short of money, particularly appreciating how expensive children are! And yet it was also so funny- even when she said "got this aneurysm". Mind you would be even worse perhaps if she does realise how serious an aneurysm could be.

Using a diary did help to guide my thoughts, allow me to become more comfortable with the information given to me and realise that my own integrity was not in question, however, the feeling of being a "mother confessor" did not completely leave me and in retrospect if the patients felt better after telling me something, knowing that I had guaranteed confidentiality, well it could only be considered a positive outcome of the interview process for the patient.

A further positive outcome of the interview process was that for some of the patients it was a cathartic moment. This had not been considered prior to the commencement of the interviews as I been more concerned with the negative aspects of the interview process particularly I was concerned with issues regarding increasing the current pain being experienced because of the topic of the interview and perhaps exposing patients to memories that they did not want to recall. The realisation of the potential for positive outcomes was at the time of my very first interview. This patient [F56] was very emotional throughout her interview. She had a long history of chronic bladder pain and had spent many years being treated by various urology consultants before she was referred to a pain clinic. I had made the mistake of not having a box of tissues in the interview room, a mistake I had to rectify within the interview and I never made the same mistake again. I was fortunate that having to go and fetch a box of tissues had not interrupted her train of thought. Towards the conclusion of her interview she said to me "I think it's probably done me a bit of good because it's bottled in isn't it?" and when I was giving her instructions on keeping her month-long diary she also said to me:

I don't mind what I write; at least you won't see me crying in there (points to her diary). I won't cry though, you see because this doesn't happen very often. Yet

you've seen me teary before, that's because of the pain but today it's because we've been talking about it. But normally I'm quite a happy person [F56].

I found it very interesting that this lady felt that she had to emphasise the fact that she was normally “*quite a happy person*”. I had obviously made her feel that she had to qualify that she wasn't always crying and yet I had known her as a clinic patient for several years and knew her to be a very nice and pleasant well adjusted lady. On reflection I queried whether rather than trying to confirm to me her happy nature she was trying to convince herself that she was happy with her life:

I know F56 is lovely and that her life has been altered by chronic pain but I do feel she thinks about what her life would be like if her life hadn't been affected in this way. What a hard life she must have if she is continually trying to resist the urge to say “what if” or “if only”

Interviews can be described as a “conversation with a purpose” (Rose, 1994a) and although the purpose was to gather information for future analysis it was pleasing to think that there was a positive outcome for the patients.

Only two of the participants had children of school age living at home [F37 and M58]. The effect of chronic pain upon the family has been discussed in chapter six but one of the unique experiences described is accredited to F37 (chapter seven). This lady had two young sons the second pregnancy being complicated by a separation of the symphysis pubis. This had caused her “*horrendous pain*” and although reassured by the obstetricians that the pain would resolve following delivery “*it just got worse and worse*”. Her youngest son, she told me, was being bullied at school because he was the cause of her chronic pain:

A child has started to bully Sam too. Turned round to him and said my mummy told me that you caused your mummy's problems, that's why your mummy's so poorly [F37 interview].

The connotations of this are almost unbelievable. For a child to have this information someone has had to divulge it in the first place. Of course it is not disclosed who told the child's mother that Sam had caused his mother's pain problems, what is worse is to think that a physiological complication of pregnancy could be blamed on the child of that pregnancy:

Absolutely incredible! Does F37 think that Sam is the root cause of her pain problem? I'm thinking I should have explored this further and I did try to elicit more information but she just said that she does tell him it's not his fault and that it could have happened at any time, like when she was expecting Jimmy rather than him, but it didn't. I'm not just astounded; I'm horrified to think a five year old child is carrying guilt for his mother's ill health. I am so angry and the more I listen to the tape the madder I get. I did not expect the interviews to involve me so emotionally. For a while it gave me an ethical and moral dilemma about what I should I do for this child but was delighted (and very, very relieved) when she told me later in the interview that the young carers association have links with the family. This was the first time I had felt very uncomfortable with what a patient was telling me. I still feel uncomfortable thinking what effect this might have on the Sam as he grows up and in addition to this she also told me that she had previously tried to take her own life which her elder son, nine year old Jimmy, had been witness to; "but then again he's seen the suicide attempts as well so that plays on his mind as well". Again I am delighted to say that F37 does have a CPN so obviously there is support for this young family.

Not all my reflections were a record of concern or sadness. One of my female participants [F58] had just become engaged to get married. When she presented for her first interview I noticed that she had an different look about her, an inner glow and her interviews were delightful as she described her future husband and the young boy she was about to become step mother to. Her interview focused very much on her current happiness and although I tried to bring the focus back to her pain it was very difficult:

She was so bubbly today. Almost a different woman. It was very hard to have to bring her back to the topic in hand as she really only wanted to talk about her new love and after all who am I to prevent her from talking about him? I've known her for years, even going back to my orthopaedic nursing days, so that seeing her so happy was lovely for me too. I knew I was trying to justify my poor interview focus by thinking well, she's still talking about her life and her life is living with chronic pain but not sure if that's really acceptable.

Fortunately my concern at poor interviewing was eased when I read her diary. Although still the story of a woman in love she had detailed how difficult life could be managing her pain, her home and now that of her relatively new relationship:

I feel so privileged to read this diary. It's like having a window into a person's life and heart. F58 has not held anything back from me and I can appreciate her concerns and feel as if I'm looking at life from her viewpoint. She writes beautifully and through her writing has provided me with so much rich detail- I now understand why they call it rich.

13.5 Discussion

I included a research diary within my study design because it would contribute to establishing the audit trail necessary within qualitative research (Koch, 1994). I also felt that I would perhaps develop further understanding and insight into my patients' efforts at diary keeping if I maintained a research diary parallel to each of them. Indeed there were occasions where the process was onerous particularly as I had decided the reflection on the interview using my reflective framework based on Maslow's hierarchy of needs would be written within two hours of the interview ensuring that I could note down as much of the finer detail as possible before I could forget it this formed an addendum to my main research diary. I commenced a research diary from the day I registered for my doctorate and have used my diary through all the research stages including the interview process, transcription and analysis and I am still recording my thoughts and reflections as

I work towards the completion of my thesis. Jasper (2005) recommends recording all ideas that a researcher generates along the way as she states once an idea is committed to paper it allows it to be considered in a coherent manner and then either developed or discarded appropriately.

This process contributes to the development of understanding through an exploration of a particular issue, particularly an issue of concern. It allows for clarifying one's own thoughts and feelings and can contribute to the development of critical thinking (Jasper, 2005) which can only enhance the analysis of the data obtained.

Reflection is considered within nursing practice and education to be a necessary and useful tool for learning (Hannigan, 2001). Jasper (2005) applies the same consideration to the research diarist by suggesting that reflective writing can be a means of learning through drawing attention to the outcomes and processes involved in that writing. My own learning was clearly outlined as I realised the importance of bracketing and the influence of my own beliefs and values. Koch *et al.* (2005) recommends the use of a research diary to enable disclosure of personal assumptions, presuppositions and choices which may influence interpretations of data and also maintain an awareness in which the researcher's horizon is operating.

Mantzoukas (2005) explored the relationship between reflection, research and bias and states that if the researcher's bias is acknowledged and made transparent throughout the study it would suggest that the study is reflexive rather than reflective. I feel now considering the analysis, my personal reflection and the reflexion needed to reduce bias that perhaps it is a combination of both reflection and reflexivity. I would certainly admit that some bias was not immediately identified until on reflection. Freshwater (2005) argued that a researcher's bias can never be completely acknowledged as he/she can only acknowledge what is conscious proving the adage "we don't know what we don't know".

13.6 Conclusion

This chapter has attempted to provide transparency to my study through an acknowledgement of my own assumptions and presuppositions which may have influenced the choices I made within my analysis. My research diary has helped to “develop thinking” (Jasper, 2005:251) and has been a vehicle for personal discovery and learning in my role as nurse-as-researcher and nurse-as-analyst. Reflective writing has provided me with a means to develop in my role as a novice phenomenological nurse researcher through facilitating creative and critical thinking whilst allowing me to self analyse my motivations, values and beliefs parallel to that of my patients. It has been a personal journey of enlightenment and enjoyment.

Chapter Fourteen

Discussion and conclusions

14.1 Introduction

The findings and conclusions of this study are discussed throughout this chapter, first through a discussion of the phenomenological contribution to this study and then through a consideration of the original aims of the study and how far they were achieved. The discussion then considers what this study might be seen to be contributing to existing knowledge about patients' reported pain experiences and what implications for further research and for practice there might be. The chapter closes with a critical reflection of the limitations of the work and what conclusions can be reasonably drawn.

14.2 Phenomenology as inspiration and method

This study utilised a phenomenological methodology underpinned by the philosophy of Martin Heidegger. This helped to guide and shape this study as I strove to understand what it meant to live the chronic pain experience. Through acknowledging each individual's viewpoint within the world and the very essence of their sense of Being it was possible to explore the chronic pain phenomenon. The decision to employ a phenomenological approach was prompted by listening to a lecture in which Van Manen's phenomenology had been used to underpin a study exploring the experiences of women donating eggs (Maggs-Rapport, 2001; Maggs-Rapport, 2000; Maggs-Rapport, 1999). This lecture inspired and excited me to such an extent that I obtained every reference provided. It was at this point that I realised that phenomenology would assist me in deepening understanding and serve as a vehicle to explore the issues that had been highlighted through my own clinical practice.

Through reading both primary and secondary sources on the subject of phenomenology I decided that as the data was to be collected through the use of both diaries and interviews – two different sources productive of text – hermeneutic phenomenology would be the most suitable method. It also would take into account the bio-psychosocial nature of chronic pain and the influences these have on the chronic pain experience. The patient's

view of where he/she was in the world was an essential element in understanding the lived experience of chronic pain as through personal experience of assessing chronic pain in a nurse-led clinic it seemed to me that each patient managed their pain in very individual and unique ways depending on their own personal outlook on life which included beliefs, cultural influences and family and social relationships. The decision to use hermeneutics to interpret the text was taken as I realised that the primary way that the patients presented their experiences, through the use of language, would be best explored in this manner.

The contribution of phenomenology to this study was to ensure that the wealth of data and rich thick descriptions given by the patients were explored in such a way as to enable each individual's experiences of the same phenomenon to be considered in a thoughtful, measured iterative manner until a deeper understanding was reached of what it meant to be living with chronic pain. Hermeneutics provided the method of analysis in which the patients' perceptions of their world and their individual experience of chronic pain could be understood (Jasper, 2004: 3). The hermeneutic circle provided an ongoing process to develop insight and deepen enlightenment and understanding as the interpretation of the text progressed.

The phenomenological methodology allowed me as the researcher to distinguish and reveal hidden meaning through an extensive in-depth interrogation of the data obtained. Using Heidegger's interpretative hermeneutic phenomenology enabled me to explore lived experience whilst recognising personal prejudice through the process of recognising the world through our existence in it. Husserl's descriptive phenomenology would not have allowed this recognition and demanded that the researcher bracket themselves from the lived experience being recounted and although not being a chronic pain sufferer the trust established through the nurse-patient relationship was used to advantage within this study. To maintain rigour and trustworthiness acknowledgement and recognition of this relationship was essential.

14.3 Aims of the study

This study proposed three major aims. The first aim was to explore the living and lived experience of patients with chronic pain using a hermeneutic approach within a phenomenological framework, through data forming a narrative account from a combination of interviews and patients' diaries. The diaries provided the data needed for an exploration into the living experience of chronic pain and provided a sense of the essence of the chronic pain phenomenon whereas the data from the interviews and diaries contributed to an analysis of the effect chronic pain has on relationships with family and friends. The devastating effect that chronic pain imposed on one young family was illustrated through the use of a case study.

The second aim was to examine the effect of 'being believed' by the health professional on the patient with chronic pain through an exploration of the effect upon the patient of having health professionals accept the patient's chronic pain experience as being credible. This was achieved in several ways: firstly through analysis of the unseen nature of the chronic pain experience. Patients explained how they were well aware that their pain experience could not be supported through clinical investigations, objective measurements or public visibility which then added to the negativity of the chronic pain experience. This then had the effect of increasing feelings of isolation and depression and making them feel as if they had to prove the existence of the pain experience through illness behaviour or language. Rhetorical analysis of the form of language employed by the patients to express their pain suggests they strive to gain credibility by sharing the nature of their experience and attempting to make it more visible. That they did not always achieve credibility is evidenced by the fact that the patients still reported incidents where they were treated as liars or made to feel as if their pain was imaginary, exaggerated or psychosomatic.

The final aim was to develop an understanding of why some patients are able to successfully move from seeking a pain cure to accepting pain management and through hermeneutic analysis of the interviews and diaries it was possible to appreciate some of the barriers that patients face in their quest to manage their pain successfully. The diaries

and interviews revealed a gamut of passive and active coping strategies that the patients employed in their quest to relieve their pain. Another case study also showed that health professionals can 'pigeonhole' patients into categories which are not accurate and the case study illustrated how one patient was deemed to be seeking a pain cure by hospital staff but on reading his diary and listening to his interviews it became more apparent that this man was actually successfully managing his chronic pain.

The overarching aim of the study was to explore the lived and living experience of chronic pain with the second and third aim having been developed from personal observations of patients attending a nurse-led pain clinic. As analysis developed and familiarity with the data increased it became obvious that exploration of each aim contributed to the analysis of another aim. This inter-relationship served to strengthen the insight and understanding into the chronic pain phenomenon and contributed to the very essence of living with chronic pain.

Ensuring I did not impose the second and third aims of this study onto the data was an important consideration. The first aim was to explore the lived and living experience whereas the second and third aims had developed through observation of patients attending the chronic pain clinic. The second aim which examined the effect of 'being believed' was central to the thesis and had prompted the research initially. The review of the literature suggested that the importance of 'being believed' by the health professional was not a unique concern of mine but had not been fully explored. The questions raised through consideration of the effect of having health professionals believe or disbelieve chronic pain patients' accounts had to be thought through carefully. I was very conscious that if I asked a leading question such as "have all health professionals believed your pain?" then it would be very possible that the patients would give me the information they thought I wanted to hear. Through using the primary aim of an exploration of the lived experience I hoped that issues surrounding being believed would be revealed voluntarily and spontaneously by the patient. In all cases this proved to be true except in the one incident where I had led the patient (M48) and could tell immediately from his response that being believed was not and had never been an issue within his chronic pain

lived experience. This served as a lesson to me how easy it is for pre-conceptions and biases to creep back in and that there is a constant struggle not to impose my agenda onto the data.

Similarly the third aim was to attempt to develop an understanding of why some patients manage pain when others continue to seek a pain cure. Again through an exploration of the lived experience it was possible to see how patients managed their pain, some more successfully than others. The use of the rating scale to provide distinct dichotomies between the two categories of patients assisted in rigour and trustworthiness through an exposure of preconceptions. I strove to eradicate my own preconceptions which is fundamental within all phenomenology and discovered how hard it is to bracket thereby coming to an understanding of the Heideggerian approach whereby bracketing is not advocated.

The third aim was also identified through shared professional observations. Hence when I introduced the rating scale to my colleagues they did not question the rating rationale, the two distinct categories of patients I had identified, and/or the degree of consensus it actually produced. The rating of each patient was undertaken individually without discussion between us as a team therefore my own professional observation was validated by theirs. The patients recruited to the study, therefore, were only those who had scored at either of the extremes of the rating scale and were either categorised as “pain managers” or “seeking pain cure”.

The interviews were always initiated with a very open question about the patient’s chronic pain story in accordance with the dictates of the hermeneutic approach chosen and the diary similarly contained no guidelines with the only verbal instruction just to “write about the day” rather than the pain experience. This approach also helped to ensure that the second and third aims were not imposed on the diary but would and did emerge through analysis as understanding deepened and hidden meanings were exposed. It could still be claimed that the analyst’s preconceptions could be ‘read into’ the data. Indeed this claim could only be tested through independent reading of the transcriptions

and as a test of ‘trustworthiness’ M48’s initial interview is included in the appendix (see appendix 7). Such a test of reliability is often the only one available in qualitative research (Cohen *et al.*, 2000:92).

The chronic pain phenomenon needs to be explored in its entirety and although studies that look at specific aspects of the chronic pain phenomenon contribute to the understanding of the chronic pain lived experience a meta analysis of all phenomenological studies that contribute to this understanding may be of benefit in developing further insight. The multi-dimensional nature of chronic pain, incorporating emotional, physical and psychological factors as well as social and cultural influences means that no one element can be explored independently if the true nature of the lived experience of chronic pain is to be revealed.

Thomas’ (2000) purpose in her phenomenological study of chronic pain was to explore the deeper meaning of what it is like to live with chronic pain. Similarly this present study builds and contributes to that body of knowledge but through the addition of two further aims regarding the effect of having health professionals believe the chronic pain patient and an exploration into the reasons between those patients who can manage chronic pain versus those who are still seeking a pain cure a more robust and illuminating account is given.

Through the use of a form of language about pain, which employs clear rhetorical devices, patients appear to be seeking to give emphasis and provide clarity to their pain experience. Their necessarily unseen chronic pain is made more visible by directly appealing to others’ emotions and comparable personal experiences. By making their pain more visible to others the patients may be trying to gain credibility for their own personal pain experience. Being considered ‘credible’ is evidently an important aspect of the patient/health professional relationship and one which patients strive to achieve (Werner and Malterud, 2003). If the patient does not feel that they are being believed or listened to then help will be sought elsewhere or symptoms can go undiagnosed. Questioning a person’s credibility is often seen as an attack on a person’s integrity and

patients do not want to feel that their pain experience is being disbelieved. This almost constant need to prove the existence of chronic pain is demonstrably an inherent underpinning of the lived experience of chronic pain (Steihaug *et al.*, 2002; Soderberg *et al.*, 1999).

Of equal importance though are the assumptions behind the concern as to whether all patients are telling the truth about their pain experience. Many studies do explore the issues surrounding secondary gain and whether the chronic pain experience does, in some way, contain benefits for the patient (Gatchel *et al.*, 2005; Fishbain *et al.*, 2002).

Secondary gain can be achieved through many different means whether it is financial reward, increased attention or improved life style in general. Papers have been published which explore whether patients with chronic pain are seeking to feed a drug habit (Bloodworth, 2006; Weaver and Schnoll, 2002) although even this should not necessarily lead to the assumption that the patient is lying about their pain. Chronic pain is more likely to be under treated as some physicians have a reluctance to prescribe and support the use of opioids often because of a fear of a drug dependence developing (Heit, 2003) although some patients have developed a drug dependency because the physician has prescribed inappropriate analgesia to control chronic pain (Fisher, 2004). If, however, health professionals begin by believing the patient with chronic pain an assessment of the secondary gain factors and analgesic needs could perhaps be more accurately gauged.

Although previous phenomenological studies have identified themes relating to “living with a reluctant body” (Dysvik *et al.*, 2005) and “the altered, recalcitrant body” (Thomas, 2000) within this study no one participant appeared to place blame for their chronic pain onto the inadequacies of their physical body instead the pain was seen to be the invader of their body. This finding was in sharp contrast to these other studies where the patients appeared to ‘place blame’ for their pain onto their physical body. Within this study the patients did not ‘blame’ their physical body for the chronic pain but could recall the instant in time when the pain started, which was usually associated with a trauma of some description.

Despite the chronic pain and its daily onslaught the patients, although reporting feelings of “isolation”, “negative mood experiences” and “alienation”, were still able to report “having good times” and the ability to make the “most of pain free moments”. Few studies report lived experience of chronic pain as having a positive element to it and although it must be stated that the positive aspects of living with chronic pain are in spite of the pain rather than because of the pain it does show that chronic pain sufferers do have a life which is not all doom and gloom. This aspect of living with chronic pain is often overlooked and although many studies report a correlation between chronic pain and depression (Kothe *et al.*, 2007; Naughton *et al.*, 2007). This is also supported by the findings within this study and the fact that patients work hard at overcoming their chronic pain to enable them to “pass the time pleurably” illustrates that this group of patients do manage to maintain a good quality of life. And this is despite the fact that they are often thought of as being difficult patients because they complain a lot, are anxious or place demands upon health services which cannot be met (Walker *et al.*, 1990).

Such determination to enjoy life despite chronic pain was shown in how patients reminisced about holidays. One female participant shared her future plans for married life with a man and his son. And although for some patients chronic pain prevented the patient from participating in some family activities the beneficial aspects of family life in general was discussed. But given how vital family life was seen to be it was not surprising that the times when family could not be fully appreciated were talked about with regret and with distress. Distress was also expressed at how chronic pain had affected the lives of their children and yet through the eyes of the chronic pain sufferer it could be seen how their children adapted to this life and were even able to adopt caring skills. Similar findings are reported in other studies (Gatchel *et al.*, 2005; Kemler and Furnee, (2002) although there does not appear to be any literature available on the long term effect of a parent’s chronic pain experience on the child as he/she reaches adulthood.

Managing chronic pain or continuing to seek a cure for that pain is a very individual response which will be dependent upon the patients’ own family dynamics and social and

cultural influences. Before pain can be successfully managed the patients have to accept that pain is going to be a part of the rest of their lives (Risdon *et al.*, 2003). It could be argued that it is the responsibility of the health professional to ensure that at the very least discussion about the long term nature of chronic pain has taken place. This is a very difficult concept for patients to grasp and for some it is impossible. The single case study within this thesis that focussed on this issue showed how one man who appeared to the health professional to be seeking a pain cure was in fact managing his pain quite successfully. Accepting pain management does not mean that patients lose hope that one day a cure may be found and in all cases the patients within this study would hope that a cure be found but until that day will continue to live their lives in the best manner possible to give them the highest quality of life available to them under very difficult circumstances.

14.4 Contribution to knowledge

This study, despite its small sample size, builds on the existing body of knowledge that explores the lived experience of chronic pain. Due to the varying dimensions that contribute to the chronic pain phenomenon there are great opportunities for researchers of all disciplines and levels to take advantage. This study's focus was the lives of eight patients who I was privileged to know through the auspices of a nurse-led pain clinic.

The original contribution to knowledge within this study is the focus on 'being believed' which although was a primary aim of the study has become a recurring theme throughout the thesis. Although this aim had been included within the study's design because of a personal curiosity fostered through having a number of patients express relief at 'being believed' it was identified and developed through an exploration of the lived and living chronic pain experience. A thorough search of the literature identified papers that considered the issue of 'being believed' and allocated it as a theme amongst many others identified through the foci of each of those particular studies. Within the literature there was no single study that had considered the effect of 'being believed' as a contributory factor to the lived experience of the chronic pain phenomenon. The present study through interviews and diaries has been able to offer further insight into the effect of having a

health professional believe or disbelieve the pain experience has on the chronic pain phenomenon as a whole.

Through an exploration of the living experience of chronic pain that patients illustrated through their diaries and interviews, I was allowed to see how they lived their lives, looking after children and grandchildren, functioning as husbands, wives and lovers, planning weddings and then, frequently through role reversal, how the participants within this study managed to maintain a quality of life whilst they lived with chronic pain. The findings presented here confirm other studies such as the inter relationship between chronic pain and depression, anxiety, sleep and mood disturbances. Mood, however, was not consistently negative. Maintaining as near as normal a life as possible was seen to be very important to the patients and some worked very hard to maintain that normality and it was not being able to achieve what each considered to be their normal routine which frequently increased frustration, caused feelings of anger and lowered mood in general. Patients did detail periods of happiness, feeling positive and enjoying life in general. This finding is not one that has been documented previously in the literature as the literature generally focuses on the negative aspects of having chronic pain.

Living with chronic pain, whether the patient was managing the pain or still seeking a pain cure, was made more difficult for the patient because they had a need to 'feel believed'. Often through having no physical injury, disability or acceptable label or diagnosis the patients felt there was a need to 'prove' the existence of pain. The way in which they sought to prove their pain was through the use of a form of pain language. The exploration of the language employed by the participants revealed the rhetorical devices used by the patients to make their pain more visible to others. Although pain descriptors have often been examined in previous studies and formed the basis of pain assessment tools such as the McGill Pain Questionnaire there does not appear to be any paper which examines rhetoric in great detail. Within the rhetorical devices used, patients employed imagery to give their pain substance and shape, often comparing to a pain which most people could identify with. All of these devices combined to make the

chronic pain experience more visible, more understandable and in essence, more believable.

The negative effect upon the patients of feeling that a health professional did not believe their pain experience was discussed in depth through a further exploration of the interviews and diaries. Whilst identifying the themes associated with not being believed it could be shown that for these patients feeling disbelieved made them feel like liars, and therefore questioned their own personal integrity. It made them feel as if they weren't genuine and therefore they felt as if perhaps their pain was imaginary, "in their head" or in the case of one young woman made her feel suicidal to the extent that she had made attempts to end her own life. The frustrations and indignities caused by health professionals, although perhaps inadvertently, added to the negativity of the chronic pain experience as a whole.

I would like to think though that my greatest contribution to knowledge from this study is not just acknowledging the impact that we as health professionals can have on patients with chronic pain when they feel that their pain account is not believed but also the ways in which practice can be improved to ensure that these patients feel believed. Indeed the ways in which we can improve practice to make patients feel believed is by such simple means it seems almost trite. Patients respond to active listening, not feeling patronised, judged or belittled. They do not want to feel "like a burden", or "a waste of space" but want and deserve to be treated with empathy and compassion to enable the relationship between health professional and patient to develop into a therapeutic relationship which empowers the patient to place their energies into managing their pain and maintaining as good a quality of life as possible instead of having to use valuable resources simply to gain credibility from those very people they trust to help and advise them. In this way we can help to alleviate some of the negativity of this most human of phenomena.

14.5 Implications for further research

Each of the three aims has identified areas where further research would be of benefit to provide further understanding and greater insight into the lived experience of chronic

pain. From the findings developed from an exploration of the lived experience of chronic pain and the effect of chronic pain on family members it is suggested that the following studies may be of future value:

- Further research into living with a spouse/ partner with chronic pain would be beneficial in identifying how partners could work together to develop joint coping strategies.
- This study has identified a need for further research into the effect of having a parent with chronic pain has on the child, which could be explored from both the parent's and child's perceptions.
- The effect of living with a mother with chronic pain is an area for further research. It would be interesting to be able to interview the children of mothers with chronic pain once they reach adulthood to determine if the effect is as great as the case study (chapter 7) within this thesis purports. In addition to this, research into how children of parents with chronic pain cope themselves with pain would also be a further area for future research.
- Exploring the effect of 'being believed' has been discussed in great detail within this thesis and has been a central theme which has been demonstrated to be an important issue for the participants in this study. Although there are papers which have previously highlighted the patients' need to have their chronic pain legitimised or confirmed by health professionals there is very little literature which examines this aspect of chronic pain in detail. The patient/health professional relationship is based on a mutual trust to provide a therapeutic rapport which can be easily damaged if the patients do not feel that they are being treated as credible patients and this study contributes to that understanding and insight. The positive effects of believing patients accounts, however, has not been previously studied and would be an area for future research.

- The final aim which considered why some patients with chronic pain are able to successfully accept pain management whilst others still relentlessly seek a pain cure utilised a crude dichotomy to determine two patient groups, one which managed pain successfully the other which was still seeking a pain ‘cure’. It is possible that if greater numbers of patients were to be interviewed that more subtle variation between the two categories would emerge. It is vital not to make the assumption that any one strategy is the correct route to dealing with the very individual and subjective pain experience. The evocation of a pain management approach might conceal a deep-seated malaise not revealed in ordinary encounters with health professionals and/or researchers. Similarly those not ‘accepting’ their fate may be more psychologically stabilised by their ‘mission’ to seek a cure. There is no doubt that further research, on a larger scale, is needed into discovering why some patients are able to move successfully from seeking a pain cure to accepting pain management within the chronic pain experience.

14.6 Recommendations for practice

Throughout this thesis the term health professional has been used to encompass all those who come into contact with a patient with chronic pain. This includes nurses, doctors, physiotherapists and pharmacists. The recommendations that follow are those that could be implemented by all of those professionals – but clearly this would need to be informed by more focussed studies that explored differential relationships between patients and the different categories of health professionals that they encounter in reporting their experiences.

The unseen nature of the chronic pain experience has been illustrated within this thesis through an exploration of the rhetoric used to emphasise the pain experience whilst attempting to gain credibility. The lack of clear explanations for the continuance of pain and the lack of a definitive diagnosis or an acceptable label for the condition also adds to the invisible nature of the chronic pain phenomenon. Health professionals need to confirm the validity of the expressed pain account through means that do not enforce illness behaviour but empower the patient to accept their chronic pain and live with it

rather than be ruled by it, thereby enabling the patient to place their energies into developing appropriate coping strategies to manage their pain instead of using valuable energy to convince health professionals and significant others such as employers of the credibility of their pain experience.

To achieve this suggests that health professionals and patients should enter into a therapeutic relationship based on a shared medical decision making context where the health professional actively engages the patient in choosing the treatment plan that is the most appropriate for that patient, from a nursing perspective this confirms the concept of holistic care and individualised patient care planning, implementation and evaluation. Although this could be seen as accepted principles of care the findings of this study do not confirm that this is currently happening. Patients within this study (and in the literature) are consistently highlighting that they feel that their health professionals disbelieve their account of their personal pain experience. Surely through enforcing a truly holistic approach to pain assessment which begins with listening and believing the patient might we then expect to begin to develop an appropriate treatment plan for managing chronic pain?

The emphasis on accurate pain assessment being the foundation for successful pain management is a principle which is expounded within acute pain. This needs to be extended to chronic pain assessment across all disciplines and settings and not restricted to pain clinics and pain management health professionals only. Although it can be a laborious and lengthy process an accurate chronic pain assessment will provide the health professional with insight into the patient's beliefs, values and concerns which will serve to develop the therapeutic relationship needed.

Once this therapeutic relationship is established it is possible to empower the patient to manage their pain. Successfully managing pain as shown through this study is dependant on many variables but most importantly is dependant on that one individual and the context in which he/she is living. As illustrated through one case study (chapter 12) health professionals may consider patients to be inappropriately seeking a pain cure when

in fact they are managing pain and unless, as health professionals, we actively listen to patients this will not be accurately ascertained.

This joint collaboration of pain assessment and treatment planning should provide a forum for discussion and would present an opportunity for the patient to be given a clear explanation of chronic pain physiology whilst providing an appropriate label which does not hinder the patient from managing pain but actively encourages it.

This study does not provide an answer to chronic pain *per se* what it does show is that through simple means health professionals can assist patients with chronic pain to manage their pain and in turn retain a good quality of life. These simple means can be defined as active listening, being non-judgemental, accepting the pain experience as credible as recounted by the patient which will confirm to the patient that the relationship is based on caring and empathy. It is possible that these simple means appear to be so mundane to health professionals and also most health professionals would consider them to be accepted/normal practice that the vitally important impact that they have on the patient with chronic pain is overlooked.

14.7 Limitations of the study

Acknowledgement of the limitations of a study and the steps taken to reduce the impact are important considerations within any research project (Murray, 2002: 234). The limitations of this study are itemised and discussed next:

14.7.1 Sample size

Having a small sample size in phenomenological research is not unusual and there are many examples of phenomenological research where the sample size is ten or below (see for example Hwang *et al*, 2004; Werner and Malterud, 2003). The sample size of eight adopted here produced a large quantity of data that was adequate for extensive hermeneutic analysis. On submitting the research for journal publication there were some journals who rejected the work on the grounds of “small sample size” (Personal correspondence) but that may be a reflection of the growing demands placed on journal

editors emerging from the dogma of systematic review and meta analysis which is increasingly used as grounds for judging the value of a study (Greenhalgh, 1998). Phenomenological research in focusing on lived experience and enabling the development of an understanding of shared experience through hermeneutics does not preclude the unique and unusual, indeed it relies upon it. Considering the lived experience of just one person, as in chapters 7 and 12, can still generate deeper understanding and provide insight into the phenomenon under study. In the classic balance between the nomothetic and the idiographic works from both perspectives combine to generate valuable insights into complex phenomena.

14.7.2 Adding to Knowledge

Until research is complete, analysis performed and results discussed, it is impossible to predict what the outcome of a piece of research will be. Exploring lived experience often contributes to an existing body of knowledge through maximising the depth of insight into the experience as well as aspects of it that might be considered unique. In exploring the living and lived experience associated with chronic pain, this study examined the effect on patients of perceiving health professionals to disbelieve their pain narrative and consider why some patients appear to be able to successfully cross from seeking a pain cure to accepting pain management. Both the first and final aims have been researched before (Hwang *et al.*, 2004; Thomas, 2000; Mullersdorf and Soderback, 2000;) so it is hoped that this present research has contributed to this existing body of knowledge through deepening understanding and offering further insight via the intensive investigation of the patients studied here. Extensive literature searching suggests that the second aim had not been explored to any depth although many papers did allude to patients feeling disbelieved by health professionals as an issue (Blomqvist and Edberg, 2002; Paulson *et al.*, 1999; Henriksson, 1995b). Consequently a more detailed exploration of these concerns has provided further insight into the lived experience of chronic pain.

14.7.3 Audiotape Recording

Data recording is acknowledged to be one of the most challenging judgement calls in any research informed by a phenomenological perspective. No method of data recording can

really capture accurately and fully the experience as lived. This is an existential problem which sets a methodological challenge and is one of the reasons some researchers have opted for a phenomenographic approach to work such as this (van Manen, 1990: 29). Some thought was given to the use of a video camera to record body language, gestures and facial expressions in recognition of the range of communicative devices and channels that could be employed by patients to represent their experience. But there was a concern that the patients might have found a video camera more intrusive than an audiotape recorder and the production of much more complex data would have necessitated the combined analysis of language content, style and techniques of non-verbal communication which was beyond the scope of the present project. Transcription of the tapes was done immediately on the day of each interview and notes recorded in the research journal at the time. So any particularly noticeable or apparently significant gestures, tone of voice, or body language that could be recalled was noted, although the accuracy of this is necessarily dependent upon an individual researcher's memory and personal observational skills.

14.7.4 Diaries

The lack of guidelines given to the patient for the recording of their daily lives could be seen as a limitation. The diaries were given to the patient at the end of their first interview with each patient being given the verbal instruction to "write anything you like, whatever you're comfortable with, and don't try to concentrate too much on the pain" or something similar; this meant that the diaries varied from brief entries to lengthy descriptive and reflective entries. If written guidelines had been given, perhaps in a series of questions, for the patient to consider on a daily basis, the content of the diaries may have been more focused. But the rationale for keeping the instructions as wide and open as possible was in keeping with the research aims and in order to elicit the "living experience" of chronic pain. Consequently I was interested in everything that was recorded so had made the decision not to provide any more directive formal guidelines.

14.7.5 Compliance

Compliance was 100% on behalf of the sample and all fixed appointments for both initial and debriefing interviews were attended by the patients. Having to cancel two debriefing interviews due to my own ill health was unfortunate but the two patients involved returned their diaries using the postal system. Both patients were sent follow-up pain clinic appointments to see the clinical nurse specialists to ensure that the diaries and the first interview had not left them feeling exposed and vulnerable – these were treated as clinic appointments and not research interviews so no recordings were made. This provision helped meet the ethical requirements of the study but does represent a minor methodological compromise and an inevitable completion risk factor for all single researcher studies.

Addressing such limitations is intended to contribute to the transparency of the research process as required within phenomenology. All of these limitations had been considered prior to the commencement of the study, ensuring that any negative impact was limited or at least controlled.

14.8 Conclusion

Even a small scale hermeneutic phenomenological analysis can demonstrate the interconnections between the many aspects of the complex experience that constitutes chronic pain. Narrowing the focus of such a study to the chosen aims is necessary for pragmatic reasons and, although it does an injustice to the broader experience, when put together they do offer extra insight into the essence of living with chronic pain. My broad research interest in chronic pain originally stemmed from working as a clinical nurse specialist in pain management but the more specific focus on the lived and living experience developed from a concern for and observation of the people who presented as patients to nurse led chronic pain clinics. Often these patients expressed relief that their pain experience was believed and accepted at face value for the first time in a medical trajectory that had seen them seeking multiple consultations with varying specialities. Yet there were also patients who despite crippling pain appeared to manage their pain more

successfully than others. It was this interest in the patients with chronic pain and their lives that prompted this study into the lived and living experience of chronic pain.

There is only one method which can be used to explore lived experience and that is to ask the person who is experiencing the phenomenon. Knowing the patients from attending the clinic and utilising a low structured but highly focused interview strategy appealed to me as I felt that having this previous nurse/patient relationship would contribute to the manner in which the patients related to me and I hoped this would help them to feel more at ease and enable them to tell me their lived pain experience. In this I was not disappointed and although a novice interview researcher I was not an inexperienced pain nurse and was therefore used to listening to pain experiences in a positive non-judgemental manner. The use of the diaries further developed the idea of exploring living experience as well as lived experience and although no such definition for living experience exists I was satisfied that a diary was the best tool in which this data could be captured other than by observational studies which of course becomes subject to the researcher's interpretation whereas the diaries provided, for some of the patients, a means to reflect, describe and reveal inner thoughts and feelings which are not available to simple observation means.

This study builds on the body of knowledge attributed to the lived experience of chronic pain. Despite the small sample it shows the negativity of the pain experience and the contribution to that negativity by health professionals when they express disbelief at that experience. The issues surrounding whether patients feel that health professionals believe their pain account, the effect upon them and the reasons why the patient with chronic pain needs to be believed is an original contribution to the existing body of knowledge. To date although the literature examining chronic pain issues frequently refer to the fact that patients feel they are often disbelieved by health professionals and others there has been no research into this emotive area of living with chronic pain. This study confirms those earlier findings but significantly develops that theme and highlights the importance of a congruent and empathic relationship between health professional and patient.

This study has been a personal journey. It has not just been an exercise in developing research skills such as interviewing, hermeneutic analysis and writing but has been a window into patients' lives as they live with that all consuming sense of chronic pain. I have felt privileged and humbled in the face of such honesty, such stoicism in some instances and such great sadness in others. As a nurse with a passion for people, and an interest in those with chronic pain, I hope that the insight and further understanding of living with this very human phenomenon offered by my study will provoke health professionals into considering how by such simple means we can help turn a negative experience into a more caring and empathic relationship:

It doesn't give the doctors the right though to treat you as, well as, a nobody really, you know... if you've got a doctor that's saying "I don't believe you" well what do you do? And this is why when I came in that time and I had such compassion and care from the pain relief team. It was such a new experience – and to be believed (emphasised) [F56 interview].

Appendices

Appendices

Appendix 1 Sample, study design and main findings in the analysed articles of the chronic pain experience

<i>Author</i>	<i>Chronic pain site/condition</i>	<i>Sample size and gender</i>	<i>Study design</i>	<i>Author's overall comment</i>	<i>Personal commentary</i>
Bates and Rankin-Hill (1994)	Various	372 mixed gender (ratio not stated)	Quantitative methodology incorporating the use of the McGill Pain Questionnaire, the Ethnicity and Pain Survey, the New England Pain Control Centre Admission Questionnaire and the Ethnicity and Pain Questionnaire. Qualitative	Locus of control style has a significant impact on chronic pain patient's abilities to adapt to their conditions and to live what they see as worthwhile lives.	Loss of control is experienced by numerous patients during the chronic pain experience however some patients were able to regain control and "get on with life".

			methodology included formal and informal interviews and intensive case study interviews.		
Dewar <i>et al.</i> (2003)	Various	53 male and female (ratio not stated)	Nominal group technique (NGT).	Chronic pain is a challenging problem for both patients and health professionals.	Main focus of paper was to explore client-perceived needs and potential solutions. Issues identified: medical and treatment, problems with daily living, emotional distress, social issues, sleep disturbances and financial issues.

Gibson and Kendrick (1998)	Peripheral vascular disease	6 men 3 women	Grounded theory using interviews as data collection tool.	Patients should be encouraged to share in pain management decision-making.	This paper concentrates on chronic disease management and living with peripheral vascular disease. Pain is a major theme within the data analysis but reflects acute pain episodes superimposed on a chronic pain/disease state.
*Hitchcock <i>et al.</i> (1994)	Various	204 persons	5 page survey questionnaire	This study explores the perceived effect of pain on quality of life and suggests further research is needed to investigate	This paper concentrates on type of pain, pain intensity and medication although there was some consideration given

				perceptions and practices of people with chronic pain.	to use of health care services but the results were mainly quantitative.
Hwang <i>et al.</i> (2004)	Rheumatoid arthritis	5 women (Korean)	Phenomenology utilises Colaizzi's 9 step methodology for analysis	Patients with rheumatoid arthritis should be empowered to believe that they can take control of their illness	Syntax stilted in part – possibly due to translation from Korean and I question that perhaps some meaning lost through translation. Culture differences vast between the women in this study and Western women. I question how much of this research could be transferred to a westernised female population.

Johnstone C (2003)	Peripheral vascular disease (PVD)	N/A	Literature review	Living with PVD incorporates living with pain. Patients have to make lifestyle changes to manage both the disease and the pain.	The review of the literature identified pain as a theme that ran through many articles on PVD. Pain was linked to a feeling of powerlessness expressed by patients living with the phenomenon of PVD.
Lillrank (2003)	Back pain	30 women 12 men – although analysis was limited to the women’s narratives.	Patient narratives analysed using Ricoeur’s analytical framework.	Doctors that do not take pain seriously add to the problems associated with chronic pain.	Through narratives submitted for a writing competition patients discuss their back pain and the process leading to a medical diagnosis. Analysed as a story

					therefore themes produced followed a time line of episodes leading to medical diagnoses: “Initial help-seeking experiences”, “Coping with puzzling bodily pain”, “Seeking specialists’ knowledge”, “It is all in your head”, “Turning points” and “Solving the riddle”.
*McHugh and Thoms (2001a)	Various	245 patients who had attended a pain service.	Interviews using a structured questionnaire. Patients were also invited to discuss	The study raises awareness and understanding of chronic pain. States implications for	The patient experience of chronic pain is limited to issues that were asked within the

			the effect of living with chronic pain.	practice which advocates specialist pain services using a multi disciplinary approach.	questionnaire structure consequently the results become very number focussed rather than individual to that patient.
*Paulson <i>et al.</i> (1999)	Fibromyalgia-type pain	17 nurses 4 physicians working within a Swedish rheumatic hospital	Phenomenological-hermeneutic approach (using Ricoeur's philosophy) utilised narrative interviews to bring out the nurses and physicians lived experiences in their encounters with men suffering from	When the mens experiences of their pain is confirmed by the health professionals they disclose their pain experiences more honestly.	Interesting paper exploring the lived experiences of the health professionals to better understand the chronic pain experience. Themes identified: "needing to be manly" "struggling for relief from pain" "needing human support".

			FM.		
Paulson <i>et al.</i> (2002)	Fibromyalgia-type pain	14 men	Phenomenological hermeneutic methodology (Ricoeur) used to interpret text obtained from interviews.	This study demonstrated that a positive attitude and support from family encouraged the men to take control and gave a feeling of worth.	Pain is the focus of this paper despite the FM association, chronic disease management is not explored. Themes developed from the textual analysis were: “Experiencing the body as an obstruction”, “Being a different man” and “Striving to endure”.
Schaefer (1997)	Fibromyalgia (FM)	8 women	Diaries were used which incorporated description and quantitative data (pain scores, stress level and fatigue).	Each woman’s illness has its own unique pattern; Pain is expressed as being mental as well as physical.	Pain is the overarching theme with several sub categories emerging: “pain is both mental and physical”, “fear

					of pain and discomfort interferes with ability to do things”, “suffering results from doing things out of the ordinary routine” “Knowing the self helps control the illness” and “doing things that are pleasant and appealing helps to ease the discomfort”.
Seers and Friedli (1996)	Various	75 persons (76% being female)	Semi-structured interviews which generated both quantitative and qualitative data. Full notes taken	Using the patients’ perspectives with quantitative data deepens knowledge. Personal meaning of chronic pain is	Nine themes were identified: “experience of health care” “psychological state” “physical health state”

			during the interview and extensive field notes written up after the interviews.	crucial in helping patients to come to terms with their pain and improve their quality of life despite the pain.	“Relationship with family/friends” “social activities” “employment/finance” “comments on relaxation and describing” “comments on pain” and “lack of personal control”.
Soderberg <i>et al.</i> (1999)	Fibromyalgia (FM)	14 women	Phenomenological-hermeneutic method (Ricoeur philosophy) was utilised to interpret the text obtained from interviews.	Care has to be provided that will empower women with FM to use their resources to manage their illness rather than struggling instead to maintain their human dignity which is stripped	Powerful results. The paper explores FM but pain is a major symptom. The patient’s experiences are explored from a chronic disease management issue rather than chronic pain syndrome but

				from them through lack of professional understanding.	the issues raised are synonymous with those of chronic pain.
Thomas (2000)	Various	9 women 4 men	Eidetic phenomenology in-depth interviews	The findings from this study which demonstrated that the patients had little awareness of the external world can assist nurses to understand the chronic pain patient and provide empathic and supportive care.	Patients experiences are clearly explored and themes identified such as “the altered, recalcitrant body”, “separation from other people”, “Moments of time, existential crisis, and thoughts of death”.Nursing is not referred to at all although through the interview process some of the patients have expressed some release.

Walker <i>et al.</i> (1999)	Back pain	12 men 8 women	Narrative accounts interpreted inductively using a phenomenological framework.	Findings that demonstrated negative experiences of being “in the system” raised communication and management issues which need to be addressed by clinicians as well as policy makers.	Chronic back pain is explored from the patient perspective. Five major themes identified: “the pain takes over”, “sense of loss” “in the system” “they don’t understand” “coming to terms” although this paper focuses on the theme “in the system” and its sub categories
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Appendix 2 Sample, study design and main findings in the analysed articles of ‘being believed’

Author	Type of pain/condition	Sample size/gender	Study design/type	Comment
Blomqvist and Edberg (2002)	Chronic pain	90 people over the age of 75yrs.	In-depth interviews using open and structured questions	A typology was constructed which under the sub headings of “confident and serene” and “resigned and sad” it was stated that examples were provided of how people felt their pain complaints were not believed or understood. Unfortunately these are not discussed in any depth but used as an example of a commonality.
Bowman (1994b)	Chronic low back pain	15 individuals	Interviews using a phenomenological approach	Small comment only on the effect of believing the chronic pain patient and it is discussed only briefly. It states that patients who have experienced pain are more believing of others in pain.

Carson and Mitchell (1998)	Chronic pain	10 women 7 men	Descriptive exploratory design which utilized discussions between researcher and participant to answer the research question: what is it like to live with persistent pain?	Believing the pain patient not specifically explored but the need to understand the pain experience is extolled. They state that understanding is essential to any helping relationship.
Clarke and Iphofen (2005)	Chronic pain	N/A	Literature review	A review of the literature looking specifically at believing the chronic pain patient.
Henriksson (1995a)	Fibromyalgia (FM)	40 women	Semi structured interviews	This paper concentrates on how the women feel because there is discrepancy between their own illness perception and lack of objective findings. Thematic analysis provided a category “disbelief” which highlights the impact on the women’s self esteem of being disbelieved. These negative encounters can be detrimental and can influence the patients’ life situation.

Hwang <i>et al.</i> (2004)	Rheumatoid arthritis	5 women (Korean)	Phenomenology utilises Colaizzi's 9 step methodology for analysis	The major theme cluster "negative feelings" identified sadness as a direct result of pain not being understood. Being believed is not identified as a separate issue.
Jacques (1992)	Acute post operative pain	N/A	Discussion of factors that may influence pain and that should be taken into account when assessing pain.	Believing the patient in pain is not a central message within this paper although within the conclusion the author states that key to accurate pain assessment is for the patients to feel that nurses actually believe them.
Lillrank (2003)	Back pain	30 women 12 men – although analysis was limited to the women's narratives.	Patient narratives analysed using Ricoeur's analytical framework.	Within the thematic analysis a category was identified "It is all in your head" – within this category patients had experienced negative encounters with doctors. As objective findings were not substantiated many doctors had said that the pain was psychosomatic. This had varying effects upon the patient; some sought

				help from elsewhere others became uncertain and began to question their own mental health status.
Paulson <i>et al.</i> (1999)	Fibromyalgia-type pain	17 nurses 4 physicians working within a Swedish rheumatic hospital	Phenomenological-hermeneutic approach (using Ricoeur's philosophy) utilised narrative interviews to bring out the nurses and physicians lived experiences in their encounters with men suffering from FM.	This paper, in part, examines the need to believe chronic pain patients narratives from a health professionals viewpoint. By confirming to the men that their pain is believed encourages the men to share their pain experiences more honestly. One of the conclusions drawn from this paper is that health professionals feel it is a prerequisite within pain management to believe their patients.
Seers and Friedli (1996)	Various	75 persons (76% being female)	Semi-structured interviews which generated both quantitative and qualitative data. Full notes taken during the interview and extensive field notes	Within the thematic analysis a sub category named ""Believing the pain"" is identified. The category explores the patients lived experience of feeling disbelieved particularly as there was no definitive diagnosis to explain the

			written up after the interviews.	pain. The paper overall examined the family dynamics of patients with chronic pain.
Smith and Friedmann (1999)	Chronic pain	30 persons (73% being female)	In-depth interviews analysed for recurring themes using the constant comparison coding procedure as outlined by Strauss.	Under the theme “inability to share feelings” were the statements that patients didn’t express their feelings because they felt they weren’t understood or believed.
Soderberg <i>et al.</i> (1999)	Fibromyalgia (FM)	14 women	Phenomenological-hermeneutic method (Ricoeur philosophy) was utilised to interpret the text obtained from interviews.	The theme “Threat to integrity” contained a sub theme “Loss of credibility and the invisibility of the illness” – this related to fibromyalgia being a chronic pain condition which is invisible to others. The pain was often seen as being imaginary and the women often felt disbelieved. When they were believed they perceived themselves as being lucky.

Ruckert (1995)	Acute pain/renal abscess	N/A	Personal reflective account	This paper focuses on pain being disbelieved as the illness was “masked” by another condition i.e. pregnancy and subsequent caesarian section. Author states that her own nursing practice will change as a result of own experience and she will now listen and believe patients’ self report of pain.
Steihaug <i>et al.</i> (2002)	Chronic muscular pain	24 women	Focus group interviews using Giorgi’s principles of phenomenological analysis	The focus of this study was to examine actions and interactions that women considered to have benefited from by having group treatment for chronic pain. Relevant to the believing the patient was listening, understanding, acceptance and confirmation. Conclusion is that pain should be recognized despite not having an explanation for cause.

Thomas (2000)	Chronic pain	9 women 4 men	Eidetic phenomenology in-depth nondirective interviews	Believing the chronic pain patient takes the form of the patient mistrusting the physician due to previous experiences of not being listened to. Although this paper explores the chronic pain lived experience the effect of not believed is not examined in any detail.
Waterhouse (1996)	Acute post operative pain	1 woman	Case study	This case study follows the post operative recovery of a patient. Pain control was not achieved despite pain assessment. The author felt this was not due to a failure of the pain assessment tool but because the nurses did not believe the patients self report of pain.
Werner and Malterud (2003)	Chronic muscular pain	10 women	In-depth interviews analysed using Giorgi's phenomenological four step method.	This study focuses on the effort women put into to appear credible to their doctors. The paper focuses on negative encounters with the medical

				<p>profession although it states there were many positive encounters also. The women feel that they have to adopt certain strategies to ensure that they don't look too well to convince a doctor of their chronic pain experience. The authors conclude that this effort would be better utilized into managing the pain rather than trying to fit into the stereotype expected by the doctor.</p>
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Appendix 3 Sample, study design and main findings in the analysed articles relating to barriers to chronic pain self-management

Author	Type of pain/condition	Sample size/gender	Study design/type	Key points
Dewar <i>et al.</i> (2003)	Various	53 male and female (ratio not stated)	Nominal group technique (NGT).	Barriers to self management: <ul style="list-style-type: none"> • Medical and treatment issues. • Problems with activities of daily living. • Emotional distress • Social issues • Fatigue
Jerant <i>et al.</i> (2005)	Multiple chronic disease conditions	37 female 17 male	Focus groups with data being analysed using the grounded theory method.	Barriers to self management: <ul style="list-style-type: none"> • Depression. • Weight • Exercise

				<ul style="list-style-type: none"> • Fatigue • Poor communication with medics. • Lack of family support. • Financial problems
Robinson <i>et al.</i> (2004)	Various	96 female 84 male	Telephone follow-up survey using the Participant Compliance Reporting Scale, the Participant Satisfaction Reporting Scale, and the Participant Pain Reporting Scale.	<ul style="list-style-type: none"> • Treatment compliance

Appendix 4: Sample, study design and main findings in the analysed articles relating to the self management of chronic pain.

Author	Type of pain/condition	Sample size/gender	Study design/type	Key points
Dysvik <i>et al.</i> (2004)	Various	76 persons	The development and evaluation of a multi-disciplinary pain management programme on coping, quality of life and pain intensity.	<ul style="list-style-type: none"> • Problem-focused coping is improved by active pain management programmes. • Participants experienced better health which might be attributed to an increased understanding of the multiple aspects of pain. • On patient evaluation the therapeutic dialogue was considered to be the most successful part of the programme.
Jerant <i>et al.</i> (2005)	Multiple chronic disease conditions	37 female 17 male	Focus groups with data being analysed using the grounded theory method.	<ul style="list-style-type: none"> • Active self-management has a therapeutic value. • Realistic individual goal setting is important in managing chronic conditions.
Huntington and Gilmour (2005)	Endometriosis	18 women	In depth interviews, analysed thematically, with the research design informed by general feminist research principles	<ul style="list-style-type: none"> • A prolonged diagnostic process contributed to the severity of the pain. • Having a diagnosis gave a name to the pain and assisted in the decision to make life style changes. •
Robinson <i>et al.</i> (2005)	Various pain conditions	110 patients	Cross sectional design that defined treatment success from the patients	<ul style="list-style-type: none"> • Success criteria across the four domains were negatively correlated

			perspective. Areas considered pain, fatigue, distress and interference with activities of daily living.	<p>with education indicating that those patients with more formal education have lower target values for treatment success.</p> <ul style="list-style-type: none"> • Work also had a negative correlation with success criteria for pain and fatigue indicating that work is associated with lower target values for successful treatment of these two domains.
Witonsky and Whitman (2005)	Various pain conditions	N/A	Discussion of the philosophical theory of pain: <i>externalist perceptual theory of pain</i> through the presentation of a dialogue at a fictional case conference.	<ul style="list-style-type: none"> • A goal achieved by the chronic pain patient on attending a chronic pain clinic is that the patient obtains an understanding of his pain.

Appendix 5 Patient Information Leaflets (English and Welsh versions)

PATIENT INFORMATION

1. Study title

Chronic pain – cure or management? A research approach to understanding the lived experience of chronic pain.

2. Invitation paragraph

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW. Thank you for reading this.

3. What is the purpose of the study?

The purpose of the study is to help nurses better understand the chronic pain experience.

4. Why have I been chosen?

You have been chosen as you have attended the nurse-led chronic pain clinic. In total 12 patients will be included in the study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

6. What will happen to me if I take part?

You will be interviewed for approximately an hour, on two separate occasions. The interviews will be audio-taped. The interviews will take place a month apart and will either be held in clinic, in an office in the School of Nursing or in your home whichever is convenient for you. You will also be asked to keep a pain diary detailing your thoughts and feelings about the pain that you have on a daily basis. This diary will be commenced following the first interview and will be collected from you at the second interview.

The research method used is concerned with the patients' viewpoint of a particular experience, in this case, chronic pain.

7. What do I have to do?

Please just continue as normal except give up some of your time to be interviewed and to keep a pain diary for one month.

8. What are the side effects of taking part?

There are no anticipated side effects.

9. What are the possible disadvantages and risks of taking part?

There are no anticipated disadvantages and risks to taking part in this study.

10. What are the possible benefits of taking part?

The information we get from this study may help us in the future to improve the treatment of patients with chronic pain.

11. What if something goes wrong?

If you wish to make a complaint during the duration of the study you can address any complaint or comment to the hospital's patient liaison officer, Mrs. Ita Hawkins. After a complaint has been made you will receive an acknowledgement within two working days. After the complaint has been investigated you will receive a response from the Patient Liaison Manager and a letter telling you what steps you can take if you are not happy with the response. You should receive the response within 20 working days of making the complaint.

*Mrs. Ita Hawkins, Patient Liaison Manager
North East Wales NHS Trust
Croesnewydd Road, Wrexham LL13 7TD
Direct line: 01978 725598*

12. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital/surgery will have your name and address removed so that you cannot be recognised from it. Your GP will be notified of your participation in this study

13. What will happen to the results of the research study?

The results will be reported in the nursing press however you will not be identified in any report or publication.

14. Who is organising and funding the research?

The study is being organised by Mrs. Kath Clarke, clinical nurse specialist in pain management, Wrexham Maelor Hospital and University of Wales Bangor.

15. Who has reviewed the study?

The North Wales Health Authority Research Ethics Committee has reviewed the study.

16. Contact for Further Information

For further information please contact Mrs. Kath Clarke, clinical nurse specialist in pain management, on telephone 01978 291100 bleep 5872.

Thank you very much for agreeing to take part in this study.

GWYBODAETH AR GYFER CLEIFION

1. Teitl yr Astudiaeth

Poen barhaus – iachâd ynteu rheolaeth? Dull ymchwil tuag at ddeall y profiad o fyw gyda phoen barhaus.

2. Paragraff gwahodd

Gwahoddir chi i gymryd rhan mewn astudiaeth ymchwil. Cyn i chi benderfynu, mae hi'n bwysig i chi ddeall pam y mae'r ymchwil yn cael ei chynnal a beth y bydd yn ei olygu. Os gwelwch yn dda, cymerwch amser i ddarllen y wybodaeth ganlynol yn ofalus a thrafodwch hi gyda chyfeillion, perthnasau a'ch Meddyg Teulu os ydych yn dymuno hynny. Mae Defnyddwyr dros Foeseg mewn Ymchwil (CERES) yn cyhoeddi taflen yn dwyn y teitl 'Medical Research and You'. Mae'r daflen hon yn rhoi rhagor o wybodaeth ynghylch ymchwil feddygol ac yn edrych ar rai o'r cwestiynau fydd arnoch chi eisiau eu gofyn efallai. Gellir cael copi gan CERES, PO Box 1365, Llundain N16 0BW. Diolch i chi am ddarllen hyn.

3. Beth ydy pwrpas yr astudiaeth?

Pwrpas yr astudiaeth ydy cynorthwyo nyrsys i ddeall y profiad o boen barhaus yn well.

4. Pam y cefais i fy newis?

Cawsoch eich dewis oherwydd eich bod wedi bod yn mynychu'r clinig poen dan arweiniad nyrsys. Bydd 12 o gleifion i gyd yn cael eu cynnwys yn yr astudiaeth yma.

5. Oes rhaid i mi gymryd rhan?

Chi sydd i benderfynu p'un a ydych am gymryd rhan neu beidio. Os byddwch yn penderfynu cymryd rhan byddwch yn cael y dudalen wybodaeth hon i'w chadw a gofynnir i chi arwyddo ffurflen gydsynio. Os byddwch yn penderfynu cymryd rhan, rydych yn dal yn rhydd i dynnu allan o'r astudiaeth ar unrhyw adeg ac heb roi unrhyw reswm dros wneud hynny. Fydd hyn ddim yn effeithio ar safon y gofal y byddwch yn ei dderbyn.

6. Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?

Byddwch yn cael eich cyfweld am oddeutu un awr, ar ddau achlysur gwahanol. Bydd y cyfweliadau yn cael eu recordio ar dâp sain. Bydd y cyfweliadau yn digwydd o fewn mis i'w gilydd ac fe'u cynhelir naill ai mewn clinig, mewn swyddfa yn yr Ysgol Nyrsio neu yn eich cartref, p'un bynnag sydd fwyaf cyfleus i chi. Gofynnir i chi hefyd gadw dyddiadur poen, yn rhoi manylion eich meddyliau a'ch teimladau ynghylch y boen sydd gennych o ddydd i ddydd. Dechreuir y dyddiadur yma yn dilyn y cyfweliad cyntaf ac fe'i derbynnir gennych yn yr ail gyfweliad.

Gelwir y dull ymchwil yn ffenomenoleg ac mae a wnelo â safbwynt y cleifion ynglŷn â phrofiad arbennig, yn yr achos hwn poen barhaus.

7. Beth fydd rhaid i mi ei wneud?

Os gwelwch yn dda, ewch yn eich blaen fel arfer ond rhoi i fyny beth o'ch amser i gael eich cyfweld ac i gadw dyddiadur poen am un mis.

8. Beth ydy sgîl effeithiau cymryd rhan?

Ni ragwelir unrhyw sgîl effeithiau.

9. Beth ydy'r anfanteision a'r peryglon posibl o gymryd rhan?

Does yna ddim anfanteision na pheryglon mewn cymryd rhan yn yr astudiaeth yma.

10. Beth ydy manteision posibl cymryd rhan?

Efallai y bydd y wybodaeth a gawn o'r astudiaeth yma'n ein cynorthwyo i drin cleifion gyda phoen barhaus yn well yn y dyfodol.

11. Beth os aiff rhywbeth o'i le?

Os cewch chi niwed oherwydd cymryd rhan yn y prosiect ymchwil yma, does yna ddim trefniadau iawndal arbennig. Os cewch niwed oherwydd esgeulustod rhywun, yna efallai y bydd gennych sail ar gyfer achos cyfreithiol ond efallai y bydd rhaid i chi dalu am hynny. Er gwaethaf hyn, os ydych yn dymuno cyflwyno cŵyn ynghylch unrhyw agwedd ar y modd y siaradwyd â chi neu'r ffordd y cawsoch eich trin yn ystod yr astudiaeth yma, efallai y bydd y mecanweithiau ymdrin â chwynion arferol y GIG ar gael i chi

Os ydych yn dymuno cwyno yn ystod cyfnod yr astudiaeth, gellwch gyfeirio unrhyw gŵyn neu sylwadau at swyddog cysylltiadau'r ysbyty, Mrs. Ita Hawkins. Wedi i chi gwyno byddwch yn derbyn llythyr o gydnabyddiaeth ymhen dau ddiwrnod gwaith. Wedi i ymchwiliad gael ei gyflawni i'r gŵyn byddwch yn derbyn ymateb gan Reolwr Cysylltiadau Cleifion, a llythyr yn dweud wrthyhych pa gamau y gellwch eu cymryd os nad ydych yn hapus efo'r ymateb. Dylech dderbyn yr ymateb ymhen 20 diwrnod gwaith o amser cyflwyno'r gŵyn

*Mrs Ita Hawkins
Rheolwraig Cysylltiadau Cleifion
Ymddiriedolaeth GIG Gogledd Ddwyrain Cymru
Ffordd Croesnewydd
Wrecsam LL13 7TD*

Llinell Union: 01978 725598

12. Fydd y ffaith fy mod yn cymryd rhan yn yr astudiaeth yma'n cael ei chadw'n gyfrinachol?

Bydd yr holl wybodaeth a gesglir amdanoch yn ystod cwrs yr ymchwil yn cael ei chadw'n hollol gyfrinachol. Bydd eich enw chi a'ch cyfeiriad wedi eu tynnu oddi ar unrhyw wybodaeth amdanoch chi fydd yn gadael yr ysbyty / y feddygfa, fel na ellir eich adnabod oddi wrthi. Hysbysir eich Meddyg Teulu eich bod yn cymryd rhan yn yr astudiaeth yma.

13. Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?

Adroddir am y canlyniadau yn y wasg nyrsio. Fodd bynnag, ni fydd eich enw chi'n cael ei grybwyll mewn unrhyw adroddiad na chyhoeddiad.

14. Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Trefnir yr ymchwil gan Mrs Kath Clarke, arbenigwr nyrsio clinigol mewn rheoli poen, Ysbyty Maelor Wrecsam a Phrifysgol Cymru Bangor.

15. Pwy sydd wedi adolygu'r ymchwil hon?

Mae Pwyllgor Moeseg Ymchwil Awdurdod Iechyd Gogledd Cymru wedi adolygu'r astudiaeth.

16. Cyswllt ar gyfer gwybodaeth bellach

Am ragor o wybodaeth, os gwelwch yn dda, cysylltwch â Mrs Kath Clarke, arbenigwr nyrsio clinigol mewn rheoli poen, ar y ffôn 01978 291100 bipiwr 5872.

Diolch yn fawr i chi am gytuno i gymryd rhan yn yr astudiaeth hon.

Appendix 6 Consent form

Dear

Re: your experience of living with chronic pain.

I am a nurse with a professional interest in chronic pain and I am currently studying the experience of living with chronic pain for my research degree. I understand that you have been attending the nurse-led pain clinic and wonder if you would be prepared to share your experience of living with chronic pain with me.

I do not have a list of questions, but I will ask you to describe your chronic pain experience in your own words. This should take approximately an hour. I would like to tape-record our conversation so that I do not miss the important details. Everything that you say will be treated in the strictest confidence. Your name and details will not appear in the report and the tape will be destroyed after use. No information will be passed to any other agency. The interview may take place in your home, the hospital, or in an office in the School of Nursing, whichever you prefer.

I will also be asking you to keep a pain diary detailing your pain experience over one month starting from the date of the first interview. Again the information from this will be kept entirely confidential and destroyed after use. Following completion of the diary I would like us to talk again, this second interview should take no longer than half an hour.

If you are willing to talk to me and to keep a diary, please return the attached consent form giving your name, address and telephone number so that I can contact you to make an appointment. If you would like further information please contact me on the telephone number at the top of the page. Please do not feel any pressure to participate – I fully understand if you prefer not to and your decision will not in any way affect your future treatment or care.

Thank you for your time, I look forward to meeting you in due course, should you decide to accept this invitation.

Yours sincerely,

Kath Clarke, Clinical Nurse Specialist – Pain Services

Consent form: Your experience of living with chronic pain.

I am quite happy for Kath Clarke to interview me on two occasions about my chronic pain experience. I am also prepared to keep a pain diary for one month for research purposes.

I understand that everything I say and write will be treated in the strictest confidence, that I am able to withdraw from the study at any time I choose without any need for explanation, and that such a decision will not affect any aspect of my future treatment or care.

NAME (please print)

SIGNATURE

ADDRESS

DATE

TELEPHONE NUMBER

The best time to contact me is:

WITNESS' NAME (please print)

SIGNATURE

ADDRESS

DATE

Appendix 7 Sample characteristics

For ease of identification each patient has been allocated a code which denotes first their gender, second their age and is used throughout the study, fortunately these were unique identifiers.

Participant's Code	F44	F37	F58	F56	M48	M74	M58	M37
Participant's Characteristics								
Age	44	37	58	56	48	74	58	37
Gender	Female	Female	Female	Female	Male	Male	Male	Male
Pain Location	Back	Back	Back	Bladder	Foot	Back	Stump	Abdominal
Length of time attending clinic	3 years	6 years	5 years	5 years	6 years	6 years	3 years	6 years
Religion	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian
Place of residency	Wales	Wales	Wales	Wales	Wales	Wales	Wales	Wales
Ethnicity	White	White	White	White	White	White	White	White
Marital Status	Single	Married	Single	Married	Single	Married	Married	Single
Lives with parents	N/A	N/A	N/A	N/A	Yes	N/A	Yes	No
Children living at home	No	Yes (Under 10)	No	Yes (Adult)	No	No	Yes (13-18)	No
Place of 1 st interview	Clinic room	Clinic Room	Clinic Room	Clinic Room	Clinic Room	Home	Clinic Room	Inpatient – on ward
Place of 2 nd interview	Clinic Room	Inpatient–on ward	Clinic Room	Clinic Room	Clinic Room	N/A	N/A	Home

Appendix 9 Example of an initial interview transcript

- K It's about the things about living with pain without focussing on the pain because that will make your pain worse.
- M48 If you think about it.
- K Absolutely.
- M48 I always think get out and annoy somebody and you're all right.
- K That's fine. So it's what you think you feel what you're doing its all those sort of things that need to go in it really and truly, but if you don't want to write in it on a particularly day then you don't have to. But if you've done something perhaps something different something extra and pain has had an impact one way or another and you've thought well I've had a bad day because – stick it down, or it's a good day because – all right? So it's not a negative thing.
- M48 No no.
- K Right.
- M48 Some days you do something and it kills you and another day you can do it and you're all right.
- K That's fine, that's right. It's those sort of things which I know would have been in your information leaflets but I feel sure I forgot to mention it when I was recruiting.
- M48 I just read it quick when I got in the car and I just told Dad and he said its okay then and that was it.
- K Good.
- M48 He said well if it helps you.
- K I think what the plan is.
- M48 I don't know whether it will help you or not but.
- K Well it should do. From a nursing view point what we are starting to realise is that it's not just this science, the pure science that is going to help, so yes, pure science could you know cut people up and have a good look.
- M48 Oh aye yes.

K And say okay we know this does this and this does this. Fine. But from a nursing viewpoint we are not into that what we actually want to know is what is it like for our patients, and there are some things that I am finding are coming out as well that we actually as nurse had never thought about before, so if some of these things come out can we make our clinic any better or can we put another service in there that will make things better or I mean, I don't know until I've done it. I mean like I've said to you.

M48 Well you only know if you try something.

K That's right and you're number three of twelve, and you're the first man.

M48 Oh.

K There's going to be six men and six women. Because we might see differences there but we might not everybody might be the same.

M48 That's it.

K Everybody might be very, very different although saying that so far with the two there are some things coming out that I think wow its looking as if that might be important. So at the end of it when I've got all the twelve interviews and the twelve diaries well I look at them and I analyse them and try and pick out what is important and perhaps why it is important and look and see how we can improve things. So that's how it will work.

M48 Yes.

K And you were picked on really because you have been coming to the clinic for over three years.

M48 Too long.

K No, no, not too long at all. But that was all part of the criteria, having somebody who's been coming to the clinic for a while, so you know me.

M48 Yes.

K Because this sort of interview otherwise wouldn't work would it?

M48 No, no.

K If I was a total stranger.

M48 You wouldn't bother talking to a stranger would you?

- K No. So that's the whole reason it had to be someone who had been attending for three years.
- M48 Oh I see.
- K And you're the right age group, because you're not over 65 or under 18.
- M48 Not just yet! (Both laugh) getting there though.
- K So you're working on it!
- M48 Yes.
- K Are you in your wheelchair all the time?
- M48 No. I use my crutches at home and when I come here for acupuncture, say I came about three weeks ago, didn't I? And I can use my crutches up to the end of the third week more or less round the house and then my shoulders go and you think arghhhh, I'm not going to touch them today cos they're going to kill me.
- K Yes.
- M48 Well you could use them but you're in pain and then sometimes if you have a sudden pain and it jerks you and you drop, fall, dead!
- K Have you got stairs at home?
- M48 No. No. We're in a bungalow.
- K So you don't have to worry about going upstairs?
- M48 No.
- K So at home you are actually very independent.
- M48 Oh yes.
- K Do you drive yourself?
- M48 Yes, three wheeler (laughs).
- K Makes no odds does it?
- M48 No, well it does, it helps if you can get out and about doesn't it? Without depending on someone to come and pick up or it's like waiting for a bus, waiting for somebody, it never comes.

K That's right or they all come together (both laugh).

M48 Yes that's it. We can't wait to come and take you out today M48.

K Because you live (pause) well out in the sticks (laughs).

M48 In Cerri

K Out in the sticks, well I shouldn't say that really should I?

M48 Well we have two shops there.

K Wow.

M48 And one post office, two pubs - that's most important.

K I was going to say, I was going to say.

M48 And we've got a library and we've got our own doctor's surgery.

K Oh so it is improving now. You get a lot of rain don't you?

M48 No.No. That's Blaenu Ffestiniog you get a lot of rain. (both laugh). So. And we've got a snooker club.

K And I suppose you go to all of them do you, the pubs and the snooker club?

M48 I go to the pubs. I go to the snooker club when I'm fit, when I can stand up without my crutches and bend over but I don't play as often as I used to. I play whist a lot though.

K I like a game of whist.

M48 Three, four times a week.

K Do you?

M48 Yes, and I play cards, bridge and in the afternoons sometimes if I can con someone to play - and chess, on the computer. That's it.

K Have you got a computer at home?

M48 Oh yes, just to play games on.

K That's fine.

M48 I don't pretend to think I can send e mails to someone or anything. I just play the games on it, chess, draughts, solo, all the card games and different things.

K I like solitaire.

M48 Yes.

K With the Vegas scoring on it.

M48 That's good.

K I won't play any other way.

M48 The hard way I like. Anything that's a challenge.

K One card at a time.

M48 No, no.

K I don't turn over three, got to turn one card at a time.

M48 No you've got to have a load.

K Do you think its harder turning over three than one?

M48 Makes it more interesting doesn't it?

K Don't know, haven't thought about it.

M48 Its like if you're playing chess on the computer if you have it on grade one, you get as bored as anything, you're waiting for the computer to work out what move it makes and by the time he makes that move you're ten moves in front of him. But if you have it on grade 7 or 8 then you have to start thinking don't you?

K Yes, I'll try it on three next (both laugh).

M48 I like anything like that. The only trouble with me is I can't read or spell very well so anything that you have to spell or read a lot. Ta ra, I don't want to bother about it. Too lazy you see.

K I was just going to say that sounds more like impatience than anything else.

M48 Yes, yes, well if I've read the paper in the day then that's enough reading for me today.

K But if you read the paper a day that's more than most people do.

M48 I like my daily papers. I have the Sun and the Daily Post.

K So you read both of them?

M48 Oh yes.

K I wouldn't worry about your reading.

M48 I wouldn't sit there and read a book like some people read book after book. I couldn't do that. I'm all right reading but if someone said spell something, forget about it. Yes but arithmetic to do, I can do that.

K So you like your maths rather than the English side of it.

M48 Oh yes.

K And there's me giving you a diary to keep for a month.

M48 Aye I know.

K Don't worry about it don't worry about the spelling cos I can sort that out

M48 And if you can't you can always ask me and I'll say oh that's that word.

K (laughs) well if I get stuck I probably will.

M48 What I do is spell the way I say it.

K Yes phonetically.

M48 Like they do in Welsh don't they, they spell it as they say it?

K Yes.

M48 Well that's the way I spell.

K Are you Welsh speaking?

M48 No. But I used to be.

K Ah right.

M48 When I was in - what is it? The baby school?

- K Infants?
- M48 Aye that's it. They taught us all in Welsh and then they sent me to Llandudno school for disabled and there was no Welsh there, so it was in English wasn't it, so I was spelling the English word the Welsh way. And they would say "oh that's wrong, that's wrong" like I couldn't get hold of the English way of doing it so I've never, I can't I've got no patience for reading or writing. But like as you say doing a diary its just jotting a few words down a day.
- K It is yes. It might improve your spelling.
- M48 Ohh, you're wishing for something.
- K That would be an outcome we had never imagined.
- M48 No. I can't I haven't got the patience. And like they said in school you haven't got no patience for reading, spelling, you want to do something not sit down and read.
- K And yet you've got patience with other things haven't you? You've got patience with bridge and chess. Because they're games that take patience aren't they?
- M48 Because something's happening isn't it?
- K Is it? Okay then I believe you.
- M48 Well it is. You've got to be thinking about it all the time haven't you, whereas reading its just one word after the other or spelling - no point in that is there? (Both laugh). I say as long as you can tell somebody to hell with it. And today with most things you can ring them up and tell them can't you?
- K Yes, most definitely.
- M48 So.
- K Although e mail is bringing back the written word a little bit and text messages with mobile phones.
- M48 Oh I never bother with that. I've got a mobile phone.
- K But you don't text.
- M48 No.
- K And yet I say its bringing back the written word, we all abbreviate on that. It's awful.

M48 Yes.

K Some of the spellings on that.

M48 Yes it's like Morse code innit?

K Yes it is most definitely. It's terrible.

M48 When people text me on my phone I just read 'em and think what the hells all this about? You have to learn the language before you can read it.

K Yes it is like another language you're right. It is definitely, definitely another language.

M48 Like you've got a degree in shorthand to read texts. I don't like, not that I don't like, I just don't do it.

K Just don't do it.

M48 No.

K So your normal day..?

M48 My normal day is I get up about, I wake up somewhere around half past five, six o'clock when the pain kicks in.

K So the pain actually wakes you in the morning?

M48 Yes.

K Pain where?

M48 In my shoulders or in my leg, but in my shoulders mostly. Then I get up make a cup of coffee, put the pain machine on my leg.

K Your TENs?

M48 Yes TENs then stick that on for half an hour and that's okay, well could be okay for five or six hours then so I don't bother with that. Take er if my backs really bad or my shoulders take a couple of not DGs them that have changed instead of DGs DCs? Or something.

K Yes.

M48 Yes, I take a couple of them and if its not better within four hours or three I take a few more. I always go down for my paper by quarter past nine. I make a point doesn't matter how much pain I'm in.

K How do you go for your paper, the car, your crutches or chair?

M48 Go to my car on my crutches, get in my car and go down in the car, go in the shop and then if I'm - doesn't matter if I'm in pain or anything I've always made a rule I've got to go for the papers.

K Why have you made that rule?

M48 Because it makes me get up and get out.

K Good.

M48 Cos I think if I've got to do that I've got to work for that and I've got to work for that time, cos I think if you don't do that you'll miss one day and you think to hell with it I missed it yesterday so I wont bother today. That's my rule, it might be a daft rule to you.

K No, no.

M48 Or to anybody but I always make a point. I've got to get up and go for the paper and then Dad getting up himself and asking for the paper, we have breakfast then I decide what I'm feeling if I'm feeling all right, I'll go maybe go out shopping or something or to shop! Oh no I go to the drill hall Wrexham.

K Yes.

M48 I just do it then I don't know sometimes you have to go and see someone because you haven't seen them for ages and then well, (pause).

K Have you ever worked?

M48 Yes. I used to work in a door stripping place. Putting doors in caustic and lifting them out but I couldn't do that after I couldn't - after I had the heel and the ankle bone taken out.

K Yes.

C I couldn't stand up to do that could I? So.

K Why did they take the heel and ankle bone out in the first place?

M48 Because it was rotten.

K Right.

M48 Because I had an operation when I was six or seven to straighten my feet because they said I got club feet or something and they had grown and they had to cut a tendon and it had gone so I couldn't walk at all and then they done that and it went septic and they left a big hole in the back of my heel and when I was about 32, something like that my feet started to get like bumps on it and stuff coming out. So they said the heel and ankle bone was rotten. So they asked me, well they said that I would have to go and have that taken out so I thought well I don't want to die from it cos they said it might be poisonous. So I had that out, well they said you could have your leg off below the knee. So phew - anyway they said they'd try and save it and they done and they just took the heel and ankle bone out.

K Did you have much pain in the foot before all of that?

M48 Er not much really. No I can't say, well I don't bother if you've got a bit of pain then you're alive aren't you? (Both laugh). Well people say to me how do you put up with the pain but I say if you're in pain you're alive aren't you? That's the way I look at it.

K So having a little bit of pain doesn't bother you anymore?

M48 O crikey no. I wouldn't know if I was dead or alive. I'd do something to make it hurt wouldn't I? Like well I can't remember when I haven't had pain.

K Even as a child?

M48 Well I had some sort of pain innit but well you don't bother with it do you unless it's bad, bad, bad but like Dr Fred, my old, old doctor, he's retired now he used to say if I was in pain I was in terrible pain because like I didn't feel very much and if I was complaining about pain he said he would be through the wall with it. I mean if I'm not in pain I'm not in pain, well I have a little bit of niggly pain all the time but that doesn't matter does it? It's like long distance tooth ache.

K When you have your niggly pain where is it?

M48 Sometimes in the bottom of my back and mostly in my foot. Just around there (points to outer aspect of foot) and er its just throbbing, not a - how can I put it well long distance tooth ache, and then some days its really bad and you think well I'm not going anywhere today, cos it feels as if you're foot's going to jump off innit but its not bad now so and then me back. My back throbs there's always a niggly pain there as well but as I say if you don't well if it's not out of the ordinary you don't bother with about it do you? It's like I say it's normal, it's the same as it was yesterday. As long as it's the same as yesterday it's all right today. You know what else can you do, you can't do anything about no point in going

around moaning "oo I'm in pain today", otherwise you'd always be moaning wouldn't you?

K Probably.

M48 Well that's the way I look at it.

K Overall do you think that pain has greatly affected your life then?

M48 No, I don't know (hesitant and unsure, I think he doesn't quite understand the question).

K Do you think your life would be any different without the pain?

M48 Yes I would think I was dead. (K laughs, M48 joins in)

K Well you see your pain as being quite positive don't you.

M48 (Still laughing) oh yes.

K (Laughing loud and long) oh God I'm going to have great fun transcribing that one (still laughing).

M48 Well its true isn't it? If I didn't have pain there would be something drastically wrong or I'd be dead wouldn't I?

K Fine.

M48 You know I've always got pain of some sort, not that you can't bear it and things but I say niggling you, well as long as I can go out and annoy somebody it takes your mind off the pain if I aggravate somebody else and you see them go red in the face don't you.

K Oh that explains then doesn't it (both laughing) fine.

M48 So that's the way I do it. And then well you're bound to have really off days aren't you? So I just stay in the house so nobody sees me cranky, only me dad. And then he thinks hey up get out the way.

K At least your dad is different then.

M48 Oh aye I can take it out on him, he doesn't bother does he?

K No that's right.

M48 He just knows, right get out the way.

- K Is there just you and you dad at home?
- M48 Yeah, and oh Rex the dog.
- K Well don't forget the dog.
- M48 Oh no you can't forget him because well if I'm feeling a bit down or something he comes there and he sits on my knee and I stroke him. So its all right he's always there in he?
- K It's unconditional with a dog.
- M48 Yes.
- K Yes unconditional. Do you have any problems or have you had any problems with having people believe that you've got pain?
- M48 Alan my GP.
- K How does it make you feel then?
- M48 Oh I don't bother with him. I just said the day you see me as a patient is when I'm dead because well I've got nothing to say to him at all.
- K What brought that on? What did he do to make you feel like that?
- M48 First of all he upset me by saying to me dad that there's nothing wrong with you, about me dad, me dad went there oh it's going back 15, 16 years and Alan had just come there, Dr Knight, just come there and dad went there with an ear infection and Knight said oh you're all right you can back to work this afternoon. So dad said aye okay but me ears hurting. Well I can't see nothing. I come home. Dad was lying on the sofa cos he said I can't go back to work with this pain he had a cold flannel on his ear and stuff come, he had burst his ear and when he went back to Knight, Knight just said Oh I must admit I didn't take no notice. So that was the first time. Well and another time when me mam was dying, she got up at six o'clock in the morning and she had a stroke - was it? And er I rang the doctor, Dr Knight was there and he said what do you expect me to do about it. I said me mam's collapsed in the toilet and she's on the floor and he said what do you expect me to do about it? Then I just said I expect you to be down here within 5 minutes and he come then he said you was right in calling me. So I'm sorry but I've lost my confidence in him.
- K So more than just disbelieving your pain you feel as if he just disbelieves you full stop?

- M48 That's it, he's Irish in he? (Laughs)
- K If I was a film maker I would have to say "cut" but as I'm not we won't worry about it.
- M48 I don't care. No I don't get on with him at all.
- K What about other health professionals nurses, doctors?
- M48 Oh the nurses are brilliant. And we've got a new doctor in now, brand new, but I've only ever seen her the once and I went there with a pain in the sole of my foot and she was ready to send me to hospital with it and I said "no thanks" and that put me off going to her if she's going to send me to hospital with a little scratch or something. I don't want to be bothering with her do I? So I see the district nurse now, the practice nurse and they know me so ...
- K And that's the difference really between the new doctor and the nurses is that one knows and the other doesn't.
- M48 Yes but this old doctor knows me but he doesn't well he's had his chances with me I'm afraid.
- K When you report pain to other people, when you're having a bad day and you actually tell people you're having pain do you feel that they always accept what you're saying or do you feel that you have to try and prove it.
- M48 Oh no they know when I'm in pain cos they know that I can't joke or anything cos I just tell 'em to (blows a raspberry) when other times I'm messing about and so well you know. My Godchild lives across the road, she's 12 now and she knows when I'm in pain, she says "Leave him alone today he's in a baaad mood" (both laugh). She's known me ever since she was 18 months old and she can tell straight away, to get the way or whatever and her mum can. So they know to get out the road and different things and me dad does.
- K So when you're having a bad day that's literally all you do, keep yourself to yourself.
- M48 That's the best isn't it? There's no point going out and well you know you know you're gonna annoy people proper if you're in pain and in a bad mood, so you just keep yourself to yourself and hope for the best that it's better tomorrow and then get out and go where you want too don't you?
- K When you have your severe pain episodes do they last just for a day or can they last longer?

- M48 They can last two/three days, I think, four days is the most I think. I mean they start, go down here (points to side of foot) but you can't well you know when it's coming on and you just sort of gear yourself down to sort it out when it comes.
- K Do you still go for your paper on your bad days?
- M48 Oh yes, always yes got to. That's a rule, a bad rule I know but I've made it and I've got to go for my paper. Well on those days I just go in, get my paper and come out innit. That's it but you've got to get up to go for the paper, cos once you start staying in the house you may as well be shot mightn't you. You know I hear of other people they won't go out today, they wont go out tomorrow and they wont bother the next day well I don't want to be like that.
- K Um.
- M48 Three years ago, no two years ago I was in bed rest for six months that killed me. (Both laugh). Never again.
- K Was that at home or in hospital?
- M48 Oh at home, it was better at home, I had the choice of staying in hospital or go home and I said go home; at least you can make a cup of coffee.
- K Was that because of your foot.
- M48 No, I had er, at the bottom of my spine, I have no feeling there, and er well what's the word, what do they call er an ulcer at the bottom of my spine and it burst and cor it was a hell of a mess.
- K Was that actually painful or? You have no sensory feeling?
- M48 No.
- K Well that was lucky!
- M48 Yes that's what I said but when I said that to what's his name, Dr Drew, he said it isn't lucky, if you had known it, if you've been in pain, you would have known it was there.
- K You'd have done something about it sooner.
- M48 Yes, but I didn't know, until-.well what it was I went to the doctors for MOT I call them and they took me blood sugar, and they said you're going to hospital, and I said why, she said you're a diabetic your blood sugar is high. So I thought well it's all right, I'm feeling all right, anyway I had to go. I come in for ten days and that was all right, my blood sugar was all right, they checked it and checked it and

no, anyway they said you can go home, keep an eye on your blood sugars innit. So I went home, three days later I thought crikey what's this mess on the bed when I was getting up. The district nurse was coming in to do my blood sugars and I thought I had better tell her about it anyway she looked and there was a hole in the bottom of the spine like that, (holds finger and thumb in a circle).

K Good grief.

M48 And all this yakky stuff coming out. So that was six months of bed rest. So I didn't like that very much, captured for six months.

K So who went for the paper then, your dad?

M48 Me dad had to go then didn't he? (K laughs) So that was it I couldn't do anything about that but. I don't stay in bed unless I have to; once I'm awake I'm up.

K Um.

M48 Like this morning I was awake about quarter to six so I got up, made a cup of coffee let the dog out, waste a bit, bin down for the paper. Dad got up, we had breakfast and then we come here.

K Is your dad with you today.

M48 Oh yes, he comes for the ride and Rex did. (Both laugh)

K What sort of a dog is he?

M48 A terrier.

K O right.

M48 A Jack Russell. A good dog. (Silence) well I don't know what else I'm all right apart from that. Like I always say I'm all right as long as I can get up get out and annoy somebody. And that's the main motto.

K Well good on you, good on you.

M48 And if I can annoy anybody on the way anywhere I will.

K So going onto very womanly things then, who does the housework?

M48 Er I do the washing up, dad does the cooking, cos he doesn't think I'm safe, in case the door bell goes and I jump and I've got a saucepan or something in my hand, er me dad does the hoovering, I do the dusting.

- K Who does the washing?
- M48 Washing machine (both laugh).
- K Fine, so whoever's around just shoves that in then.
- M48 Oh no, we shove it in but we both shove it in then and then when it's loaded I put the washing machine on and that's it. And I take it out, and I put it on the line or in the tumble dryer and then, well I get up, have a shower every morning, and then that's the way I go all day then, just trotting along, and sometimes you have to have another shower because your bags leaked and then, not very often though like. But it does happen. You can be out and the next thing you look at your leg and you think what the hell's happened there. (Both laugh).
- K And here we go again?
- M48 Aye that's it. It's all right around the village they know if like if you go down in the shop and the bag bursts straight away or your catheter comes off on top of the bag, scream a leak don't you. So they know straight away well they don't know but they just think that's M48 and he's gone again, and that's it! So even at the whist drives they know, I can be there one minute and gone the next and they have to find somebody else to take my place.
- K Do you think that's one of the advantages of living in a small village?
- M48 Having everybody know you? Oh yes. Oh aye.
- K Would you manage in a town like Wrexham?
- M48 I don't know. I don't think so, like nobody knows you do they? I mean I go to my brothers once or twice a year and he doesn't know his next door neighbour.
- K Where does your brother live?
- M48 Gloucester.
- K Oh that's quite sad not knowing your next door neighbour.
- M48 Oh I'm not saying he doesn't them, he knows them to say hiya and that's the end of it.
- K Yes.
- M48 My next door neighbour I can shake him up or you have a good laugh with them innit it? But I wouldn't like to live where my brother lives because he doesn't

know nobody does he? He goes down to the pub and he doesn't know anybody there and when I was there last time he knew him by sight.

K Um.

M48 But he doesn't know where he lives or anything like I know where all my mates live and I know if he was to ring them up they would be round there in as soon as they can or whatever. (Silence). Like Jonesy, me mate, he's had little uns and they kept on asking him what was wrong with me, cos we don't see each other all that often and he says don't say nothing and I always say no tell em if there's something wrong and then that's it - finished.

K Its over and done with I quite agree.

M48 Whereas if you say don't ask...

K They ask all the more.

M48 What's wrong with him, why, why? Why's he using the chair? Why's he using the sticks? When I said to him you tell em that I'm disabled and I've hurt my leg or tell em something and then they'll understand well they won't keep on wondering will they? It's like Elaine, she's another one, she's got three little girls, they're my godchildren I was telling you about when I first knew her and Elaine was four and the other two were a bit older and they kept on saying why is M48 using sticks and different things. She used to say don't ask he has to use them and that's it but I said just tell em I've hurt my leg or something because and then when they're get older you can tell em a bit more can't you? But if you give them an answer...

K Yes.

M48 They don't bother. They just think oh its M48, its okay. Like Elaine says now the kids go to school, the big one's in big school and she helps disabled people where the other children there are scared of them so Elaine reckons it's done them some good, knowing me so that they're not scared of people, different, aren't they? So I don't know (silence) I just think get on with it.

K What was it like in school when you went to the school in Llandudno?

M48 Oh that was all right, cos there was all disabled people there. In the first school I went to it was hell. They kept on calling me stink bomb, slow coach and everything because I was wearing bags and they leaked, well I wasn't wearing bags then they hadn't put bags on me so I was always wetting myself and things, until I was eight it was hell. I was always in fights (both laugh).

K It didn't stop you fighting?

M48 Why should it? It was part of the enjoyment of school.(both laugh) well like Dave, he's in Canada at the moment , he used to be in school with me and he used to catch and he used to shove em in the kids cloak and I used to go in and duff em in. it was the only way I could catch em wasn't it? (K laughs) and then they'd go home and tell their parents that they had had a fight with me and get a good hiding for fighting with me. Dad had to tell em don't take it on them when they get home they've already had a good hiding (both laugh) so that's the way to sort that out.

K Once you went to Llandudno then that was better?

M48 Oh aye, compared to them in Llandudno I wasn't disabled was I? I was the lucky one I could walk. I could do everything whereas a lot of them was in wheelchairs, they couldn't get out of wheelchairs, they couldn't do this, they couldn't feed themselves some of them could they?

K So you went from one extreme to the other than really?

M48 Oh aye, yes. I was top dog, I was you know, if anything was wanting doing and the house parents weren't around "send for M48 he'll do it".

K Was that a boarding school then in Llandudno?

M48 Oh yes.

K Were you home at weekends? Or...

M48 No full term. Forced.

K Was it good fun?

M48 Oh aye.

K Midnight feasts and things like that, or did you not bother?

M48 Oh aye.

K I suppose the novelty wears off after a while doesn't it?

M48 Oh aye, yes it was all right, it was all right I don't mean good but you miss your home life. Like it takes you a bit to get used to being at home when you, I always say I done it the wrong way round I left home when I was eight and come home when I was 16, when I should have been leaving home shouldn't I? But it did help me a lot, school, the only thing was you weren't at home at all, but it was one of those things though (quietly spoken, sounds wistful, almost sad).

- K Yes (quietly).
- M48 It's like my brother he was at home whilst I was at school and when I left school he was in the airforce so I don't really know him as a brother and he doesn't know me cos if I say oo I'm having a little bit of pain today he's panicking, he's rushing me off to hospital before I can even take a tablet for it. He panics, but then again he doesn't know me does he?
- K Have you just got the one brother?
- M48 Yes.
- K Is he older or younger?
- M48 Older. He panics something terrible. Like one side I had a stone moving from the kidney to the bladder and you're in pain with them you are.
- K Yes you are.
- M48 And he was petrified. They brought me in here because the doctor seen me and said oh well take him in, and Tony was pacing up and down the ward and everything. Petrified. He said well why aren't they doing anything? But what could they do, they had to wait for it to pass don't they?
- K Yes. Not a lot they can do really.
- M48 No, no. they give me what is it, pethidine or something?
- K Um, um.
- M48 That's all they can do innit unless they shoot you and get rid of you proper.
- K We're not allowed to do that.
- M48 No, no, but he was panicking that time. I mean like now well we were there for Christmas I was allowed to move off me chair in case I hurt myself. I said hang on I can do things you know I'm not thick.
- K So you and your dad went down for Christmas?
- M48 Oh yes (pause) and Rex!
- K Of course.
- M48 No, no we went down on the Tuesday before Christmas and come back on the Saturday?

K To have New Year at home?

M48 Yes you can have a drink at home can't you?

K Absolutely.

M48 A bottle of Bacardi and coke.

K Did you stay in or go out?

M48 No I don't go out on New Years Eve it's too dangerous.

K Dangerous? (K laughs) What it is or you are?

M48 Its too dangerous to go the pub in case you get pushed or something like that and they knock you off the crutches, they don't mean too but on a night like that you might as well stay at home and that's it, like on another night I'll go there and its all right.

K Quite safe.

M48 Yes.

K Like now when nobody's got any money.

M48 That's it.

K It's very quiet in the pubs at the moment.

M48 Its boring isn't it?

K I don't know there's something...

M48 It's always dead in January.

K Yes, a huge anticlimax isn't it.

M48 On Christmas day you think thank God that's all over, then you think crikey it's boring now.

K Got to wait another 11 months before starting to get hyped up again.

M48 Yes that's it. Its all hype I like seeing my God child a cross the road she's just about two years since she stopped believing in him, but up until then I could wind her up and say the chimney, the wind howls in the chimney and I'd say oh there s

father Christmas and she'd be quiet for a month or two before Christmas and (K laughs) and do anything you tell em because Father Christmas's up the chimney. Now she says Oomph you don't get me on that no more. (both laugh) so they're a great help the Godchildren like when I was in bed rest for six months they was always in and out, they'd come straight after school, wind me up a bit, then go home, then come back and wind me up.

K Passed the day a little bit for you?

M48 O aye.

K Where was the dog?

M48 We've only just had him.

K Oh have you, so he wasn't on the bed with you?

M48 Last March.

K So he's a pup really.

M48 Oh yes he's a proper pup do anything, chew your shoes, he's a good dog

K (Laughing) I wouldn't call that being a good dog!

M48 Oh aye it's me that says you can tell whose dog he is by how much trouble he gets into.

K So who takes the dog for a walk then, you or your dad or both?

M48 My dad takes him for a walk and then I'll take him in the car and let him out and he'll come running back to me. But I take him up to a quiet place so he doesn't get run over.

K Well yeah, you can find quiet places can't you?

M48 Especially where we live.

K Yes.

M48 Well I know all the Forestry roads and I can go up a road and let him run up there, like I've lived there all my life and so I should know everywhere shouldn't I?

K He always comes back does he?

M48 Oh aye, he might be away for an hour and a half but he'll come back.

- K So what do you do, just sit there and wait for him?
- M48 Always got something to do, there's always birds or something running around isn't there? Rabbits or foxes to watch.
- K So you literally just country watch, nature watch?
- M48 Yes, I can sit in the middle of nowhere just watching what's going on around me better than sitting in town and watching people go past. No I don't, I prefer that to be on my own just watch something go by or in the middle of the Forestry or up to the Brenig lake, find a quiet place up there just watch the water and whatever happens.
- K So you're quite comfy with your own, just being you aren't you?
- M48 Yes.
- K You know you don't need anybody else as such?
- M48 No, no why should you?
- K And yet you always come over to me as being very social.
- M48 Yes you have to be don't you?
- K So you're half and half?
- M48 You've got to be, there's no point in being grumpy, sitting in a hospital with a load of patients is there? You might as well go to the nearest one to you and wind him up, get him going. (Both laugh) You've got to; it's where you are, in which situation, innit? Its as Molly's Mam says "You can be as daft as anything when Molly's about but as soon as something goes wrong, you're there straight, you don't bother, you concentrate on whatever's happened" But she said Molly can pull you to pieces or do anything to you and you wont bother but somebody annoy you, God help em. (Both laugh).
- K Have you got a temper then?
- M48 Oh yes, yes and everyone says watch his eyes. When people can notice, well my cousin, she says, she lives in Ruabon, and she says when your eyes go you just get out of the way. I don't know what happens to em but she says I can see it in your eyes. And once they go you've had it, you just get out the way.
- K Do you lose your temper easily then or does it take a bit to get going?

M48 Oh it takes a bit, but when I do, well ...

K When you're having a painful day do you lose your temper more easily?

M48 Oh quite easy. Very easy then. You lose your temper when you're in pain but then I think crikey I shouldn't have done that then. You know it's just that you get a jolt of pain don't you and er kill!! Toothache's the worse. I hate toothache.

K Yes I don't like toothache. I hate the dentist but I hate the toothache worse.

M48 Well that and the stone is the worse pain you can get.

(Tape finishes)

K Can you imagine, well I have...

M48 Wasted an hour.

K Well I have, but what would I do, would I be really honest and say to the patient I'm sorry can we do that all over gain? Or would I not say anything and just try and recruit another person. I don't know. I don't know.

M48 It hasn't happened yet then.

K No, no it hasn't happened yet, hasn't happened yet but it's my worse nightmare particularly when you listening to stuff and you're thinking that's really helpful, that's something I haven't thought of before, or you know. You've said things today that the others haven't said which is right - are we going to see this coming out in all the men now or ...

M48 Oh.

K Do you see what I mean?

M48 Yes.

K You just don't know what's going to happen so you can't help thinking ooh that's really good. (Laughs)

M48 I don't know that's I just think get on with life. And I always, Dr Wood says you could be, you want to think about next week or next year or something like that, I say as long as I'm all right today to hell with tomorrow, I could be dead couldn't I?

K I suppose it depends which way you're thinking of. If he's thinking of your health next year, do you smoke?

M48 No.

K So fine. Do you drink?

M48 Yes

K How much?

M48 Not a lot really, it's ...

K As long as your drinking is within acceptable limits.

M48 Well I drink about three pints a week and me Bacardi, a couple of drinks of that a week.

K Perfectly acceptable, well within safe limits well you know.

M48 It's not as though I'm down at the pub every five minutes.

K You are not horrendously overweight; you are as active as you can be.

M48 I go swimming once or twice a week.

K Oh do you? Where do you go swimming?

M48 Bala, because Martin lives in Bala and he can help me out if I need any help.

K Yes.

M48 All I need is my wheelchair bringing to the side of the pool. I get in it.

K Are you a good swimmer?

M48 I don't know. I don't use my legs at all.

K Just your upper body.

M48 Like when I'm in the water I haven't got any legs they just float about.

K Yes.

M48 And Martin it annoys him, he can't float but I can lie there and just float all day.

K Yes.

M48 But if he tries that he sinks!

K Tell him to cross his legs.

M48 Oh is that what it is?

K Well, I don't swim very well at all and I started having swimming lessons and we were asked to float and I can just do it and the girl said to me she said "just cross your legs" and I can do it now. So I just cross my legs and I can just, but I think its down to the same as you were saying you're legs aren't there when you swim, when you cross your legs your legs aren't there either. You can't kick them or move them or flap or anything like that. I mean I find it makes a difference.

M48 See when I was in school, mind you we all went swimming didn't we? They used to chuck, you know the ones with muscular dystrophy, they can't do nothing can they?

K No.

M48 They used to just get hold of them and chuck them in and just floating about. They didn't bother. Because they couldn't fight it, they just floated. And that's what they said to me, if you fight it you drown if you just float.

K And we're designed to float at the end of the day aren't we?

M48 So if I get in the pool I have a few laughs and then if my shoulders are aching I just lie back and float about.

K What stroke do you use in the water then? Breast stroke or over-arm?

M48 Back stroke.

K So you swim on your back?

M48 Yes. Well I do swim on my front but back strokes the best. But I don't use my legs at all.

K So as far as your GP's concerned you are thinking about next week, next month, next year in a round about way. I mean you are, your health overall is very good.

M48 Oh yes.

K Considering everything that you have to put up with.

M48 I know I'm overweight and all that but, a lot of people are overweight today aren't they?

K The majority of people are overweight.

M48 Aye but I can't go running down a field like other people can I do as much as I can, I walk, I (pause) go swimming and different things. It's not as if I'm the same as I was yesterday to hell with tomorrow.

K Absolutely.

M48 Why worry about tomorrow? (K starts to laugh) you might not be here might you?

K No.

M48 I mean nobody can say they might not be here tomorrow can they?

K Oh don't say that. (K laughs) I haven't got such a positive outlook on life, me. I like to think I'll be here tomorrow.

M48 Well I like to think but I can't guarantee it. That's it, that's life innit? I mean you look at me mate he was 44 he was a wheelchair, but he had a heart attack and died. So if he can die anyone else can't they?

K How old are you now?

M48 I'm 48. Getting on now.

K Yeah, the big five o is looming isn't it?

M48 That's it. But when I was born they told me mam I wouldn't last 6 hours.

K Really.

M48 And then when I was born they said there wasn't much hope but we're sending him to Liverpool and I was christened under the Mersey tunnel.

K Ohhh. You were actually christened on your way to Liverpool.

M48 Yes, because when I went under the tunnel I stopped crying and they thought I had kicked the bucket then but as soon as I came out the other side I started crying again. And they christened me under the Mersey tunnel.

K Now there's a claim to fame.

M48 There you are. And they still haven't got rid of me yet.

K So you were born a fighter weren't you?

M48 I dunno. (Both laugh)

K Well I have to say this has been the most entertaining one I've had to do. You haven't cried once (K laughs)

M48 What do people cry about?

K Oh you'd be surprised, people do cry. You've been very good and I'm very grateful.

M48 Cry I haven't cried from the pain cos you can't do anything about it and it's been going on for weeks.

K Stuck in bed for 6 months.

M48 That was the hardest time. When you were stuck in bed, and you couldn't get up and you couldn't do nothing and you thought oh it's a good day and you can go out and sit in the car and you couldn't! That was oohhh terrible. Now I say to people you don't know if you've got to get up, get up, be happy, annoy somebody.

K (Laughs)

M48 That's it.

K I think you've done marvellous and I'm very grateful.

M48 I hope I've helped you in any way.

K You have. I'll turn this thing off now.

(Tape ends)

Appendix 10 Example of a diary (F56) transcript

October 21st '03

Felt embarrassed after crying in front of Kath but later when I thought about it, I realised I had cried not because of the way I have felt over the years, but of not being believed by Doctors. If I had a broken leg, it would have been visible, but you can't see pain my pains don't go really bad until lunch-time, strange but it has always been like that, if I have to go and see a GP at my surgery I don't put make up on, in case they think, well she looks fine. Most of the appointments are in the morning when I'm not in severe pain, they don't realise that in the afternoon I could be in chronic pain. I think the reason I'm like this now (i.e. no make up) is because of the treatments in the past given by doctors.

October 22nd '03

Really bad day. Looked after my granddaughter for two hours at her house in morning. Glad to get home. Lay down with hot water bottles. Feel guilty didn't do any housework and quite a lot needs doing. Glad to get to bed at 9pm.

October 23rd '03

Looked after my granddaughter in my house for 4 hours. Really bad pressure pains, my friend came for coffee, it was hard to be jovial while I felt like this, but you can't be down and miserable or people will not want to visit, it would be too depressing.

October 24th '03

My granddaughter still not well, so I looked after her again, didn't have any pain and it was 11 am. Was I going to have a pain free day? No! It went severe about 11.30. Jenny was staying until 3.30 pm and it was difficult nursing her on my lap, because my stomach was very painful. Felt a bit down, everyday seems the same and it's boring. Must make an effort to go out.

October 25th '03

Hardly any pain in morning, went to Chester (pm) for a bit of shopping, had a nice couple of hours. It was good to get out. Pain came about an hour before arriving home, but not as bad as it has been this week.

October 26th '03

Stayed in and did a few bits of housework, reached 3pm and still no bad pain just mild, can't believe it. I was doing paperwork when the bad pain started about 5pm, had a pain evening.

October 27th '03

Went to clean my daughter's house at 9.30, pain started at 11.30 am, got home for 12.30 and lay down with hot water bottles. Took medication and severe pain eased. My daughter came with her two girls (half term) couldn't interact with them as I felt lousy, I stayed in conservatory, granddad entertained them, glad when they left.

October 28th '03

Had withdrawal from not taking as many painkillers yesterday. I found it difficult to do housework. My pains yesterday were not as bad as previous days, so didn't warrant a lot of medication. It gets me one way or another, you have to have pain relief when pain is bad, but you suffer this awful withdrawal when you don't need pills. Because of this life becomes drab I just sit watching the world go by. My life is so boring, I'm really fed up today.

October 29th '03

Decided to get out and we went for a walk around Chester, my pains had started before I left the house and I thought I would work through them by taking my mind off them, it didn't work, the pains were severe but it was good to get out, home for 2 pm and I did my ironing for 2 1/2 hours had to have more morphine than the last few days, I was even in pain going to bed, but at least the day hadn't been humdrum.

October 30th '03

Went to my daughter's house to clean, there for 2 ½ hrs, could have cried with the pain, in fact I did when I got home. Took morphine at 12 noon, I will force myself to do my own housework this afternoon. I've got to try to overcome the way I feel pain wise. I'll be starting the higher dose of MST tomorrow, it has taken a while to come through from the hospital. I have had to take a sleeping tablet to ease the pain, will that mean I will be too tired to do my jobs? Have to wait and see.

Yes I was too tired, will start housework early tomorrow.

October 31st '03

Started new dose of MST seems to be working already. My friend Margaret came for coffee and I wasn't in pain!! She went to Alton Towers last Monday, last night she went to the theatre, she's off to have lunch out today, out tonight and off to a late afternoon wedding tomorrow in the evening wear, the last time I went out was in March, when my daughter, son in law and my son took me to bingo for mother's day. I remember the car journey I was in tremendous pain and going over bumps was painful. They complained they couldn't keep up with the "caller", who was going very fast. I joked and said well at least you haven't had pethidine!! It's twice as bad for me. I couldn't wait to get home I was so uncomfortable. Hearing of my friend's social life makes me realise what a normal life must be. I'm a little jealous.

November 1st '03

Went out for the afternoon although the car journey was painful it's more detached because of the increase in dosage of the MST, the pain eases as I walk around a but it doesn't go altogether. Needed the loo while I was out and I find it difficult waiting in a queue, if I looked disabled it would be easier and I could use the disabled toilets, but other people are not aware of the need I feel. The journey home was as bad as the journey going. Glad to get home for a hot water bottle. Didn't need as many break though tablets, so that is good.

November 2nd '03

Up too late to go to church, I did a lot of sewing which I sat down to do, so the pain was bad, but still easier with the increase in the MST. Actually felt a bit of happiness which doesn't happen often.

November 3rd '03

Another boring day. Went to clean at my daughters house, had severe pain which started at 8.30 am, had to lay down in the afternoon with hot water bottles. Maybe if I were younger and had more energy, I would go for a walk to try to take my mind off the pain, but I am physically tired after the cleaning. I used to be able to keep on the go all day and then go to work in the evening. Those days are long gone.

Woke in the night with terrible pain, had to get up, stayed up for about 1 ½ hours until pain subsided.

November 4th '03

Did housework, pain went chronic at 11.30, rest of the day was hard to get through, my only refuge is night time and sleep.

November 5th '03

Had pressure pains in my bladder, so we decided to go for a walk to see if it eased, it did slightly. Out for about ¾ hour, can't go too far in case I need the toilet. I came back with a feel good feeling. It was a nice dry day and crisp, the rest of the day was the same as usual, hot water bottles and lay down for ½ hour.

Pain started when I was in bed at 2.30 am, had to get up. I'm glad we have sky TV, it's something to do while I'm downstairs.

November 6th '03

Pressure pains started at 9 am. Forced myself to go out for a walk, the pain is still there but because you use all your other senses, walking, seeing, smelling, it takes your mind

off things. You can't walk all day though. My friend came for coffee, she's off to a party tomorrow night. It must be nice to have things to look forward to.

November 7th '03

Pressure pain started at 9 am, went to my daughters house to clean. Lasted until 10.45 and then I had to have a pain relief tablet. It eased but started up again about 2.30 pm took more and lay down, with hot water bottles, same as usual, boring!

November 8th '03

Miserable day, weather wise, couldn't go out because I had to do some clearing out of loft and airing cupboard having a new boiler fitted on Monday, usual boring day.

November 9th '03

Jim is going out today to a radio market in Llandudno with a radio pal.

I had an hour of indulgence with an invigorating shower and used some expensive clinique body cream which smelt lovely, it's nice to feel nice. It's a pity we have no intimate times, since our sex life stopped when I was 37 or 38 I've missed those times, it used to be nice to look forward to going to bed together and for quite a few years I felt bitter that those times had gone. It was difficult when I was working and mixing with females when talk of that nature was mentioned. I had to pretend my life was full in every sense and it made me feel less of a woman I felt I'd let my husband down and had a recurring dream he was leaving me because he was having an affair, I still have these dreams but not as often now. I could only equate my feelings and bitterness by thinking that widows have the same problem. I sometimes think that if my husband died I would never be able to marry again because I couldn't fulfil those duties. Having said that I wouldn't want anyone else anyway because of the love I have for my husband.

November 10th '03

Had to stay in because men have come to fit a new boiler. The water and gas has been switched off, so there is nothing I can do. I don't like not doing anything because I think

it's not helping my weight, which is making me feel down. I feel it's a vicious circle, my pain when it starts makes me want to lie down with hot water bottles, so I am not burning off any calories. When I feel depressed because of the pain, it's also my weight that adds to the depression. When I was working my weight kept steady, but since giving my job up, I've put on nearly two stone because it's easier now to just give in to the pain. But when I think of the times when I went to work in pain and how hard it was, I'm glad I don't have that burden. It was like a weight around my neck. Often had to come home which used to make me feel terrible because I was very conscientious, and felt I was more of a burden than an asset to work. I feel that life has nothing to offer me anymore, I don't know if I feel like that because of my pain or because I'm just getting older and maybe healthy people of my age feel like this.

November 11th '03

More workmen today, this time for the garage roof, so can't go to my daughter's house. I'm not going to be idle today I'm going to clean my kitchen cupboards.

November 12th '03

Got ready and went to visit mother-in-law, we feel guilty because we haven't visited for a few weeks. We left at 10 am and got back for 12.30. Usual painful journey on way home. Phyllis my mum in law is lovely, she's 89 but has got all her faculties just a bit of memory loss. I've had this bladder problem for 20 years but she still doesn't remember what is wrong. She keeps telling me to have the "operation". She had a hysterectomy years ago and I think that's the "operation" she tells me to have. Me and Jim always have a laugh after seeing her because she says it every-time we see her or speak on the phone.

November 13th '03

Going to clean my daughter's house this morning. At lunchtime pains started. Took pain relief and lay down while it started to work. Unfortunately a couple of our friends arrived but I just had to stay in the conservatory until the pain eased, they didn't stay long. After my pain eased I cooked a curry ready for our meal tonight. At least I have got good pain

relief tablets that do work. When I think back to how it used to be with just DF118 I don't know how I coped.

November 14th '03

Went to clean my daughter's house again, pain came at usual time, took S & M and it eased but came back about three hours later.

November 15th '03

Housework today, pain was only mild today very unusual. Grandchildren called with their mum & dad and I was able to play with them had a lovely time. Went to bed and my bad pains started had an uncomfortable night, going to toilet a few times.

November 16th '03

No church again, tired after getting up in the night. Went to Chester shopping, pain really bad, took M & S and it eased for a couple of hours then came back. There were crowds in Chester doing Christmas shopping and queues for toilets were a nightmare. Glad to get home.

November 17th '03

Had only been up an hour and I had pressure pains really uncomfortable and sore. Did some housework and then had severe pains, took M&S sevredol had to lie down until they started to work, then I feel tired, so rest of the day just went by. Managed to cook tea, then just waited to get to bed. Felt miserable.

One of the worst things I experience through this pain is guilt. I feel guilty when I don't interact with my family. I get on edge when the pain is bad and I just want to be left alone, I feel guilt when I lay down because it means I'm not doing housework which equates to me not pulling my weight around the house and since I gave my job up I'm not bringing any money into the house.

Appendix 11 Example of a debriefing interview (F44) transcript

- K this one is, not like the last one, very short really
- F44 It's all right.
- K The reasons for some are like a closure. Because of having done the journal for so long and it's just a case of like closing it up and if you have any questions, for most people, sorting out their next clinic appointment and we haven't done yours! Ann will do it. I didn't give you the sticky did I?
- Ann No
- K Don't worry Ann will do it.
- F44 Okay. 27th July will you?
- K yes. Good job we said that. What's your date of birth F44?
- F44 1961.
- K And I didn't need that for the tape! But Ann needs it
- F44 is the tape on? (K nods) Oh wonderful.
- K so how did you manage keeping the journal?
- F44 Fine, once you got into the habit of it. I couldn't say it was a habit; it wasn't a chore at all. I just wrote down what I thought and how I felt.
- K Did you find that easy?
- F44 yes, yes
- K Good. One of my big concerns about these diaries is whether I was going to get people to focus in on their pain, you didn't feel it made your pain worse in any way?
- F44 No, no. if I had a pain I put it down, if I felt good I put it down. If I thought that I had done too much, like gardening, going for a walk, erm I just put it down that maybe I thought that was why I felt like this, because you know, you just got to think what have I done to make me feel like this.
- K it's your own fault?

F44 Yes, it's nobody else's is it? But you can't just say tara to doing nothing, you have to get on with it (both laugh) with stuff

K Because you do actually lead a fairly active life don't you?

F44 I do, it takes a lot to get me

(Tape stops)

K Oh we had a power cut. They never last very long. Don't worry

F44 I can't remember what you asked me

K No don't worry, neither can I. The tape is working. So what we were talking about is how active your life is.

F44 Yes I want to do things. I enjoy doing things, but when I do get it bad I know I have to stop, I gotta think of myself, I gotta lie down, I go to bed, I just don't want to bother with people and that's my way of dealing with it. I just get my book and read or I just fall asleep because I can't keep my eyes open if I've taken diazepam, they make me drowsy anyway, they relax me and the next day I have to take it a bit easy if I move around.

K The last time you mentioned being asked to go camping and you knew it was physically impossible, now this is a really awful question, would you want to go camping anyway or is it not your cup of tea full stop. Do you see what I mean? So is it a case of...

F44 I used to go camping when I was a child and I really enjoyed, when, (pause) well yeah I'm getting older now (both laugh).

K What I was trying to think about was whether there was genuine regrets that you could no longer go camping, you see, I wouldn't want to go camping today. I've done it all and the thought of having to spend even a night in a tent does nothing for me, so today I would be quite happy to say "no thanks".

F44 if I could go up a grade to a caravan I'd be fine

K You'd be okay? (Both laugh)

F44 They could have a tent outside and I could be in the caravan, fine.

K So it was only a half regret thing.

F44 Yes it was.

- K So it's not something you would really opt for.
- F44 No, it's not the be all and end all that I can't go. It's just that it's nice to do things, you go back in years.
- K Yes you do, everyone camped then didn't they?
- F44 Yes they did.
- K Mind you it was the only way you could afford a holiday I think?
- F44 Yes. We used to have a girl in school and she used to say she had a luxury caravan; her grandparents had a luxury caravan. I was dying to see this luxury caravan and I never did see it, but there you are, not to worry.
- K We always went camping
- F44 Never saw the girl after leaving school (both laugh) She was a good friend though! Not really she was just a girl in school.
- K So where do you holiday now?
- F44 well, when we go, we went down last year to – where did we go- Cornwall, and we just have a B and B and do nice places, erm...
- K potter and do the things you want to see.
- F44 Yes, if I have a nice place, nice relax, nice meals, go for a walk, just relax, it's hustle and bustle all the time when you go to school, doing this, doing that. Just to get out.
- K The washing, the cooking, the cleaning
- F44 but you've got it all to come back to anyway
- K 'I know but there's something about not doing it while you're away.
- F44 Oh yes.
- K I often think that sometimes I look at the amount of clothes that we all go through and I think oh I've got to do all that before I go back to work
- F44 and the washing up – because I haven't got a dishwasher
- K oh I have

- F44 I haven't got the room for a dishwasher so no; it's nice not to do the dishes. That's nice.
- K I think the other side of it is just having all day to yourself, without having any appointments or anything to do, you can just do what you want isn't it? That's a lovely side of it as well.
- F44 and I tend to think before going on holiday last year I was so pleased I was able to finish my college course, my first year college course and I had all my work in, and it's a lovely feeling, as you're going to see when you finish this. It's a lovely feeling to hand things in. Every month now, I go to college and tutorial, I can't work in tutorial people go there from half past three until six and they do work there, other people do work there, I can't concentrate. To me a tutorial is somebody standing up in front of you, giving you information, so maybe I'm remembering how it was years ago, a tutorial now you can go there, discuss a few things, but you're all in the same room, you don't have any privacy and you hear them say oh what am I going to do for the husband for supper tonight. You can't concentrate. So I just go in, hand my work in, I try to do a unit every month and then
- K Keep on top of it
- F44 yes you know.
- K there is a lot of written work with these NVQs
- F44 I did college work on Sunday and then I find when I'm sitting down, and when I get into something and I enjoy writing about something, oh God I can't move. I'm stiff as a poker (K laughs). Ohh I'm like a duck trying to move from the table but I just get stiff you know when I've been sitting for too long
- K But you don't notice it until you've finished the work?
- F44 No I don't until I move, it just goes over my head and erm I'm having a few problems with erm health and safety issues. And the unit I've got to do, but a lot of its just common sense really. I'm enjoying it at the moment yes
- K Good.
- F44 I feel sometimes I'm taking too much on erm I think why am I doing it? But I'm doing it for my own good really. I want to I want to satisfy myself because I'm in this job now and I want to carry on to level three and I don't want to let myself down.
- K well that's a good enough reason for doing it at the end of the day.

- F44 yes, a learning support assistant does not have to have qualifications which I find very wrong myself. They can have in-service training they can go on different course but I think if you can do for yourself you can show people you have done it when you want to go on to down the line, you know. So I want to get all my work done by the end of July.
- K and another holiday again? Are you going away in August this year?
- F44 I haven't planned anything. I want to change the car.
- K well we can't have everything, it has to be said.
- F44 No no. I'm not at the top scale of the wages yet, so I want to change the car this year.
- K But you've got all that time at home anyway, so you get a break anyway
- F44 Oh yes, it doesn't mean to say I'm home every day does it, we can, Tina, my friend came over last night and she said there's a few coach trips going you know, we don't have to worry about parking. Tina doesn't drive and she thinks that we should have a runway when we park (Both laugh) a real back seat driver you know, whatever, so we might do a few coach trips this year because I want to change the car. So
- K you can get some good ones as well
- F44 yes
- K You really can. I mean for us it's different
- F44 A glass of wine with my dinner
- K well this is it, you don't have to think about it do you?
- F44 No No
- K Because my mum and dad look at them quite a lot, the Chelsea flower show and things like that because there was one
- F44 I'm going to Southport
- K yes that's there favourite one
- F44 its not to the flower show – it's a shopping one
- K Oh is there?

F44 yes, I haven't been to Southport for a long time. I went quite a few years ago now and the bus broke down between Bootle, broke down in Bootle and we were waiting an hour for another bus. It was lovely.

K Not one of the best places to break down.

F44 we got to Southport and we found this lovely café and we had coffee and we saw Hilda Ogden

K Honest?

F44 and she's in now, what's she in? 'Last of the summer wine'.

K 'Last of the summer wine'

F44 She lives in Southport doesn't she?

K Oh I don't know

F44 Bit of useless information

K I used to like her in Coronation street I have to say

F44 Ruth – who did she see in Southport? And they bought her some flowers.

K She's quite well spoken isn't she? Not like on Corrie she was quite common really.

F44 I think she just quite quickly frittered past us because she heard – it is her isn't it? She must have heard that bit (Both laugh) frightened her off.

K Well thank you very much, for all of this information.

F44 You're welcome and thank you.

(Tape ends)

Appendix 12 Thesis Dissemination

Since the work contained in this thesis has been developing over a period of time some of the material reported upon has been disseminated or published in a variety of different arenas. These are listed below with comments upon authorship.

Material contained within Chapter 2 (Review of the literature) has been drawn upon, presented and/or published in the following ways:

- Clarke K (2004) Believing the chronic pain patient. Poster presentation at the RCN Research Conference, Cambridge.
- Clarke K (2004) Believing the chronic pain patient. Oral presentation at the Chief Nursing Officer of Wales Showcase Conference, Llandudno, April 2004.

...and published in...

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- The above paper was also cited in Mann E, Carr E (2006) *Pain Management* Blackwell Publishers, Oxford

Material contained within Chapter 3 (Methodology) has been drawn upon, presented and/or published in the following ways:

- Clarke K (2004) Maslow: hierarchy of needs – or reflective framework? *Nurse2Nurse* 4(2): 14-15
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- Clarke K (2006) If only they could see my pain. Oral presentation at a Pain Study Day, Medical Institute, Wrexham. April 13th 2006 [Presented on invitation].

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