

**Managing life with chronic pain:
an interpretative phenomenological analysis**

Danuta Orłowska, BA (Hons), PhD

**Thesis submitted in partial fulfilment of the requirements
of the degree of D. Clin. Psy.**

University College, London

June 2000

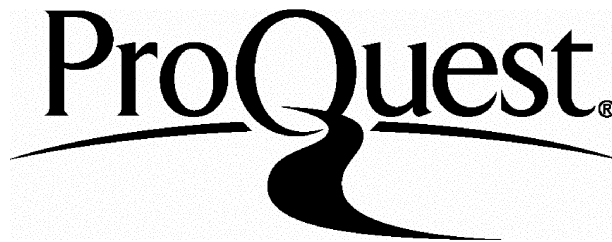
ProQuest Number: U641900

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest U641900

Published by ProQuest LLC(2015). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

ABSTRACT

Life with chronic pain presents considerable physical and psychological challenges for the individual and those around them. This qualitative study asked eighteen volunteers (nine men and nine women) with non-malignant chronic pain at an inpatient pain management programme about situations in which they feel understood, or not, when talking about their chronic pain and ways in which they talk about their pain. Each participant was interviewed twice: during the first two weeks of a four week multi-disciplinary programme and two to three months after leaving. Supplementary data were sought using the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris and Horne, 1996) and the Beck Hopelessness Scale (Beck, Weissman, Lester & Trexler, 1974).

Interviews were processed using Interpretative Phenomenological Analysis (Smith, 1995). Four main themes were found in the first set of interviews. These were experiences of treatment, self-perception and comparisons, experiences of the reactions of others and attempts to manage the impact of chronic pain on self and others. The follow-up interviews also generated a theme of experience of treatment (pain management and beyond) and a theme of integrating pain management strategies into everyday life. This study answers the call for more emphasis on the personal experience of pain (Osborn & Smith, 1998) in the psychology literature, and makes a contribution to the suggested focus on the social and linguistic processes and dynamics of how people with chronic pain construct their identity (Eccleston, Williams and Stainton Rogers, 1997). The individual with chronic pain is conceptualised as attempting to manage the impact of their chronic pain considering short term and long term psychological and other consequences on not just self but others.

The road you trod has led you here
The Magic Flute, Act I, Scene XV, Mozart/Schikaneder

Acknowledgements

I would like to thank all those who took part in this research and told me about life with chronic pain. Without their time and good will this study would have been impossible.

My field supervisor, Dr Amanda C de C Williams shared her extensive knowledge of the field of chronic pain and provided opportunities for challenging discussion. My university supervisor, Dr. Nancy Pistrang shared her experience of the use of qualitative research methods and was ever calm. I am grateful to both for their feedback and support.

A number of others contributed to this project in various ways: Dr Jonathan Smith, Senior Lecturer in Psychology, Birkbeck College, University of London with whom I had an interesting discussion about the use of Interpretative Phenomenological Analysis and who made comments on my data analysis; Professor John Weinman, Unit of Psychology, UMDS Guy's and St. Thomas' Hospitals, who gave permission to use the Illness Perception Questionnaire; Dr Chris Eccleston, Department of Psychology, University of Bath who offered me the opportunity to talk about my research at the Annual Pain Society Conference at Warwick (April 2000); Liz Pereira, Assistant Psychologist who extracted demographic data about my participants; Dr Clare Daniel, my placement supervisor, and all the staff who were colleagues during this research.

My friends have been a huge support and special thanks go to Jenny Hazell, Rosamund Smith, Anita Whitley, and Dr. Charles Wood.

Thank you, all.

Contents

Abstract	1
Acknowledgements	2
Table of contents	3
List of appendices	5
Chapter 1: Introduction	6
1.1 Overview of chronic pain	6
1.2 Psychological research in chronic pain	8
1.2.1 Common concepts in pain research	9
1.2.2 Families and chronic pain	17
1.3 Chronic pain management programmes	18
1.4 Capturing the experience of life with chronic pain	22
1.5 Research questions	28
1.6 Choice of research method	29
1.7 Summary	31
Chapter 2: Method	32
2.1 Research setting	32
2.2 Ethics	34
2.3 Participants	34
2.4 Procedure	35
2.5 Research interviews	36
2.6 Quantitative measures	37
Chapter 3: Qualitative data analysis and the development of themes	40
3.1 Introduction	40
3.2 Analysis of main interviews	40
3.3 Analysis of follow-up interviews	47
3.4 Summary	48

Chapter 4: Results	49
4.1 Introduction	49
4.2 Illness perceptions and future orientation: quantitative results	49
4.3 Qualitative results: main interviews	54
4.3.1 Experiences of treatment	54
4.3.2 Self-perceptions and comparisons	60
4.3.3 Experiences of the reactions of others	65
4.3.4 Attempts to manage the impact of pain on self and others	70
4.4 Reflecting on pain management: the follow-up interviews	77
4.4.1 Experiences of (pain management) treatment	
4.4.2 Integrating pain management strategies into everyday life	81
4.5 Summary	84
Chapter 5: Discussion	85
5.1 Overview	85
5.2 Discussion of themes	86
5.2.1 Experiences of treatment	86
5.2.2 Self-perception and comparisons	89
5.2.3 Experiences of the reactions of others	93
5.2.4 Attempts to manage the impact of pain on self and others	96
5.2.5 Experiences of (pain management) treatment	99
5.2.6 Integrating pain management strategies into everyday life	100
5.3 Overview of themes	101
5.4 Clinical implications	103
5.5 Methodological issues	104
5.6 Suggestions for further research	109
5.7 Summary	110
References	111
Presentations	117

List of appendices

Appendix 1: Ethics Committee approval letter	118
Appendix 2: Participant information and consent form	120
Appendix 3: Audio-taping consent form	122
Appendix 4: Main interview schedule	124
Appendix 5: Patient guide for main interview	127
Appendix 6: Follow-up interview schedule	129
Appendix 7: Illness Perception Questionnaire	131
Appendix 8: Beck Hopelessness Scale	134
Appendix 9: Worked transcript	136

Chapter 1: Introduction

1.1 Overview of chronic pain

Chronic pain is a considerable physical and psychological challenge for the individual and for those around them. It is often associated with substantial losses and/or changes in many areas including physical function, work and financial security, family and intimate relationships, leisure and social life, future plans and aspirations and self-perception. Further, pain and discomfort themselves make a significant contribution to the negative subjective assessment of general quality of life (Skevington, 1998). Chapman and Gavrin (1999) state that a disruption in life such as the onset of chronic pain can cause suffering, which they define as “perceived damage to the integrity of the self” (p.2233) and more broadly in chronic illness, Charmaz (1999a) argues that “loss of control, loss of certainty, and loss of an anticipated future all cause suffering... [and] loss of certainty means losing the collective myth of a taken-for-granted future as well as the personal belief in sustained health” (p.366).

The definition of pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain, 1979) highlights the psychological as well as the physical components of pain. Pain is conceptualised as a psychological experience with sensory-discriminative, motivational-affective and cognitive-evaluative aspects influenced by a variety of factors including cultural influences,

appraisals of the meaning of the situation, past experiences and levels of arousal (Melzack and Wall, 1982).

Unlike acute pain, in which there is more likely to be a clear cause, healing process and subsequent end to pain, chronic pain presents a more complex picture. Chronic pain challenges the biomedical model as “it obscures the traditional borders between mind and body, objective and subjective, real and unreal, physical and psychosocial” (Borkan, Reis, Hermoni and Biderman, 1995, p.977). Turk and Okifuji (1999) point out that the features of chronic pain “are incompatible with the assumption of a single one-to-one correspondence between the report of pain and the presence of underlying disease” (p.1784) and Hallberg and Carlsson (1998) note that it is difficult or impossible to give causal explanations for many pain syndromes, which is frustrating for both doctors and patients (Notcutt, 1998).

Prevalence of chronic pain in epidemiological studies conducted in the general population ranges from 2% - 40% (Verhaak, Kerssens, Dekker, Sorbi and Bensing, 1998). A recent United Kingdom report on services for patients with pain indicated that approximately 7% of the population have chronic pain at any one time (Clinical Standards Advisory Group, 2000). People with chronic pain frequently experience decreasing levels of mobility and activity arising from fear of exacerbating the pain and a belief in an association of pain with inevitable damage and harm. Spurred on by the distress of their situation, they may repeatedly seek a variety of medical consultations (and complementary therapies) in attempts to rid themselves of their

pain which may have come to dominate their lives. However, Kleinman, Brodwin, Good and DelVecchio Good (1992) point out that “medical care has more often than not compounded the suffering as a result of iatrogenic effects of powerful but dangerous surgical and pharmacological treatments and of costly and at times equally dangerous tests” (p.6).

Where treatment attempts do not succeed and chronicity develops, feelings of frustration and hopelessness may arise in both the patient and those providing treatment. Kleinman (1988), a doctor, writes that:

“chronic pain discloses that the training and methods of health professionals appear to prevent them from effectively caring for the chronically ill. Reciprocally, chronic pain patients are the *bête noire* of many health professionals, who come to find them excessively demanding, hostile, and undermining of care. A duet of escalating antagonism ensues, much to the detriment of the protagonists” (p.57).

Eccleston, Williams and Stainton Rogers (1997) put this another way: “in chronic pain, when the cause remains lost, the patient reappears to own that loss; *the patient becomes the lost cause*” (p.700) [my emphasis]. Such a perception may accompany the patient as he/she is referred through the medical system to an anaesthetist-led pain clinic where drug therapies, nerve stimulation and nerve blocks are tried and/or eventually to a pain management programme following the failure of other attempts.

1.2 Psychological research in chronic pain

The patient with chronic pain has been the subject of a great deal of psychological research addressing both individual and family factors. Research relies heavily on

questionnaire methods to measure subjective perception of pain and variables associated with pain. Notable areas of individual focus are cognitive areas such as coping strategies and self-efficacy, which will be considered here alongside more recent contributions to the area of cognitive aspects of pain such as comparison processes and acceptance of pain. Depression, which is often measured in evaluations of treatment effects, will also be briefly considered. Beyond the dominant research focus on the individual, there is also research on the responses of families to the person with chronic pain. Given the prevalence, challenge and impact of chronic pain, the search for variables which could contribute to the attempt to support better physical function and/or better psychological function is likely to continue.

1.2.1 Common concepts in chronic pain research

Coping is described as the use of cognitive and behavioural strategies to manage demands which challenge or exceed the resources of the individual (Lazarus and Folkman, 1984). Given the considerable challenges posed by life with chronic pain, much research has examined the use of coping strategies and pain management programmes typically teach the patient a range of cognitive and behavioural coping strategies. A consistent finding in the pain and coping literature is that patients who avoid catastrophizing about their pain, believe they are not severely disabled and those who believe they can control their pain appear to function better than those who do not (Jensen, Turner, Romano and Karoly, 1991).

The commonly used Coping Strategies Questionnaire (Rosentiel and Keefe, 1983) covers seven styles of coping: coping self-statements; diverting attention; ignoring pain sensations; reinterpreting pain sensations and increasing activity level; catastrophising and praying or hoping. More frequent use of so-called passive strategies is associated with maladaptive physical and psychological functioning more strongly than the frequent use of so-called active strategies is associated with physical activity and better psychological functioning (Snow-Turek, Norris and Tan, 1996). However, the *a priori* sorting of strategies into passive (catastrophising and praying or hoping) and active (all others) without taking the situational context into account has been criticised (Schmitz, Saile and Nilges, 1996).

Looking at specific coping strategies, coping self-statements and reinterpreting pain sensations have been found to predict self-assessed control over pain, whereas ignoring pain sensations predict low control, regardless of pain severity and education level (Haythornthwaite, Menefee, Heinberg and Clark, 1998). However, the context-free wording of items used to assess coping (e.g. 'although it hurts, I just keep on going') does not illustrate in what situations such a strategy might be used instead of another, for example, when alone, when with others, under conditions of particular emotional and/or physical demand and in conditions of increased pain. Nor does it allow for the advantages and disadvantages of particular strategies and their perceived meaning to the individual to be explored.

The frequent use of *several* coping strategies has been found to be associated with high perceived control over pain, regardless of pain severity (Haythornthwaite, Menefee, Heinberg and Clark, 1998). This carries with it some implication of situational adaptation. Further attention to the interaction of coping strategies with pain severity and the issue of coping flexibility across time and varying pain severity would expand the concept of coping (Haythornthwaite, Menefee, Heinberg and Clark, 1998). It suggests a move beyond the static conceptualisation of the person with chronic pain as someone with more or less fixed cognitive styles, beliefs and perspectives on control, towards one of a flexible individual using their resources to respond to and attempt to influence the environment around them. This would be consistent with a functional approach to coping attempts which is evident in the work of Ferguson and Cox (1997) who suggest that only the individual can understand why a particular coping behaviour is used. As an alternative to coping styles, they suggest four main *functional* dimensions of coping: approach, emotion, reappraisal and avoidance.

Such an environmental and functional focus on the individual with chronic pain can be argued to be implicit in the dual-process model of assimilative and accommodative coping of Brandtstädter (1992) which Schmitz, Saile and Nilges (1996) apply to chronic pain. Assimilative coping focuses on attempts to maintain pre-existing personal goals and aspirations by “instrumental activities aimed at changing the contextual features of the problem, self-corrective strategies for enhancing actional

(sic) competency, and compensatory measures that reduce the negative or undesirable effects of the problem” (Schmitz, Saile and Nilges, 1996, p.43) to alter unsatisfactory life circumstances. In contrast, accommodative coping involves “a revision of self-evaluative and normative standards... the downgrading of personal standards, a more accepting reappraisal of the problem, the disengagement from blocked goals, and a reorientation towards new, feasible goals...” (Schmitz, Saile and Nilges, 1996, p.43) in accordance with perceived losses.

The ability to adjust goals (hence use of accommodative coping strategies) was argued to be valuable in buffering the adverse effects of chronic pain on psychological well-being (Schmitz, Saile and Nilges, 1996). They argue that conceptualising accommodative processes as “notions of denial, avoidance, or resignation misrepresents the contribution of such mechanisms to the stabilisation of self-esteem and to the maintenance of control despite anticipated or extant deficits or losses” (p.49). They suggest that accommodative coping may be more significant in terms of psychological health as pain chronicity develops. A similar perspective on accommodation comes from the work of Mikulincer and Florian (1996) on adjustment to physical disability. Their definition of reorganization as a coping strategy includes accommodation of existing cognitive-motivational structures to reality, which involves acceptance, working through the experience, pursuit of more realistic goals and the adoption of a more appropriate view of oneself.

Despite the variety of interesting work and conceptualisations of coping, some of which were described above, Weisenberg's (1994) comment that much of the data in the area are correlational so that the direction of effect is not clear remains true. Further, Strong and Large (1995) suggest that coping questionnaires measure only 'the tip of the iceberg'. A technical criticism comes from Jensen, Turner, Romano and Karoly (1991) who point out that many existing measures of coping confound the concepts of coping with appraisals and adjustment and Lackner, Carosella and Feuerstein (1996) add that coping measures ability to tolerate pain but not function, which they argue is a serious distinction given the lack of correspondence between pain and function.

The concept of self-efficacy (Bandura, 1977) or belief in personal effectiveness is clearly relevant to the implementation of coping strategies. Mastery in the face of a challenging situation through actual performance is a key influence on self-efficacy (Weisenberg, 1994). Related to self-efficacy is the perception of actions and outcomes being under individual control rather than due to chance or luck, although a perception of individual control does not imply the ability to exercise that control. An internal locus of control has been associated with less pain, less pain-related interference in life and less psychological distress by patients at a multidisciplinary pain programme (Burton, Kline, Hargadon, Shick, Ong and Cooper, 1998). However, the authors point out that the direction of causality was not determined, hence those with less distress and lower pain could be experiencing greater internal control. Patients with chronic back pain at a multidisciplinary treatment programme with

more optimistic views on their health and weak belief in control by powerful others have been found to make the biggest gains (Härkäpää, Järvikoski and Estlander, 1996) after controlling for initial scores on subjective functional capacity. Further, subjective assessment of functional self-efficacy expectancies (confidence in the ability to perform tasks) has been found to have greater explanatory power than the commonly assessed pain self-efficacy expectancies (confidence in the ability to tolerate or control pain) when anticipated pain and reinjury expectations were partialled out (Lackner, Carosella and Feuerstein, 1996). Again, this suggests the importance of specific situations or demands – coping in given situations rather than generally and expected ability to perform particular tasks.

The social comparisons made by people with chronic pain are another area of research focus and can be traced back to Festinger (1954), although his social comparison theory was not originally applied to health. Downward comparisons are of particular interest as in situations producing decreased well-being, people often use downward comparisons with those perceived as worse off in an attempt to improve their well-being (Wills, 1981). Although this would imply that they are coping strategies, Tennen and Affleck (1997) differentiate “downward comparison as a coping strategy (comparison coping), downward comparison as an inference (comparison conclusion), and downward comparison as a motivated appraisal that enhances a sense of esteem and psychological control (secondary control comparison)” (p.270). Reviewing research findings, Tennen and Affleck (1997) do

not consider downward comparisons as examples of coping strategies (which they require to be effortful, affect more than emotional well-being and change predictably in response to situational demands) nor as secondary control appraisals.

In a welcome departure from the traditional questionnaire based correlational studies Tennen and Affleck (1997) studied comparison processes in patients with fibromyalgia. They combined thrice-daily real-time measures of pain intensity and mood with a questionnaire which asked about the use of downward social and temporal comparisons for the pain on that day. They found that downward temporal comparisons (with a time when symptoms were worse in the past) were more durable and helpful than downward social comparisons (with others in the present who may be worse off). On days when such downward temporal comparisons were made, participants experienced pain abatement and improvement in mood. Although this study is of particular significance as it preserves the temporal order of events, there is no information about the antecedents of the particular form of downward comparison used at any time, which might contribute further to understanding what how the patient is implementing particular comparison processes. More examples of creative research are needed to help understand the 'necessary evil' (Strong and Large, 1997) of coping.

Turning to emotional aspects of pain, Van Houdenhove and Onghena (1997) suggest that pain and depression can be considered as the most serious forms of human suffering. Prevalence rates of depression vary in various studies but a large-scale

population-based study in the United States found that 18% of those with chronic pain were depressed compared with 8% of those without pain (Magni, Caldieron, Rigatti-Luchini and Merskey, 1990). In comparison with other relatively stable chronic conditions, Banks and Kerns (1996) report a higher rate of major depressive disorders in people with chronic pain. However, the situation is not entirely clear as a range of symptoms used in the diagnosis of depression are commonly experienced in chronic pain, for example, concentration problems, insomnia, fatigue and loss of interest (Williams, 1998).

Although the expected direction of causality might be from chronic pain to depression, a number of potential links have been considered (see Van Houdenhove and Onghena (1997) for a review) and depression is not an inevitable consequence of chronic pain. For example, Banks and Kerns (1996) found that pain was not enough to cause depression but that cognitive variables such as the perception of the impact of pain on various aspects of life mediated the relationship between pain and depression. However, pain-related limitations can reduce the likelihood of personally and socially rewarding experiences and Craig (1994) points out that some treatment suggestions for people with chronic pain such as withdrawal from activities, extended bed-rest (which is not currently recommended) and medication may in themselves have depressive consequences which are generally overlooked. Shapiro and Teasell (1997) add that the misdiagnosis of chronic pain as psychological in origin may have adverse effects and contribute to treatment failure. Pain management programmes based on a cognitive therapy model offer the opportunity for patients to learn how

their cognitive processes and patterns of activity may contribute to depression and to begin to try to make changes.

1.2.2 Families and chronic pain

Pain affects not just the individual but the family and others around them. Much of the current research on pain within the family uses an operant conditioning model to understand the responses family members may make to pain (e.g. Romano, Turner, Friedman, Bulcroft, Jensen and Hops, 1991). Although observational methods to study family interactions can be a welcome departure from questionnaire driven research, the broad conclusions from this framework suggest that family responses may act as maintaining factors, thus suggesting an element of blame, and take a one way approach (family influences patient) to the complex mutual influences operating in a family. Greene Bush and Pargament (1997) point out that much research on chronic pain in families does not consider the extent to which families contribute to the coping process.

Rowat, Jeans and LeFort (1994) emphasise the importance of including the family in interventions and point out that family members are themselves often struggling with the challenges of learning to live with the impact of chronic pain. This takes place against a backdrop of treatment attempts often in the acute care framework. Charmaz (1983) argues that when applied to chronic illness, an acute care framework “results in fragmented care, incomplete information, overburdened caregivers and isolated individuals left to handle the spiraling problems caused by illness as best they can”

(p.169). Families too may operate using an acute pain model with damage, followed by a period of diminished function, healing and subsequent return to normal function as the expected route through the experience. This may lead them to doubt the existence of the pain and lead to a range of emotions and reactions when diminished function persists and a range of adverse social, psychological and economic consequences result for the family as a whole.

1.3 Chronic pain management programmes

Multi-component pain management programmes help people with chronic pain manage life despite pain by gradual build up of exercise and stretching, goal planning and pacing of activity, education about pain and its effects on the body, gradual decreases in pain-related medication and an emphasis on psychological areas with sessions often delivered by members of a multidisciplinary team (e.g. Williams, Nicholas, Richardson *et al.*, 1993). Psychological input aims to give patients the skills to manage their pain more effectively and minimise physical and social disruption, psychological distress and preoccupation (James, 1992). However, the focus on managing life with pain, rather than attempting another cure for the pain may present a considerable change of emphasis for the patients if their goals are to return to life without pain (Turk and Rudy, 1990).

Multi-component pain management programmes have been shown to be effective. In a meta-analytic review of the efficacy of multi-component programmes for chronic back pain, Flor, Fydich and Turk (1992) conclude that multidisciplinary pain

treatment is superior to single-discipline treatments both on self-report measures of pain and return to work. Improvements remain at long-term follow-up (over six months) such that those receiving multi-component treatment function better than 75% of those untreated or treated by single-discipline treatments. However, methodological difficulties such as the lack of appropriate control groups and poor description of studies, participants and data analysis in some studies make it more difficult to draw firm conclusions about treatment effects and the contribution of specific components or to make predictions about which individual patients might do well. A more recent systematic review and meta-analysis of randomised control trials of cognitive behaviour therapy and behaviour therapy (Morley, Eccleston and Williams, 1999) concludes that treatments based on cognitive behaviour therapy are effective relative to waiting list control conditions in terms of pain experience, positive coping measures and reduced behavioural expressions of pain, but effects are non-significant on mood, negative coping measures and impact of pain on social role functioning.

Many of the programmes evaluated operate in the United States. The cultural and health care delivery differences suggest the importance of specific attention to United Kingdom programmes (Skinner, Erskine, Pearce, Rubenstein, Taylor and Foster, 1990). In the United Kingdom, patients attending pain management programmes are more likely to be medically retired from work, than those in the United States (Williams, Nicholas, Richardson *et al.*, 1983) be women, have a longer pain history and fewer invasive interventions. To establish whether techniques pioneered in the

United States succeed in the different cultural and health service context of the United Kingdom, Skinner, Erskine, Pearce, Rubenstein, Taylor and Foster (1990) evaluated an outpatient and Williams, Nicholas, Richardson, *et al.*, (1993) an inpatient pain management programme.

The multidisciplinary outpatient programme ran on a group basis one afternoon a week for seven weeks. It was successful in achieving improvements in patient mood, coping skills, physical disability (all measured by questionnaires) and decrease in the use of medication both immediately after the programme and at one month follow-up (Skinner, Erskine, Pearce, Rubenstein, Taylor and Foster, 1990). In the four week inpatient programme evaluated by Williams, Nicholas, Richardson *et al.*, (1993) patients were found to have made progress during the programme on all measures of physical function and psychological function and most changes were maintained, (albeit without further mean positive or negative change) at follow-ups one month and six months later. Medication use also generally decreased as measured from pre-treatment to six month follow-up. However, the authors comment on the lack of continued progress following treatment and the difficulties of generalising change into the home environment.

As chronic pain is a multi-component experience, change can occur at a variety of levels. Programme evaluations typically include measures of physical function, psychological variables and medication use which are compared with pre-treatment levels. However, it is possible that the frame of reference against which a person

evaluates his/her life can change. Adapting a model from the evaluation of change in organisational psychology, Norman and Parker (1996) offer a three level typology of change for health psychology. Whereas alpha level change is change in objectively measured health status, elements of which are commonly measured in programme evaluations, there are other possible forms of change. Beta level change involves the recalibration of the person's scale for measuring health status and gamma level change the reconceptualisation of the meaning attached to health. Current approaches to the evaluation of pain management programmes appear to have less to say about beta and gamma levels of change.

However, the broad focus of a pain management programme may assist the individual with chronic pain to make a range of changes on all three levels. This can include fostering the accommodative coping concept of Brandtstädter (1992) which is significant in terms of psychological health as pain chronicity develops (Schmitz, Saile and Nilges, 1996). It is also consistent with the emphasis of pain management programmes on 'life with pain that is' rather than 'life without pain that was'. This in turn leads to issues of the acceptance of pain explored by McCracken (1998): "acknowledging that one has pain, giving up unproductive attempts to control it, acting as if pain does not necessarily imply disability, and being able to commit one's efforts toward living a satisfying life despite pain" (p.22). In his study of people with chronic pain seeking treatment at a pain management centre, higher scores on acceptance were associated with reports of lower pain intensity, less physical and

psychosocial disability and less pain related anxiety and avoidance and were not simply a function of lower pain levels as the correlation between pain intensity and pain acceptance was relatively low. Unfortunately, the correlational design of the study does not allow the direction of causality to be established.

Although there is a body of evidence pointing to the value of the multi-component, intensive, inpatient approach to pain management and a variety of cognitive and affective variables have been found to correlate with greater success, there is still much to understand about what contributes to positive outcomes in pain management for individuals. Across medicine generally, Greenhalgh (1998) cautions that “the ‘truths’ established by the empirical observation of populations in randomised trials and cohort studies cannot be mechanistically applied to individual patients or episodes of illness, whose behaviour is irremediably contextual and (seemingly) idiosyncratic” (p.251). Given the nature of chronic pain as intensely subjective, research which explores the varied contexts, experiences, responses and perceptions of those living with it in their own terms is important to the development of further understanding and which may contribute to the refinement of pain management programmes.

1.4 Capturing the experience of life with chronic pain

Whereas quantitatively based psychological research has investigated many cognitive and emotional aspects of chronic pain, and identified practical implications, much is at the expense of a holistic picture of the individual, his/her experiences and how s/he

sees her/himself in his/her environment. Other sources of information such as accounts and interpretations based on interviews with people with chronic pain (e.g. Kleinman, 1988) and personal experience (e.g. Register, 1987) make the experience of chronic pain more accessible on a personal level. The illness narratives of patients are of increasing interest, “captur[ing] central aspects of illness experiences and their social contexts” (Hydén, 1997, p.51) and providing an alternative to the biomedical framework. From a medical context, Greenhalgh and Hurwitz (1998) suggest that the narrative “offers, in short, a possibility of *understanding* which cannot be arrived at by any other means... understanding the narrative context of illness provides a framework for approaching a patient’s problems holistically, as well as revealing potential diagnostic and therapeutic options which we ignore at the patient’s peril” (p.6-7).

Chronic illness can create ‘biographical disruption’ Bury (1982); “changes in self-conceptions which are reciprocal to bodily experiences, feelings and actions” Kelly and Field (1996, p.247) and requires “social, biological, and biographical accommodation” (Mathieson and Barrie, 1998, p.582). As Radley (1994) points out, the need to live with, manage and sometimes explain chronic illness means that “social psychological issues of communication and identity become central to understanding how people cope with chronic illness” (p.137), yet this does not appear to be a feature of the much of psychological literature on chronic pain and coping at present.

The medical sociology literature however maintains 'self' and 'identity' as important concepts in understanding the experience of chronic illness. In contrast, Osborn and Smith (1998) note that there is little published research in the psychology literature on the personal experience of pain. A number of studies examining the impact of chronic illness and chronic pain on the individuals and the responses made by the individual to the changes it brings will be examined from the fields of medical sociology and health psychology illustrating qualitative, but no less valuable, approaches to understanding people with chronic pain.

A noted medical sociologist, Charmaz (1983) writes that "[C]hronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones... Over time, accumulated loss of formerly sustaining self-images without new ones results in a diminished self-concept" (p.168). Her analysis of interviews with people with a variety of chronic illnesses identified four main areas in which suffering occurs: a) through restricted lives which may be more restricted than they need be and result in a focus on illness; b) through social isolation arising from lowered time, energy and concentration for maintenance of relationships, through difficult social experiences and through the potential discomfort of others; c) from discrediting definitions of the self, played out in interactions with others and in individuals' inability to meet others' expectations and d) from becoming a physical, psychological and economic burden, with associated feelings of uselessness.

Whereas Charmaz (1983) argues for a diminished self-concept, Yoshida (1993) introduces the issue of reconstructing identity in a study of people following spinal cord injury. She postulates a pendulum swinging through different identities. As a general pattern, one extreme of the swing of the pendulum represents the former self, with the disabled identity as the total self at the other. From the disabled identity as total self Yoshida (1993) posits a swing to the supernormal identity, which is characterised by activities demanding time and energy and refusal of assistance, then a swing to the disabled identity as part of the total self with a middle self in the centre of the swing. Yoshida (1993) suggests that people hold a number of views of identity depending on situations and can oscillate between them. Such a model appears to fit well with a dynamic social context for the individual adapting to a changed life and suggests a changing, responsive identity rather than an identity bound up in one concept, such as spinal cord injury, or chronic pain. This would be consistent with the conceptualisation of adjustment to illness of Radley (1994) who suggests that this is one of resolving the demands of both body and society.

This flexibility of response is also suggested by the findings of Borkan, Reis, Hermoni and Biderman (1995) who combined individual interviews, focus groups and participant observation to study the experiences of patients with lower back pain in primary care and community settings. The limitations in many areas of their lives and delegitimation of their pain by others, were associated with responses including an amplification of symptoms in an attempt to be believed or withdrawal to avoid

stigmatisation and strategies designed to maximise function or minimise pain or *selective use of the two* [my emphasis].

The accounts given of chronic illness to others are also of interest. Using Q-sort methodology, Eccleston, Williams and Stainton Rogers (1997) found that accounts of the patient with chronic pain deflected blame from the self and maintained pain as diagnostically meaningful, whereas those of the professional deflected blame from medicine and included the patient in the process of pain management. The impact of such differences in perception may emerge in consultations in which attempts to communicate pain and distress are difficult when “the patient and physician have different languages, experiences, expectations, and frames of reference” (Turk and Okifuji, 1999, p.1784). Such differences may result in poor experiences of health care encounters in which opportunities to develop a shared understanding of chronic pain are missed, which may in turn have an impact on how interventions are approached by the patient. The multiple medical referrals experienced by patients with chronic pain may provide multiple opportunities for such differences in perspectives to be reenacted, and for patients with chronic pain to remain confused and still seek explanations despite extensive contact with health services (Osborn and Smith, 1998).

As well as searching for explanations, Osborn and Smith (1998) found three further main themes in their study of women with chronic low back pain. Firstly they engaged in comparisons of their current self with other possible selves which emphasised their losses and which was an ‘equivocal coping strategy’. Secondly the

women could not rely on being believed by others and an appearance of illness (for example not paying attention to their looks) was a way of conveying their pain to others but at the cost of their self-concept. Finally, they described withdrawing from others as the restrictions arising from their pain conflicted with their ability to maintain social networks in which they feared misunderstanding and rejection. Interviews with women with fibromyalgia by Söderberg, Lundman and Norberg (1999) identified themes with elements of overlap with those of Osborn and Smith (1998): threat to integrity, the struggle to achieve understanding and relief and loss of freedom. Such findings suggest that people with chronic pain are concerned with the search for meaning and attempt to deal with the impact of chronic pain on the self in a social context in which support for their attempts may be increasingly limited and in which others' frames of reference about chronic pain may be different from their own.

Following Meichenbaum (1993), Eccleston, Williams and Stainton Rogers (1997) argue that more account should be taken of the way in which people with chronic pain construct their identity. They suggest a shift “away from pathology and behaviour to the social and linguistic processes and dynamics of identity construction” (p.708) of the person with chronic pain and suggest adopting ‘pain talk’ as a new and timely focus. There is much to discover here and earlier work on accounts of illness has already distinguished between public accounts in which there is a concern with acceptability of the account to others and private accounts which are given as if to others like themselves (Cornwell, 1984). The research carried out in this study aims

to discover something about the contexts in which patients feel understood when talking about their chronic pain and how they report talking about it to others and offers a response to the call for more attention to the personal experience of pain in psychology (Osborn and Smith, 1998) and the call for a focus on 'pain talk' Eccleston, Williams and Stainton Rogers (1997).

1.5 Research questions

This study aims to explore the ways in which patients at a pain management programme describe how they talk about their chronic pain to others. It will look at patients' experiences of being understood and not understood and the contexts in which they talk, or do not talk, about their pain using the accounts of patients as the basis for analysis (Greenhalgh and Hurwitz, 1998). The 'pain talk' focus will be contextualised by accounts of the impact of chronic pain, including explicit attention to its impact on how people with chronic pain see themselves and on how others see them. It will also look at their perception of the future as they embark on a pain management programme and attempt to adapt to the considerable change of treatment focus which this requires after years of interventions aimed at reducing or removing the pain.

Perhaps the closest existing study is that of Osborn and Smith (1998) but the present study differs from it in several ways. Participants are patients at a inpatient pain management unit with a rehabilitation focus rather than patients at an outpatient pain clinic, in which medical interventions were presumably still being tried in an attempt

to reduce or remove the pain. Secondly, part of the focus is specifically on how patients talk about their pain and positive and negative experiences of having done so, rather than asking about the personal experience of pain in general. Thirdly, the study includes both men and women with chronic pain rather than women alone. Fourthly participation is not restricted by main site of pain. Lastly, there is a follow-up of participants several months after the pain management programme in order to ask about any changes, including possible impact on self-perception and on talking about pain. Although there is of course a considerable amount of retrospective material in people's accounts of their experience of chronic pain, this modest longitudinal element aims to contribute to the understanding of possible change following a pain management programme.

1.6 Choice of research method

The use of a qualitative approach was appropriate for this work which set out to explore talking about chronic pain. These methods “are focused more holistically, value experience, and seek understanding which incorporates social context” (Chamberlain, Stephens and Lyons, 1997, p.695) and have an emphasis on “revision and enrichment of understanding, rather than to verify earlier conclusions or theory” (Elliott, Fischer and Rennie, 1999, p.216).

Interpretative Phenomenological Analysis (IPA), developed by Jonathan Smith and colleagues within health psychology, offers an appropriate methodology. Smith (1995) describes IPA as an idiographic qualitative methodology, the data for which

are the verbatim transcripts of in-depth semi-structured interviews. Smith (1996a) links IPA to phenomenological psychology, “concerned with an individual’s personal perception or account of an object or event” and symbolic interactionism, which “argues that the meanings individuals ascribe to events should be of central concern for the social scientist but also that those meanings are only obtained through a process of interpretation” (p.263). Although the thoughts of participants are not held to be ‘transparently available’ from interview transcripts, a connection is assumed “between verbal report, cognition and physical state” (Smith, Jarman and Osborn, 1999, p.219), in contrast to discourse analysis (Potter and Wetherell, 1995) which argues that no such assumption can be made. Smith, Jarman and Osborn (1999) argue that Interpretative Phenomenological Analysis is relevant to health psychology as both IPA and the social cognition paradigm of health psychology are concerned with the connections between verbal response, cognition and physical problem.

Data analysis follows an idiographic approach, looking in detail at particular interviews and moving to a broader level of categorisation across participants (Smith, Jarman and Osborn, 1999). It is conducted through the researcher’s immersion in the verbal reports and detailed interpretative activity (Osborn and Smith, 1998). Smith (1996b) argues that it is important that the reader can follow the route by which raw data are processed towards the final write up, but points out that more than one interpretation can be possible. Report writing is seen by Smith, Jarman and Osborn (1999) as part of the process of data analysis, and this may focus on different levels such as description of the typology of responses or an attempt at explanation.

Although some of the themes may originate in the interview schedule (Smith, Jarman and Osborn, 1999), others may be new. The important feature is the grounding of interpretation in the account of the participants. To this end, there is considerable emphasis on checking back with the transcripts and selection of themes is based on contribution to understanding rather than prevalence.

1.7 Summary

People with chronic pain face considerable challenges on psychological and physical levels in their everyday lives. Just as the intensity and consequences of chronic pain may vary, between and within individuals, so may the accounts which people with chronic pain give of themselves and their situation and the responses they may receive from others. This study aims to use Interpretative Phenomenological Analysis to explore the experience of people with chronic pain of talking about their pain and their experiences of being understood. It is hoped that such research can contribute further to the understanding of people who are referred to pain management programmes.

Chapter 2: Method

2.1 Research setting

The research reported here took place in a residential pain management programme attached to a large teaching hospital. Referrals to the programme come from a number of sources including GPs, pain clinics and orthopaedic departments from a wide geographical area. Patients are referred after a range of other medical interventions such as surgery, medication, transcutaneous nerve stimulation and nerve block injections as well as physiotherapy have been tried without long-term success. Many patients have also tried a range of complementary therapy approaches including osteopathy, Alexander Technique and acupuncture. By the time of referral, patients have decreased in their overall levels of mobility and activity, many use a variety of supports and aids, many are no longer working and are maintained on high doses of pain-related medication.

Screening aims to assess whether or not further physical treatment is indicated and whether the referred patient is a suitable person for the programme to treat. At screening, medical assessment and examination are complemented by a psychological assessment in which the impact of pain on daily routine and relationships, memory, mood and concentration is covered. Patients are also asked about any psychiatric history, current stressors and their view of the future. The rehabilitation rather than cure emphasis of the programme is stressed and the contribution of all disciplines explained. A decision about admission is generally made on the day of screening and patients leave with an information sheet about the programme and the recommendation of a self-help book.

Inclusion criteria are at least two of: widespread interference with non-work activity; overactivity/underactivity; excessive medication use; high affective distress related to pain; obvious pain behaviours including unnecessary use of aids and interference with work. Exclusion criteria are any of: inability to speak or write English, (although in practice some accommodation is made); inability to meet minimum physical requirements (self-care, ability to get to the accommodation and use stairs in an emergency); being psychotic or suicidal; self-exclusion; further physical treatment being indicated or anticipated; pain duration of less than one year; age under 18 and primary drug abuse.

Patients are seen once more prior to admission, when pre-treatment measures are completed and administrative matters dealt with. On admission, patients join a group of ten and live in single room hall of residence type accommodation. There is no nursing cover outside programme hours, although an on-call system is available. Each patient is assigned to a member of staff as a 'keyworker' who monitors their progress during their time on the programme. The longest, four week, programme runs over fifteen full days with patients spending long weekends at home. Following the programme, patients are invited to attend one and nine month follow-ups to share progress and solve problems.

The programme consists of education about pain and the body, much delivered by the medical staff; nursing focus on reduction of pain medication, improvement of sleep and use of relaxation techniques; occupational therapy focus on goal planning and activity pacing; physiotherapy focus on building up exercise and stretch and clinical psychology focus on making and maintaining behavioural change, basic cognitive therapy (covering

a range of issues including anxiety and depression) and communication issues. All material is delivered in a group format and supplemented by a written manual received by all patients. Patients are expected to be active participants in their treatment out of hours. They are asked to complete records of their thoughts and feelings for feedback by the psychologists and work on goals which they set themselves over their long weekends at home and share successes and problem-solve around difficulties when they return.

2.2 Ethics

Approval for the research was granted by the Ethics Committee of the hospital in which the pain management programme was based (see Appendix 1). Participants were asked to read and sign a consent form to take part in the research, a copy of which was placed in their notes (see Appendix 2). They were also asked to sign a separate form (see Appendix 3) to allow audio-taping of the initial interview and this form offered the participants a copy of their research interview.

2.3 Participants

Participants were volunteers from three admission cohorts of ten patients attending four week pain management programmes. Of the 18 participants, nine were men and nine were women. Fourteen described themselves as 'white British', two as 'Afro-Caribbean' and two did not choose an ethnic group from those offered. The ages of the participants at screening ranged from 27 to 66 with a mean of 42 years (s.d. 10 years). The men were on average younger - mean age 40 years (s.d. 12 years) than the women - mean age 47 years (s.d. 9 years). Duration of pain ranged from 2 years to 33 years with a mean of 10 years (s.d. 9 years). The men had shorter average pain duration with a mean of 7 years

(s.d. 4 years) than the women with a mean of 14 years (s.d. 11 years). Statistical tests were not performed on any of the variables as this study did not seek to compare men and women participants nor to seek a representative sample of chronic pain patients, rather being concerned with the experience of individuals at the pain management programme who volunteered to participate.

There was no selection of participants for the research by pain site or duration of pain or pain site. The most common pain site of participants was the lower back (12 participants). The remaining participants had their main pain in the hips/legs/feet (four participants) and neck (two participants). Nine participants were registered disabled. Three participants lived alone; six with a partner only and nine lived with children whether with or without a partner

2.4 Procedure

The researcher was on placement at the pain management programme during the research. The research was briefly explained to three intakes of patients on the afternoon of their first full day of the programme and it was stressed that the research was separate from the day-to-day work of the researcher whilst on placement. Patients were given a copy of the consent form, which also acted as an information sheet and the researcher returned later in the week to seek volunteers and schedule research times. The one patient per cohort who was assigned to the researcher for keywork was not accepted as a possible volunteer to maintain the distinction between the research and the work of the programme. From a possible pool of twenty-seven participants across three cohorts, 19 (70%) volunteered and 18 (67%) participated, one not being interviewed due to illness

on the evening scheduled for the interview. As the voluntary nature of participation had been emphasised, reasons for non-participation were not sought.

Participants were interviewed twice using two different semi-structured interview schedules. The first interview was conducted face-to-face, in the first or second week of the programme (Appendix 4) and patients were given a guide to the main areas covered by the interview (Appendix 5). All but one interview took place in the patient's hospital accommodation in the early evening and all but two interviews were completed in one session. Interviews lasted between 25 and 90 minutes. The comfort of patients was emphasised and they were free to move around and on occasion interviews were interrupted when patients became distressed.

Follow-up interviews (Appendix 6) were conducted by telephone some two to three months after participants had left the programme. These were brief and lasted under 15 minutes. Of the original 18 participants, 17 were interviewed at follow-up. One was not interviewed as illness had interrupted his initial admission and he returned to the programme after a considerable break. All interviews were recorded; the first with written permission and the second with verbal permission. Of 18 participants, 11 asked for and received a copy of their first taped research interview.

2.5 Research interviews

Interviews were designed to focus on several main areas starting with talking about pain but moving into a broader context of how the pain had had an impact on life. The first area of focus covered talking about pain (including questions about situations in which

participants had felt understood and not understood) and sought examples of situations in which pain was talked about or not. The second area of focus was the impact of pain on participants' lives and this included two questions from the consequences items of the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris and Horne, 1996): on self-perception and on others' perception of the individual. The quality of life literature was scanned to seek out key areas on which to focus impact of pain questions. The third area contained questions about perception of the future as the pain management programme was thought to have a potential impact on how that might be seen and the future was asked about at screening. A final section asked for comments participants would like to make on the basis of their own experience which might be helpful to medical professionals when seeing patients with chronic pain. Following ethics committee approval, three pilot interviews were carried out to check for face validity and relevance of the questions and minor changes made.

The follow-up interview focused on change since the pain management programme. It was designed to follow the main areas covered by the first interviews and allowed participants the opportunity to make any other comments.

2.6 Quantitative measures

Participants were asked to complete two short questionnaires following both interviews: the Illness Perception Questionnaire (used with permission of the first author) and the Beck Hopelessness Scale. These were generally left with the patients following the first interview (two were completed with patients who preferred this given difficulties with reading) and were sent by post following the second. All participants returned the

questionnaires following the first interviews and 14 of 17 (82%) returned the questionnaires at follow-up. Routine data collected by staff at the pain management programme were also available and of these only demographic data were used here.

Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris and Horne, 1996)

This questionnaire contains five scales corresponding to cognitive representations of illness (see Appendix 7). The **illness identity** scale contains 12 items covering symptoms of the illness [score range 0 – 12]. The remaining four scales cover **cause**: 10 items about personal ideas about aetiology [scores not summed]; **time-line**: 3 items about perceived duration; **consequences**: 7 items about expected effects and outcome and **cure/control**: 6 items about control or recovery. Scores for time-line, consequences and cure/control are presented as means of individual items scored from 1 (strongly disagree) to 5 (strongly agree). For the purposes of this research, the term ‘illness’ was replaced with the term ‘chronic pain’ throughout the questionnaire.

Discriminant validity of the IPQ has been established (Weinman, Petrie, Moss-Morris and Horne, 1996) including with groups of patients with rheumatoid arthritis and chronic idiopathic pain. Patients with rheumatoid arthritis endorsed a mean of 9.05 (s.d. 1.84) symptoms on illness identity; scored 3.62 (s.d. 0.97) on consequences; 3.95 (s.d. 0.79) on timeline and 3.41 (s.d. 0.64) on control/cure with chronic pain patients endorsing 7.05 (s.d. 2.9) illness identity items and scoring 3.57 (s.d. 0.89), 3.29 (s.d. 0.81) and 3.56 (s.d. 0.58) respectively. Chance was endorsed as the strongest cause by those with rheumatoid arthritis and own behaviour by those with chronic pain.

The Beck Hopelessness Scale (Beck, Weissman, Lester and Trexler, 1974)

This is a 20 item yes/no questionnaire [score range 0 – 20] looking at negative attitudes about the future (see Appendix 8). It was designed to measure pessimism in psychiatric patients at risk of suicide, and a score of 9 or more was found to be predictive of eventual suicide in depressed suicide ideators followed for 5 to 10 years after discharge (Beck, Steer, Kovacs and Garrison, 1985). The scale has been applied to physically ill inpatients (Greene, O'Mahoney and Rungasamay, 1982) who found no difference between mean scores for chronically and acutely ill patients and a mean score across these groups of 3.75 (s.d. 2.7), lower than psychiatric in patients and similar to the general population. It was chosen because of its future orientation, which coincides with the emphasis of the pain management programme and because its yes/no structure makes it relatively simple to use.

Chapter 3: Qualitative data analysis and the development of themes

3.1 Introduction

Data analysis broadly followed the method in Smith, Jarman and Osborn (1999). This is an outline of general principles, rather than a prescriptive technique. This chapter will describe the process used here in some detail so that the reader can follow how the themes presented in the results chapter were derived. Appendix 9 illustrates something of the process by the presentation of a worked transcript.

3.2 Analysis of main interviews

The first transcript was read several times and the left margin used to note anything of interest. This followed a policy of over rather than under-inclusion and many notes were made. After this process was completed for the interview, the right margin was used to create brief emerging themes, attempting to capture the essence of themes in a few words. The initial set of themes was the following: solidarity/pain identity, understanding what is going on, communicating about the pain (views on letting others know about the pain, attempts to describe pain, patients' pain and non-pain explanations, being believed), the medical model and alternatives, control (by doctors, patients and others), time issues, comparisons, practical adaptation to life with pain (by the person with pain and others around them), responses of others, the future, moral aspects of pain (such as guilt about its impact on others) and impact on roles. These initial themes were listed on a separate sheet and connections sought between them. An attempt was made to create theme titles which appropriately conveyed theme content. This resulted in an initial list of super-ordinate themes and sub-themes as shown in Table 3.1.

Theme 1: Making sense of having pain
Communication (patients' pain and non-pain explanations, attempts to describe pain) Understanding what's going on Medical model and alternatives
Theme 2: Dependence and control
Communication (views on letting others know about pain) Continuum of control Practical adaptation to life with pain Time issues
3. Self-perception
Solidarity/pain identity Comparisons made by patients Impact on roles Moral aspects of pain
Theme 4: Reactions of others
Communication (being believed) Comparisons made by others Reactions of others
Theme 5: The future

Table 3.1 Initial set of super-ordinate and sub-themes for interview 1

The next two transcripts were analysed in a similar way but with the themes emerging from the first interview as a starting point, whilst allowing other themes to emerge as necessary. Had the first interview not been so rich, it is likely that the alternative approach, with analysis of each interview proceeding afresh, would have been adopted. Analysis of the remainder of the interviews took place after analysis of all interviews on selected areas of particular interest: patients' decisions to talk or not talk about chronic pain and patients' experiences of being understood, both of which are key areas of the

study. This analysis was conducted in the same way as described above and the more focused attention contributed to the development of the final themes. In relation to decisions about talking and not talking about the pain, the themes shown in Table 3.2 emerged:

Theme 1: Potential disadvantages of talking about pain
Negatively affects emotions and self-perceptions of person with pain Negatively affects others No practical benefits for person with pain Risk of further losses for person with pain
Theme 2: Potential disadvantages of not talking about pain
Impact on societal understanding of pain Adverse impact on person with pain
Theme 3: Potential advantages of talking about pain
Emotional benefits for person with pain Practical benefits for person with pain Benefits for others

Table 3.2 Super-ordinate and sub-themes relevant to talking about chronic pain

Detailed focus on patients' experience of being understood, in which participants spoke about a range of medical and non-medical encounters in which they felt understood or not understood resulted in the set of themes in Table 3.3:

Theme 1: Perspective of the patient
Making decisions to communicate about the pain Maintaining normality Levels of patient power
Theme 2: Experience of listener
Experience of pain of listener Other problems of listener Experience of pain of doctor
Theme 3: Judgements and reactions of others
What a chronic pain patient should be like Implications of variation Use of acute pain models Comparison with past functioning of patient Use of 'lay' understanding by doctors
Theme 4: Medical experiences
Consultation: difficulty of describing pain Tests: pain after inconclusive results Treatment: degrees of success Treatment: stressful nature of procedures Consultation: explanations Co-ordination within health care system
Theme 5: Mind body links (in medicine and generally)
Assumptions if nothing is visible Secondary gain assumptions Insensitive use of mind-body link Appropriate use of mind-body link

Table 3.3 Super-ordinate and sub-themes relevant to being understood

Following these more detailed analyses, the interviews were returned to in their entirety and analysis was completed informed by the consideration of themes emerging from the

more focused work. All interviews were re-read and initial theme labels assessed and re-named if necessary.

The final set of themes was: medical issues (manner of doctor, expectations of doctor, health professionals' perspectives on pain, being a patient/getting treatment, being a patient/having a medical explanation and knowledge); mind-body links; living with pain (controlling self-presentation, explaining pain and the impact of pain, comparison by patients, self-perception, maintaining normality, adaptation to life with pain, impact of pain); interaction with others (patients' judgement of the situation of listeners, judgements by others, others' practical responses); time and future in pain; and other issues not categorised.

Evolution of the theme titles occurred as attempts were made to create a group of themes which were more distinct as entities and whose titles captured the experience of the participants with chronic pain. At the same time, material which did not appear to contribute to the group of emerging super-ordinate themes was removed, although there was much material of interest. Thus descriptions of the pain itself were not included, despite the sometimes vivid metaphors which were used, as the difficulty of describing pain is widely acknowledged. Consideration of the future was kept insofar as this contributed to the emerging theme of comparisons but issues of time (for instance time seeming slower when dependent on others) were not included. Initial themes were grouped into a concise framework and the decisions about the evolution of the titles and content of the super-ordinate themes presented in Table 3. 4 are described overleaf.

Theme 1: Experiences of treatment
<i>1a. Experience of fragmentation in the health care system</i>
<i>1b. Investigations and treatment</i> (including negative results, unsuccessful treatments and responses of health professionals, being and not being believed in medical contexts)
<i>1c. Explanations</i> (getting and not getting, and asking for explanations)
<i>1d. Experiences of having control as a patient</i>
Theme 2: Self-perception and comparisons
<i>2a. Current assessment of self</i> (whether positive or negative)
<i>2b. Comparisons</i> (with self and others, including past self and previously expected future self)
<i>2c. Perception of a possible future self</i> (resumption of old self; creation of a new self)
Theme 3: Experiences of the reactions of others (non-medical)
<i>3a. Experiences of being judged</i> (including being believed/not believed and basis on which judgements are made such as lay understandings of pain, own pain or other problems)
<i>3b. Others' attempts to protect the person with pain</i> (including facilitating independence, reinforcing dependence)
Theme 4: Attempts to manage the impact of pain on self and others
<i>4a. Attempts to manage the impact of pain on self</i> (including managing the reactions of others, own thoughts, emotions and experiences)
<i>4b. Maintaining vs adapting life/activity</i> (including both psychological and physical aspects)
<i>4c. Attempts to manage the impact of pain on others</i> (including managing own reactions and the impact of pain which may affect others)

Table 3.4: Themes emerging from the final analysis of first stage interview

Theme 1: Experiences of treatment

Medical issues were brought together into one category, which contained experiences of the fragmentation of the health care system and past experiences of medical or complementary therapy, particularly where there had been negative findings or treatment had not succeeded. Lay judgements by health care professionals were included as were references to the pain being 'in the mind'. Understanding what was going on (from initial work in Table 3.1) was re-framed to an explicit focus on medical explanations, and elements of patient control within medical contexts were also entered into this category to form the theme of experiences of treatment.

Theme 2: Self-perception and comparisons

Self-perception (derived in initial work shown in Table 3.1) continued to appear to be a meaningful super-ordinate theme and was retained but impact of chronic pain on roles and moral aspects of pain more easily and concisely were subsumed into it without occurring explicitly as sub-themes. Positive and negative aspects of self-perception were included, as were comparisons with self and others. Although some comparisons, for example with those worse off might be argued to be attempts at managing life with chronic pain, it was deemed more cohesive to put all comparisons made by individuals with chronic pain together, rather than assume function.

Theme 3: Experiences of the reactions of others

Analysis identified a range of responses of others, both verbal and practical. Thus reactions of others was kept as a theme and defined to include verbal judgements and the basis on which they were made (thus belief in the pain and non-belief) and practical

responses to the individual with chronic pain (whether or not they were appropriate). Although lay judgements of health professionals were originally placed in this category, it was deemed more coherent to place them in a category of experiences of treatment.

Theme 4: Attempts to manage the impact of pain on self and others

This category initially emerged as a result of analysis of decisions about whether and how participants communicated about their pain (Table 3.2). This highlighted that they considered the situations of those with whom they communicated in their decisions about whether or not to communicate, being particularly aware of the impact of their pain on the lives of those around them. Also entered into this category was the conflict between maintaining normality vs. adapting to life with chronic pain which was seen as an issue of the struggle between psychological protection of self-esteem on the one hand and physical protection from pain on the other. This expanded it from being a purely verbal category. Rather than use ‘attempts at protection of self and others’, which might imply that pain could be avoided, this was renamed ‘attempts to manage the impact of pain on self and others’ as this more appropriately covers a range of possible strategies and outcomes.

3.3 Analysis of follow-up interviews

Having been immersed in the data, the themes from the final analysis of the initial interviews served as a starting point as the follow-up interviews used questions covering the same broad areas. Attention was also paid to the emergence of other possible themes. Of the four original themes, the most relevant here was experience of treatment, now

covering experiences at the pain management programme. Also included, however, were subsequent consultations with health professionals.

Moving beyond the initial themes a further major theme emerged: integrating pain management strategies into everyday life after the pain management programme. Interwoven through experiences of treatment and dealing with change were issues of comparison, both with previous pain and ability levels and with others on the programme. It is argued that these contribute more as elements of super-ordinate themes here, than as a separate category, as comparison forms part of the commentary on treatment and life following treatment – participants having been shown videos of themselves before and after treatment and having been faced with extended contact with others with chronic pain who had made different forms of progress.

3.4 Summary

This chapter has provided a detailed account of the development of the themes derived from interviews with patients with chronic pain attending an inpatient pain management programme. It illustrates that this was an evolving process and that there may be more than one reading. One of the challenges of qualitative research is to increase reader understanding (see Elliott, Fischer and Rennie, 1999). By providing this detailed account of the process, and an associated example of an annotated transcript in Appendix 9, the interested reader will be better able to follow what was done and to judge whether the challenge of increasing understanding has been successfully met.

Chapter 4: Results

4.1 Introduction

The main interview questions covered a range of areas including situations in which participants felt understood/did not feel understood, talking about the pain, impact of the pain, perception of the future and suggestions for health professionals. Following presentation of the quantitative results from the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris and Horne, 1996) and the Beck Hopelessness Scale (Beck, Weissman, Lester and Trexler, 1974) this chapter presents the four main themes which emerged from the analysis of the first set of interviews and the two main themes from the follow-up interviews.

4.2 Illness perceptions and future orientation: quantitative results

IPQ: Illness identity

The mean number of symptoms identified by participants was 9 (s.d. 2) at both initial and follow-up interviews on a 0 – 12 scale. This suggests that they had a considerable number of symptoms which they perceived as being related to their chronic pain. This can be compared with a mean of 9.05 symptoms (s.d. 1.84) endorsed by patients with rheumatoid arthritis and 7.02 (s.d. 2.9) by patients with chronic pain (Weinman, Petrie, Moss-Morris and Horne, 1996). The factor least likely to be endorsed was weight loss – weight gain being more likely to be a problem in chronic pain as activity levels decrease.

IPQ: Causes

The causes most strongly endorsed at initial interviews were chance, other people and poor medical care in the past, each endorsed by eight participants. This compares with chance endorsed as the strongest cause by those with rheumatoid arthritis and own behaviour by those with chronic pain (Weinman, Petrie, Moss-Morris and Horne, 1996). The three least common causes were germ/virus and heredity, each endorsed by two participants and own behaviour endorsed by one. For five participants, some causes initially endorsed as ones they either agreed with or strongly agreed with moved to causes they disagreed with at follow-up: stress (two participants), and poor past medical care, other people, chance and heredity all endorsed by one person. For three participants, some causes initially not endorsed moved to causes that were agreed with or strongly agreed with at follow-up: chance (two participants), other people and poor care both endorsed by one participant. This suggests a possible impact of the pain management programme on participants' conceptualisation of the cause of their pain.

IPQ: Time-line

This measures perceived permanence of chronic pain and possible scores range from 1 (low permanence) to 5. The mean score of perceived permanence was 4.04 (s.d. 0.68) at initial interview and 4.33 (s.d. 0.69) at follow-up. This suggests that overall perceived permanence remained high, and even increased slightly following the pain management programme. The scores are similar to patients' perceived permanence of rheumatoid arthritis of 3.95 (s.d. 0.79) but higher than that of chronic pain 3.29 (s.d. 0.81) (Weinman, Petrie, Moss-Morris and Horne, 1996). It may be speculated that the patients included in the IPQ development work recruited from a private anaesthetist-led pain

clinic in Australia were earlier in their chronic pain and intervention careers than those in this study.

IPQ: Consequences

This measures perceived severity consequences of chronic pain and possible scores range from 1 (low severity) to 5. The mean score of perceived consequences was 4.03 (s.d. 0.67) at initial interview and 3.91 (s.d. 0.70) at follow up suggesting broad stability of perceived consequences. These are higher than mean scores found for rheumatoid arthritis 3.62 (s.d. 0.97) and chronic pain 3.57 (s.d. 0.89) (Weinman, Petrie, Moss-Morris and Horne, 1996).

IPQ: Control/cure

This measures perceived belief in control and cure and possible scores range from 1 (low confidence) to 5. At initial interview the mean score was 3.41 (s.d. 0.72) and 3.13 (s.d. 0.87) at follow-up. Looking at individual data, six participants made large changes: four in the direction of decreased confidence in control and cure after the programme; and two in the direction of increased confidence in control and cure. However, the combination of control and cure items in this questionnaire may be inappropriate in the context of pain management as cure is explicitly not the focus. The two questions covering personal control may be the most relevant. Looking only at the participants returning both sets of data, the mean score on these two items was 4.0 (s.d. 0.83) at the initial interview and 3.5 (s.d. 1.19) at follow-up suggesting decreased perceived control over the course of pain following the pain management programme.

BHS results

The possible range of scores on this measure is 0 – 20. At initial interviews, scores ranged from 1 to 19 with a mean of 6.4 (s.d. 5.3) and a median of 4.5. At follow-up scores ranged from 0 – 14 (the highest scorer at initial interview not returning follow-up data) with a mean of 6.5 (s.d. 4.9) and a median of 6.5. These scores are higher than those found for acutely and chronically ill inpatients (mean 3.75; s.d. 2.7) by Greene, O'Mahoney and Rungasamay (1982) suggesting the participants here were a more distressed group. A score of 9 or more has been found to be predictive of eventual suicide in depressed suicide ideators followed for 5 to 10 years after discharge (Beck, Steer, Kovacs and Garrison, 1985). Of the fourteen participants for whom follow-up data are available, ten scored below the cut-off point of 9 at initial interview. Of these, two moved to over the cut-off point at follow-up. Of the remaining four who scored over the cut-off point of 9 at initial interview, three remained above the cut-off point and one moved to below it at follow-up. Suicide risk had been assessed prior to admission with any referred patient thought to be at risk excluded and referred back for further help. However, the scores on this scale indicate that the level of pessimism about the future is high and may not be affected by a pain management programme.

All names have been changed and identifying details (apart from pain duration) removed to protect confidentiality. Scores on the BHS and 4 areas of the IPQ (excluding perceived causal factors) are presented for both time-points for individual participants: **changed name; age; pain for; BHS [pain management, follow-up]; IPQ-identity [pain management, follow-up]; IPQ-time [pain management, follow-up]; IPQ-consequences [pain management, follow-up]; IPQ-control/cure [pain management, follow-up].**

	M/F	Age	Pain duration	BHS 1	BHS2	IPQ ID1	IPQ ID2	IPQ T1	IPQ T2	IPQ CONS1	IPQ CONS2	IPQ CURE1	IPQ CURE2
Anna	F	early 50s	33 yrs	5	1	6	8	3.67	3	3.43	2.71	2.33	3.83
Bella	F	early 40s	4 yrs	4	-	12	-	5	-	4.29	-	3.5	-
Colin	M	late 30s	5 yrs	11	9	11	11	5	5	4.71	4.43	3.33	2.83
David	M	early 40s	11 yrs	6	5	10	11	4	4	4.29	4.49	4.17	3.5
Eve	F	mid 40s	2 yrs	19	-	7	-	4	-	4.57	-	3	-
Fiona	F	early 50s	20 yrs	12	13	12	11	4.67	4.33	4.14	4.29	3.17	3.17
Gerry	M	mid 40s	7 yrs	13	12	11	11	4.33	5	4.29	4.29	3	3
Hanna	F	early 40s	25 yrs	7	14	10	11	4	5	4.14	4.57	3.67	1.67
Tom	M	late 40s	7 yrs	14	7	6	9	5	4	5	4	2.5	3.17
Jack	M	late 30s	5 yrs	3	-	12	-	4	-	4.86	-	3.83	-
Karen	F	late 20s	5 yrs	1	2	11	8	3.67	3	3	2.43	3.33	4.83
Leonard	M	mid 60s	15 yrs	2	6	10	7	3.33	4.67	4	4	3	3.33
Mark	M	late 20s	3 yrs	3	12	11	11	4	5	4.14	4.14	4	2.17
Nigel	M	early 30s	5 yrs	8	-	10	-	2.67	-	3.43	-	4.5	-
Oscar	M	late 20s	2 yrs	1	2	8	11	3.33	4.33	4.29	4	4.33	4.33
Paula	F	early 50s	20 yrs	2	1	8	10	5	4	4.71	2.86	1.83	3.5
Susan	F	late 50s	9 yrs	3	6	6	4	3.86	4.33	3.14	4.29	4	2.33
Ruth	F	early 40s	7 yrs	1	0	6	8	3.33	5	2.71	4.29	3.83	2.17

Higher IPQ scores represent

IPQ-identity – more symptoms
IPQ-time – greater permanence

IPQ-consequences – more severe consequences
IPQ-control/cure – more confidence in cure/control

Table 4.1 Summary data for all participants

4.3 Qualitative results

The substantive part of this chapter presents the four themes which emerged from the initial interviews: experiences of treatment, self-perception and comparisons, experiences of the reactions of others and attempts to manage the impact of pain on self and others and the two main themes from the analysis of the follow-up interviews: experience of treatment and integrating pain management strategies into everyday life. Most participants had experienced major losses in their lives as a direct or indirect result of their pain, such as loss of work, social life and personal relationships. Whilst not asked directly, most participants also spoke of the difficulty of describing pain and several gave vivid metaphors. Such issues are not uncommon themes in the pain literature and will not be elaborated on further in this chapter.

4.3.1 Experiences of treatment

Experiences of fragmentation in the health care system

By the time participants were referred, they had generally gone through a range of investigations and treatment attempts with limited success:

I was perpetually going back to my local doctor and he would say to me ‘there’s no more I can do for you, I must refer you’. So we’re lucky where I live, we have our own pain clinic at our own local hospital. And there’s a specialist there, a doctor [name], who is very, very clever but he ran out of ideas with me but he recommended me to come up to [pain management programme] Leonard, mid 60s, pain for 15 years, BHS [2, 6]; IPQ-identity [10, 7]; IPQ-time [3.33, 4.67]; IPQ-consequences [4.00, 4.00]; IPQ-control/cure [3.00, 3.33]

Although a few participants appeared to progress smoothly through treatments prior to reaching the pain management programme, and had good communication back to their GP, others were angry at experiences which included conflicting advice, treatment for the wrong problem and being sent between departments with different philosophies:

...was put into the physio department who asked was I in pain and I said 'yes, I'm always in pain' and the answer was 'well in that case we won't touch you today, you'd better go back and see the doctor' – it was all very negative aspects of it and this happened oh, 5, 6 times, each time going back to the hospital then to the physio, the physio again wouldn't do anything and just referred you back to the doctor... **Anna, early 50s, pain for 33 years, BHS [5, 1]; IPQ-identity [6, 8]; IPQ-time [3.67, 3.00]; IPQ-consequences [3.43, 2.71]; IPQ-control/cure [2.33, 3.83]**

and delays before appropriate tests were done:

... the first doctor I went to and spoke to, he didn't do nothing for a year and I changed doctors and then I went to [location] hospital 'cos I couldn't get no result from my doctor. He wouldn't give me a pain killer. He was just shunning me off – 'oh, it's your job'. And when my wife finally took me to [hospital] that was the first time that anybody really took note of I'm in pain.... He wrote to my doctor... that he should send me for some tests and that's when they discovered that I had rheumatoid arthritis. **Tom, late 40s, pain for 7 years, BHS [14, 7]; IPQ-identity [6, 9]; IPQ-time [5.00, 4.00]; IPQ-consequences [5.00, 4.00]; IPQ-control/cure [2.5, 3.17]**

Investigations and treatment

Negative test results were a source of difficulty with participants reporting being told that nothing showing on scans or X-rays meant that nothing was wrong:

...after the first injury, the MRI scan was normal of my whole spine so a very simple, very nice letter – 'there is no abnormality whatsoever found, I hope you can get back to your life as normal', you know, that's it, you know. [As if] that's going to make, enable me to do things again just because they haven't found anything wrong in an MRI scan, that's going to change my

symptoms and actually cure me – the fact that they haven't found anything on the MRI scan.
**David, early 40s, pain for 11 years, BHS [6, 5]; IPQ-identity [10, 11]; IPQ-time [4.00, 4.00];
IPQ-consequences [4.29, 4.49]; IPQ-control/cure [4.17, 3.5]**

Participants found it particularly hard to convince doctors that the treatments which they had undergone had not worked or had only worked for a short time and this could lead to them to think doctors judged their pain as being in the mind:

I felt like, like their attitude was, well you know 'I give you that, it should have worked' and because you question that and I said to them you know 'well I'm sorry but it didn't work, you know I've still got the pain' and they look at you as if it's all in your mind this pain 'cos that should have worked. And I'm probably the first person to say 'yeah, it's really worked alleluia' and do cartwheels down the street... **Eve, mid 40s, pain for 2 years, BHS [19, -]; IPQ-identity [7, -]; IPQ-time [4.00, -]; IPQ-consequences [4.57, -]; IPQ-control/cure [3.00, -]**

Some participants had periods of beginning to doubt their own experience of pain as a result of their interactions with health professionals and several recalled insensitive comments about compensation claims, which was particularly explicit in this account:

I said to him, 'they haven't sorted out my knee, right', so I said 'it's still swollen up and it's still playing me up, there must be something wrong somewhere'. 'No, no, no, there's nothing, nothing wrong, you know, it's all in your mind'. And I thought it's not in me mind, you know. 'You'll be all right, give it a few more weeks and you'll be all right' and I thought, this is ridiculous, you know. So I said 'it's not in me mind'. 'Yes', he said, 'it's in your mind Mrs. [name], you'll be all right, don't worry about it' and I thought what the hell is he talking about? And I said, 'look, I come to see you 'cos I'm in pain'. 'Yeah, once it's all, once your accident's all sorted out and you've got your money and everything else, you'll be as right as nine-pence'. **Susan, late 50s, pain for 9 years, BHS [3, 6]; IPQ-identity [6, 4]; IPQ-time [3.86, 4.44]; IPQ-consequences [3.14, 4.29]; IPQ-control/cure [4.00, 2.33]**

Some described lack of appreciation by health professionals of how much effort went into living with chronic pain, or of the financial needs of the family:

His [rheumatologist's] attitude was 'I can't do anything for you so', you know, 'go home. And you work so it can't be that bad' – that was literally his attitude, which I found so upsetting and it made me feel pretty hopeless. So I went home and spent another year putting up with things. **Hanna, early 40s, pain for 25 years, BHS [7, 14]; IPQ-identity [10, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.57]; IPQ-control/cure [3.67, 1.67]**

An expectation of not being believed may thus arise, even following admission to the pain management programme as was illustrated by this patient:

they [doctors] wouldn't be involved in [the pain management programme] if they didn't understand pain. But even with [the pain management programme] people think that, do they think it's in your mind? Are they just saying they believe it's not in your mind, because that's what they want you to believe? You think that as well, I mean - I think that, I thought that when I first come here [...] this is clever, you know, this is brainwashing... **Eve, mid 40s, pain for 2 years, BHS [19, -]; IPQ-identity [7, -]; IPQ-time [4.00, -]; IPQ-consequences [4.57, -]; IPQ-control/cure [3.00, -]**

In contrast, being believed and health professionals expressing some awareness of what it is like to experience pain were valued. Health professionals were assumed not to have experienced anything other than acute pain but participants wanted them to extrapolate from their personal experience of pain to try and understand the patient. Where this had been sensitively done with one of the participants, this had been a positive experience:

... he [consultant] said that 'the pain that you have got must be excruciating because I had sciatica once, I only had it for a week but I couldn't move' ...he could understand what I'd been having for thirteen years. Like people get sciatica, they go and lay down for a week, ten days and

it passes – mine is permanent because it is the sciatic nerve that is damaged [...] – he had some knowledge himself of what it's like to have a sciatic nerve go on you, you know to give you pain and to live with that 24 hours a day. **Fiona, early 50s, pain for 20 years, BHS [12, 13]; IPQ-identity [12, 11]; IPQ-time [4.67, 4.33]; IPQ-consequences [4.14, 4.29]; IPQ-control/cure [3.17, 3.17]**

Explanations

Participants had a range of levels of explanation given to them by health professionals, with some getting explanations of the limits of medication, limits of test procedures or medical knowledge and in some cases an acknowledgement that the health care professional him/herself was baffled by the continuation of their symptoms:

I've got fibromyalgia, I didn't even know what that was but she took me into a room and started pressing certain points on my body, which actually every single one was excruciating, and I sort of said to her, 'goodness, you know where to touch', and she said straight away she knew what I had, that there wasn't much they could do at the moment, it's pretty new, but things could change... **Hanna, early 40s, pain for 25 years, BHS [7, 14]; IPQ-identity [10, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.57]; IPQ-control/cure [3.67, 1.67]**

In other cases, participants had years of treatment before getting a diagnosis or had to ask for explanations themselves:

I said 'I want to know what's going on'. I said 'I am fed up with you doctors saying one thing and another doctor tells you something else'... So he said 'right' he said, 'yes, you had the disc out', he said what they done and explained to me. And I thought, this is great, someone really explaining to me... This is what annoys me - the vet explains everything about what's going to happen to the dogs, but doctors don't explain what's going to happen to you. **Susan, late 50s, pain for 9 years, BHS [3, 6]; IPQ-identity [6, 4]; IPQ-time [3.86, 4.44]; IPQ-consequences [3.14, 4.29]; IPQ-control/cure [4.00, 2.33]**

Whereas the pain management programme provided welcome opportunities for participants to get explanations, several participants were unhappy with the general messages they heard as a group there that pain did not mean damage and that pain was not a progressive condition. Where participants had diagnosed progressive conditions which were associated with their pain, this might lead to patients feeling that their situation had not been understood, or indeed concern by others that this was the case:

... a chap who was recovering from [condition] which affected his legs, he was told that it's not progressive and the man was flabbergasted – he said 'I'm only [age] and I'm a cripple already – of course it's progressive' – so there is what I call a break down of communication [...] it happened in our first week, this is now coming up towards the end of the second and even now we talk about it 'cos we was offended... **Leonard, mid 60s, pain for 15 years, BHS [2, 6]; IPQ-identity [10, 7]; IPQ-time [3.33, 4.67]; IPQ-consequences [4.00, 4.00]; IPQ-control/cure [3.00, 3.33]**

Experiences of having control as a patient

Despite the debilitating nature of pain, there were many attempts by patients to take some sort of control in the process of getting treatment. This included reading up on the medication they were given, checking a doctor's qualifications, changing GP, trying out complementary therapies, confronting a doctor with previous lack of effort on their behalf and making decisions about their treatment:

...it was getting to the stage where you either go through life as a zombie or you, you know take a higher level of pain and try and keep a bit of normality and I've chosen to take more pain **Jack, late 30s, pain for 5 years, BHS [3, -]; IPQ-identity [12, -]; IPQ-time [4.00, -]; IPQ-consequences [4.86, -]; IPQ-control/cure [3.83, -]**

For several patients, attendance at the pain management programme was through circuitous referral or indeed through their own effort:

... I have to come up here for an X-ray, for a CT scan [...] I was passing and I saw this [pain management programme] and I walk in and I got some leaflets and I went home and I read them, then I took them to him [GP] and I ask him about it. [...] when he first applied for me to come I couldn't [...] get about to get dressed or anything like that so the unit couldn't have me because they have like nobody to do those things for you [...] So I decided, I had a talk with him, which he *did* listen that time, and I said to him, 'I'll try, I'm going to try my best even if it kills me to get to a point where I'll be able to come on the [pain management programme]' here, and when I find that I could manage a bit more, I went back and asked him and he referred me. **Bella, early 40s, pain for 4 years, BHS [4, -]; IPQ-identity [12, -]; IPQ-time [5.00, -]; IPQ-consequences [4.29, -]; IPQ-control/cure [3.5, -]**

Participants brought a range of previous experiences of intervention attempts and patient-professional interactions to the pain management programme. There was frustration among some at the wasted years prior to being sent to pain management and their consequent deterioration - 'how could they have allowed me to get like this?' Participants wanted more communication amongst hospital departments and greater medical awareness of pain management as an option earlier on in people's pain careers.

4.3.2 Self-perception and comparisons

Current assessment of self

The losses which participants had experienced as a result of their pain were associated with a number of negative self-assessments. Whether or not participants were working,

pain was generally perceived as having had its biggest impact on their working lives. Participants assessed themselves as failures, as having let their families down, as a burden to others and as poor actual or potential partners. However despite this, many respondents were also able to comment positively about themselves or aspects of their situation, whether a comment on their ‘good personality’, caring nature, potential, good family around them or indeed their ability to cope with their pain:

So why not me? I’m no more special than anybody else, that’s my lot. I’m given it [pain] because I presume I can handle it **Fiona, early 50s, pain for 20 years, BHS [12, 13]; IPQ-identity [12, 11]; IPQ-time [4.67, 4.33]; IPQ-consequences [4.14, 4.29]; IPQ-control/cure [3.17, 3.17]**

Several participants spoke of aspects of having reprioritised what was important to them and some referred to less emphasis on material success, the opportunity to re-evaluate career direction and the time for reflection which had emerged:

I used to do a job just manufacturing, I was just like a number – I’d like to do something where I could help someone. I’ve always fancied doing it and now that’s a bit more realistic really, but what I don’t know. I don’t really want to go back to the rat race really, sort of, just being at work all the time and not having any quality at home. **Oscar, late 20s, pain for 2 years, BHS [1, 2]; IPQ-identity [8, 11]; IPQ-time [3.33, 4.33]; IPQ-consequences [4.29, 4.00]; IPQ-control/cure [4.33, 4.33]**

Comparisons with self and others

In describing the impact of pain many participants made explicit comparisons with their lives before pain. They referred to their previous busy work and leisure lives and what they used to be able to do, their lively personalities and enjoyable social lives, their roles within their families and the financial wherewithal to maintain their lifestyles. One or

two compared themselves with others of the same age or felt that limitations they associated with old age had come prematurely:

People think 'oh they can't get out of the bath'. You don't think of that till you're like in your seventies, eighties, nineties – normally - I mean that's the way I perceive people not getting in and out of the bath **Colin, late 30s, pain for 5 years, BHS [11, 9]; IPQ-identity [11, 11]; IPQ-time [5.00, 5.00]; IPQ-consequences [4.71, 4.43]; IPQ-control/cure [3.33, 2.83]**

Others were struggling with the concept of being 'disabled':

I've like been able to understand to a certain extent what it's like to be like that [disabled] although I'm not disabled *per se*. I mean I'm, I'm certainly unemployable and I do feel sometimes like I am disabled but I view disabled as being you've got no legs or something, but that isn't strictly true, you know. I qualify as being disabled, I'm accepted by the state as being disabled. **Gerry, mid 40s, pain for 7 years, BHS [13, 12]; IPQ-identity [11, 11]; IPQ-time [4.44, 5.00]; IPQ-consequences [4.29, 4.29]; IPQ-control/cure [3.00, 3.00]**

and

I feel as if I've become disabled, you know. I feel – yeah, I feel as if I belong in that category rather than fit people. I don't have an orange badge or walk round with a stick but I feel more and more as time goes by I'm beginning to fit into that category rather than the other one and I don't like it. **Hanna, early 40s, pain for 25 years, BHS [7, 14]; IPQ-identity [10, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.57]; IPQ-control/cure [3.67, 1.67]**

Comparisons were also made with others worse off: others with a variety of other health problems, others with pain, and others struggling in different parts of the world. Whereas comparison with others worse off acted as a potential motivator for some participants, there was also an element of guilt that others were dealing with situations perceived as worse, including more directly visible disability:

... It doesn't matter how low or how horrible I feel, I look at her [friend with thalidomide] and think 'goodness me, what have I got to worry about?' I know I've got pains and yes I should worry about it to some extent but when you see something like that... **Hanna, early 40s, pain for 25 years, BHS [7, 14]; IPQ-identity [10, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.57]; IPQ-control/cure [3.67, 1.67]**

Several participants mentioned relatives with pain or other health problems and made comparisons with them. Whereas one participant wanted to adopt her father's stoical approach to health problems, for some comparisons with relatives were associated with a fear that they would follow in the footsteps of relatives who were perceived as having given up:

[relative] suffers from a similar sort of thing except she's just given up completely whereas I don't want to get like that. So even sometimes talking to her I feel down because I see the way she is and you say to yourself 'is that the way I'm going to head?' **Colin, late 30s, pain for 5 years, BHS [11, 9]; IPQ-identity [11, 11]; IPQ-time [5.00, 5.00]; IPQ-consequences [4.71, 4.43]; IPQ-control/cure [3.33, 2.83]**

Perception of future self

Having experienced multiple losses, many participants had come to fear the future with its potential for further deterioration, interrupted ambitions and the continued need to plan their lives around their pain. Being at the pain management programme after many years of deterioration and distress appeared to offer some hope. However, participants were interviewed early in the process of getting the new message of self-help and responsibility for pain management and many participants held elements of both optimism and fear. For some the future was one of anticipated deterioration as a result of

a progressive condition, concern they might damage themselves further, decades of pain ahead if they had inherited family longevity and fear of worse mood swings and further dependence on others. For some participants however, there were the beginnings of fearing the future less:

What's happened in those last 5 years has been so dramatic that you think 'what am I going to be like in another 5 years, the 5 after that?'... I hope to be better than I am, I'm still going to be in pain so I don't know even though, hopefully I'll be more agile or whatever they're going to do here **Hanna, early 40s, pain for 25 years, BHS [7, 14]; IPQ-identity [10, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.57]; IPQ-control/cure [3.67, 1.67]**

Some no longer working saw few realistic options for work, several having had jobs which relied heavily on physical strength or mobility. However, there was hope for improvement even if work was not an option: making more of a contribution to housework, improved relationships and being able to enjoy more of a social life. For most participants, thinking about the future was connected with a hoped for ability to resume at least some former leisure activities, maybe taking up new activities to keep mobile and resuming their sex lives. Some were hoping that they would not need a wheelchair as they had been told or as they feared:

But since I've been here... I'm a bit more optimistic that I might not have to be in a wheelchair in a couple of years' time, that I will still have to walk around you know, and that I still will be a bit, you know independent and I, I won't have to rely on people so much... **Susan, late 50s, pain for 9 years, BHS [3, 6]; IPQ-identity [6, 4]; IPQ-time [3.86, 4.44]; IPQ-consequences [3.14, 4.29]; IPQ-control/cure [4.00, 2.33]**

More generally, participants hoped for a resumption of self – of returning to be the person they were before the pain, even though this might not be possible in all aspects of their lives. Two participants made their desire to return to their perceived former self particularly explicit:

I see the future in being a woman again, not a cabbage, being a person, the person I was before
**Bella, early 40s, pain for 4 years, BHS [4, -]; IPQ-identity [12, -]; IPQ-time [5.00, -];
IPQ-consequences [4.29, -]; IPQ-control/cure [3.5, -]**

and for one it was already happening during the pain management programme:

You know, me, I'm coming back to me – how I used to be, you know. That's one thing I'm
really pleased about. Yes, I haven't got so much pain and I'm coming back how I used to be –
happy-go-lucky. **Susan, late 50s, pain for 9 years, BHS [3, 6]; IPQ-identity [6, 4]; IPQ-time
[3.86, 4.44]; IPQ-consequences [3.14, 4.29]; IPQ-control/cure [4.00, 2.33]**

4.3.2 Experiences of the reactions of others

Experiences of being judged

Participants were specifically asked about situations in which they had felt understood and not understood when talking to people about their pain. Most participants were able to give examples of both and these occurred in a variety of situations including medical, social and domestic. Examples were given of a variety of bases on which participants felt they were judged and believed or not believed.

Others with pain were thought most likely to understand their position, failing that, others with some experience of life difficulties:

there are very few people that actually want to know somebody else's problems and that can actually feel it because it's something that you can't see – unless somebody experiences pain themselves in a similar way then they don't really know what you're talking about anyway – to them it's just nothing. **Anna, early 50s, pain for 33 years, BHS [5, 1]; IPQ-identity [6, 8]; IPQ-time [3.67, 3.00]; IPQ-consequences [3.43, 2.71]; IPQ-control/cure [2.33, 3.83]**

Some participants reported that their relatives had explicitly commented on their greater understanding of what the participants must be going through as a result of their own health problems. However, this was complicated if relatives highlighted their own coping ability as one participant illustrated:

... she [wife] was in pain and she sort of was getting frustrated because she couldn't do anything about it and she was sort of saying 'well I'm in pain and I'm still carrying on' [...] and it got to the stage where I didn't, where I couldn't say anything that would cause an argument... **Oscar, late 20s, pain for 2 years, BHS [1, 2]; IPQ-identity [8, 11]; IPQ-time [3.33, 4.33]; IPQ-consequences [4.29, 4.00]; IPQ-control/cure [4.33, 4.33]**

Other participants spoke of belief in and acceptance of their pain from family and friends who had witnessed their deterioration over time or other health problems:

... my family know about it anyway so if you're holding your back they just say 'oh, your back's hurting – do you want to sit down or do you wanna...' – you know, and that's it – it's part of life. They just accept it and you don't go into long detail or – like you would any new person... **Karen, late 20s, pain for 5 years, BHS [1,2]; IPQ-identity [11, 8]; IPQ-time [3.67, 3.00]; IPQ-consequences [3.00, 2.43]; IPQ-control/cure [3.33, 4.83]**

Lay judgements based on acute pain were often used by family, colleagues and friends (and also health professionals at times), and often were associated with not being understood and/or not being believed. Lay judgements consisted of inappropriate assumptions based on the variable nature of the impact of pain through seeing

participants occasionally and/or on ‘good’ days, not taking into account different pain thresholds among individuals and using inappropriate estimates of recovery periods. Such judgements were used to play down the severity of the pain, to assume that participants did not want to work and that their physical status had not in fact changed:

... where I work they expect me to be bent over and really bad [...] but I’m not that bad but I’m still in a lot of pain. I think they think after two years I’d be better by now. **Oscar, late 20s, pain for 2 years, BHS [1, 2]; IPQ-identity [8, 11]; IPQ-time [3.33, 4.33]; IPQ-consequences [4.29, 4.00]; IPQ-control/cure [4.33, 4.33]**

Being on welfare benefits had various associations with the experience of being judged by others. Whereas many participants felt that this led to them being judged as a ‘skiver’ or a ‘scrounger’; in some circumstances it could also serve as an indicator of the severity of the situation and be associated with being believed:

...with my mother she sort of understands a bit, a bit more now. Originally like it’s like ‘you’ll get over it, you’ll be all right, get yourself back to work’ sort of thing. And I think she seen me when I was very low struggling with the money at the social [security] and then, then I think people really realised well, no-one’s gonna be happy off living off their little bit they give you, so, that, that’s when I think everything changed, when I actually started being on no money from [employer] but living on benefits, then people seem to think that you’re more genuine I think. **Nigel, early 30s, pain for 5 years, BHS [8, -]; IPQ-identity [10, -]; IPQ-time [2.67, -]; IPQ-consequences [3.43, -]; IPQ-control/cure [4.5, -]**

Others’ attempts to protect the person with pain

When there was acknowledgement of pain by others, even though this might vary, participants gave a variety of examples of attempts by others to protect them. Some of

these even well meaning attempts led to further distress for the participants as they implied restrictions, lessening of independence and social invisibility:

I know it's affected the way close family have seen me, because in the past it was like 'ask [Mark] to do so and so, he can do this, he can do that' and now it's like 'don't ask him because he's like disabled', you know, 'you can't keep asking him to do things because he can't do them any more', you know. But they don't actually ask me. They talk around me do you know, so it's changed their attitude towards me to a point where sometimes I have to say 'I'm still here, I still exist, please do talk to me about it. Even if you ask me and I say no, please ask me', you know. Because they just seem to think that because I've got a back problem I can't do anything and I should be molycoddled, wrapped in cotton wool and kept in a box somewhere. But you can't live your life like that. **Mark, late 20s, pain for 3 years, BHS [3, 12]; IPQ-identity [11, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.14]; IPQ-control/cure [4.00, 2.17]**

Many participants reported a decline in their social life both for reasons of the pain directly and indirectly because for many, their financial situation had altered. Some felt that their exclusion from their social network may have in part been due to friends learning not to invite them over time through an awareness of their altered financial situation:

...I think people think 'can't really ask him to come if he hasn't got any money' and that you know, and they have asked us and I've said 'no we can't go because we've got no money'... **Oscar, late 20s, pain for 2 years, BHS [1, 2]; IPQ-identity [8, 11]; IPQ-time [3.33, 4.33]; IPQ-consequences [4.29, 4.00]; IPQ-control/cure [4.33, 4.33]**

and/or anticipated limitations:

...even for things like going out bowling and stuff like that – they know you like doing it so you find that they've gone out with friends rather than ask you like they would normally do – I think sort of people tend to avoid asking you into situations where maybe you might not be

comfortable, or where you may not be able to go for different reasons **Anna, early 50s, pain for 33 years, BHS [5, 1]; IPQ-identity [6, 8]; IPQ-time [3.67, 3.00]; IPQ-consequences [3.43, 2.71]; IPQ-control/cure [2.33, 3.83]**

As well as these reasons given, there may be another set of reasons which participants felt less comfortable talking about: others feeling uncomfortable in their company, for example through perceived effort involved in social or leisure activities with someone who may need some consideration. However, participants also described responses from others which maintained their dignity and independence, involved planning around their abilities and continuation of activities and relationships:

... It's only been the last year that I've got involved with my son's football team and it was the management's decision to kind of have me on board to give me something to help occupy - so I do like the decision making, I attend the meetings and I've got a trainer, co-manager cum trainer that does all the physical side. You know that's been a massive help, without that, you know it would have been even worse than what it is **Jack, late 30s, pain for 5 years, BHS [3, -]; IPQ-identity [12, -]; IPQ-time [4.00, -]; IPQ-consequences [4.86, -]; IPQ-control/cure [3.83, -]**

One participant contrasted how her best friend and family responded to her pain:

if she come to the house and I am trying to do something and I can't really manage, she's not one of them people that will jump up and say 'let me do it'. She will assure me, she will say 'leave it, just sit down, leave it, sit down'. She'll make me a cup of tea, we'll have a cup of tea together and sometime a good laugh or a good cry and then she'll say 'do you feel better now?' and I went on - continue. She'll never do like say 'leave it, I'll do it' - she won't do that, you know, she won't take that bit of independence away from me which as my family they do - they can see I'm in agony and they'll said 'oh, mum, leave that we'll do it'... **Bella, early 40s, pain for 4 years, BHS [4, -]; IPQ-identity [12, -]; IPQ-time [5.00, -]; IPQ-consequences [4.29, -]; IPQ-control/cure [3.5, -]**

Another continued a much loved hobby with his friend, a hobby which had benefits for his psychological well-being both directly and indirectly:

The only sport or hobby I do is fishing and that's only when a friend can take me, but that is the one time that I can chill out and totally forget everything. Even my pain goes. Just sitting there by a lake and it is so peaceful and tranquil and all you've got is like the birds and what and the odd fish leaping out now and then – it's so calming, you know, it's almost like being in a relaxation class here in a way, it's a natural relaxation class for me **Colin, late 30s, pain for 5 years, BHS [11, 9]; IPQ-identity [11, 11]; IPQ-time [5.00, 5.00]; IPQ-consequences [4.71, 4.43]; IPQ-control/cure [3.33, 2.83]**

Beyond the varied interactions with family, friends and colleagues, interactions with the general public were less likely to be associated with understanding. Participants suggested that the public generally do not assume others have problems on the one hand, or where disability was visible, that it might be associated with mental health problems:

...I mean most people out there don't really have time for people with injuries, not really, you know. It's a bit like, I know it's different, but it's a bit like people view people with mental problems, you know, 'oh, he's a nutter, stay clear' or - I mean, I hate to say it but it's true... **Gerry, mid 40s, pain for 7 years, BHS [13, 12]; IPQ-identity [11, 11]; IPQ-time [4.44, 5.00]; IPQ-consequences [4.29, 4.29]; IPQ-control/cure [3.00, 3.00]**

4.3.4 Attempts to manage the impact of pain on self and others

Having experienced many years of pain, a variety of treatments and various responses from others, participants had learned to judge situations and attempt to manage the impact of pain on themselves. Feared consequences included deepening of their mood and negative self-assessment; negative assessment by others and further losses in their lives over which others had some control such as loss of a job or relationship;

deterioration and increases in their pain, whether short or long term. Given the perceived impact of pain on those closest to them, participants also described strategies they had developed to attempt to manage the impact of their pain on others.

Attempts to manage the impact of pain on self

Attempts to manage the impact of pain on themselves occurred in ways which aimed to deflect attention from their pain both as individuals and in their interactions with others: avoiding thinking about the pain, creating other pains to distract from their primary pain, giving non-pain related explanations for limitations and avoiding talking about the pain:

I try to block all the pain, I don't think about the pain because I find when I think about the pain I end up having more pain. So if I block it out, it's there but I still you know go where I go, you know, try and do what I'm doing. **Ruth, early 40s, pain for 7 years, BHS [1, 0]; IPQ-identity [6, 8]; IPQ-time [3.33, 5.00]; IPQ-consequences [2.71, 4.29]; IPQ-control/cure [3.83, 2.17]**

or actively denying or limiting descriptions of it:

You say 'my back's giving me gip today' and that's all you say. *[Interviewer: Why do you say just that?]* Because you don't want anybody feeling sorry for you. I know it doesn't make sense to a lot of people but you do. You get you 'poor soul', you know, 'fancy having to go through that' and you don't need to hear that. *[Interviewer: What's it like for you to hear that?]* Well you feel like, it's very difficult to explain it, you feel like they're talking down to you all the time and not treating you on the same level that they are. **Colin, late 30s, pain for 5 years, BHS [11, 9]; IPQ-identity [11, 11]; IPQ-time [5.00, 5.00]; IPQ-consequences [4.71, 4.43]; IPQ-control/cure [3.33, 2.83]**

Where pain was denied, or participants said they were 'OK' to avoid further details, this could have emotional costs later:

Sometimes people have said to me 'so what's wrong with you?' and I just simply said to them 'nothing'. And that make you - when you're on your own you sit down and cry, which really, really depresses you, you know, your, my self-esteem just go that low, rock bottom. **Bella, early 40s, pain for 4 years, BHS [4, -]; IPQ-identity [12, -]; IPQ-time [5.00, -]; IPQ-consequences [4.29, -]; IPQ-control/cure [3.5, -]**

Attempts to manage impact on themselves also occurred through the avoidance of thinking about the future and an emphasis on living one day at a time in the present:

...you look back and you wish – that's wrong, 'cos you can't deal with your now when you look back and wish. If you look forward and you wish – that's wrong 'cos you don't know what's going to happen in the future, you know. I didn't know this was going to happen to me [...] No you can't, you end up sort of having to deal with now because now is the safest place to be, you know 'cos the past hurts you 'cos it brings back memories of how you were and no-one wants to have their face rubbed in it because you can't be like that anymore. **Gerry, mid 40s, pain for 7 years, BHS [13, 12]; IPQ-identity [11, 11]; IPQ-time [4.44, 5.00]; IPQ-consequences [4.29, 4.29]; IPQ-control/cure [3.00, 3.00]**

Attempts to manage the impact of pain also occurred in ways which served to bring pain more to the fore for the individual and others: talking about the pain or explaining its impact, which some participants described doing quite openly and freely in some situations. One participant also described resorting to violence when attempts to explain had failed:

I've had a few ignorant people that have not understood it and er, seem to think it's fun to do things like pushing me, prodding me in the back..... One fellow that was doing it he was annoying me so much because my back was hurting anyway. I was trying to explain to him not to do it because I've got this problem and it hurts a lot and he wouldn't understand so I hurt him and then said 'now you can understand physically - and every time you come near me again I'm

going to do the same to you so you understand what the pain is like' and eventually he got the message through me hurting him, you know. I had to hurt him physically before he understood how I felt and that was a very difficult situation. **Mark, late 20s, pain for 3 years, BHS [3, 12]; IPQ-identity [11, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.14]; IPQ-control/cure [4.00, 2.17]**

Maintaining vs. adapting life/activity

Aware of the ways in which they might be judged, participants described trying to do without sticks, hiding aids and trying to 'pass for normal'. However, attempts at living their lives as normally as they could count against them as the effort involved was not appreciated by others:

But I say to them, [when friends comment that she is never at home when they phone] I work in an old people's home and I know what it is to have pain and sit down with it. The more exercise you do, the better off you'll be, so you've got to bear the pain and move along as slowly as you can but once you get in bed, you never come back out, you become a cabbage. **Paula, early 50s, pain for 20 years, BHS [2, 1]; IPQ-identity [8, 10]; IPQ-time [5.00, 4.00]; IPQ-consequences [4.71, 2.86]; IPQ-control/cure [1.83, 3.5]**

and

They don't realise how much effort goes into your life when you've got pain, chronic pain, you want to try to be normal but you can't ever be sort of normal. **Oscar, late 20s, pain for 2 years, BHS [1, 2]; IPQ-identity [8, 11]; IPQ-time [3.33, 4.33]; IPQ-consequences [4.29, 4.00]; IPQ-control/cure [4.33, 4.33]**

Participants also described a variety of ways in which they had adapted aspects of their lives so as not to exacerbate their pain and make life easier and/or safer. This included

seeking isolation when pain levels were particularly high and adaptation at home: different ways of doing household tasks, adapting their household standards, getting help in the home and choosing appropriate furnishings. For some more financially secure participants this included adapting or choosing property with their pain in mind, for one on much resented earlier medical advice which was no longer seen as appropriate following several days at the pain management programme. Adaptation also included attempting different jobs to find one which had less of an adverse impact on the pain and adapting the way in which they worked or hours worked. Adaptation of personal care also occurred: having showers rather than baths and choosing non-iron easy-to-put-on-clothes. Some adaptations appeared to be relatively straightforward to accept:

... I've learned a way to do me windows and all [laughs] – buy an 'osepipe and then a big thing and just come down like that and that's it [...] You learn to do things. I, I tend to work out things and try and make things easier like... **Susan, late 50s, pain for 9 years, BHS [3, 6]; IPQ-identity [6, 4]; IPQ-time [3.86, 4.44]; IPQ-consequences [3.14, 4.29]; IPQ-control/cure [4.00, 2.33]**

However, adaptations aimed at physical safety could be associated with psychological distress as they served to emphasise the participants' change in abilities or dependency on others, particularly in the area of personal care:

I can't have a bath any more, have to have a shower. Or if I have a bath then I've got to get my wife to get me out of the bath and then if she's going out I have to have the phone plugged into the bathroom just in case, you know, I genuinely do get stuck and there's absolutely no way I can move then I have to phone the mother-in-law up and then she has to come and let herself in and get me out. **Colin, late 30s, pain for 5 years, BHS [11, 9]; IPQ-identity [11, 11]; IPQ-time [5.00, 5.00]; IPQ-consequences [4.71, 4.43]; IPQ-control/cure [3.33, 2.83]**

For this participant, the need to maintain his self esteem at times over-rode physical considerations, with consequences on both his pain and his psychological well-being:

... I know it sounds silly – I mean we had a puncture on the car and it took me two hours to change the wheel, you know. And I had offers of help to do it but I was determined to do it but all the next day I had to lay in bed because I couldn't move – I'd stiffened right up – and that gets to you... **Colin, late 30s, pain for 5 years, BHS [11, 9]; IPQ-identity [11, 11]; IPQ-time [5.00, 5.00]; IPQ-consequences [4.71, 4.43]; IPQ-control/cure [3.33, 2.83]**

Attempts to manage the impact of pain on others

As well as managing the impact of pain on themselves, rather than being centred solely on themselves and their pain, participants also attempted to manage the impact of their pain on others. For some participants, this meant keeping going with work as best they could, despite pain, as they were the only breadwinner. Where participants were no longer able to work, there was often considerable guilt at their failure to provide for their families. Families were generally felt to be having to cope with the burden which the participants often perceived themselves as being and this often meant that talking about the pain was avoided with the family:

... when it's someone you love very much and they're doing everything they can for you, you, you really don't wanna add to their stress, because it is stressful to watch somebody in pain 24 hours a day. They feel so helpless and it is stressful for them, I know it is – I can see it. So, although I could any time I wanted to, I'm often told off because I don't speak about it enough... **Fiona, early 50s, pain for 20 years, BHS [12, 13]; IPQ-identity [12, 11]; IPQ-time [4.67, 4.33]; IPQ-consequences [4.14, 4.29]; IPQ-control/cure [3.17, 3.17]**

The same consideration might apply to other friends and relatives who had pain or other problems and participants spoke of avoiding a topic of conversation which was boring for others and/or putting on a face or a show for the benefit of others. For example, one participant spoke of trying to protect her 5 year old granddaughter from seeing her in pain but failing despite her best efforts:

'cos when she walks through that door with that smile, and I think, my God, I can't let her see. And I smile, 'hello darling, how's my favourite little girl, my favourite granddaughter' [...] She, she sees it and I, I really am good with it, I'm good with it. **Eve, mid 40s, pain for 2 years, BHS [19, -]; IPQ-identity [7, -]; IPQ-time [4.00, -]; IPQ-consequences [4.57, -]; IPQ-control/cure [3.00, -]**

Other participants spoke of concern about the impact of their pain on their children: whether through worry, being called on to help at home and on their performance:

...when I'm with my son at either football training or at a match [...] he's very sensitive and he'll pick up when I'm trying to hide my own problems and it then affects his performance so that's not a very, you know, happy time. **Jack, late 30s, pain for 5 years, BHS [3, -]; IPQ-identity [12, -]; IPQ-time [4.00, -]; IPQ-consequences [4.86, -]; IPQ-control/cure [3.83, -]**

This was an area in which it was less easy for them to be as protective as they would wish and the fear their children would be teased at school on account of the situation of their parent was particularly distressing.

Humour was used on occasion to deflect the concern of others, serving also to protect the participants from further probing:

If my pain is bad and I have something to do, somebody's there and they said 'oh, are you in agony?' I said 'it's not too bad you know' [...] you can smile but it's not real because it doesn't stay, it just wipe away and you just pray to god that that person doesn't really see what is going

on. And you try to crack jokes and make people laugh in a way to hide the agony, for me to hide the agony that I'm going through, you know. Just like you're cheering them up in a way and that cover your feeling of what you're going through because they're so busy laughing away they don't really see when you make that special twitch – something like that, so that usually covers it up for me. **Bella, early 40s, pain for 4 years, BHS [4, -]; IPQ-identity [12, -]; IPQ-time [5.00, -]; IPQ-consequences [4.29, -]; IPQ-control/cure [3.5, -]**

The success of these strategies was equivocal at times, but nonetheless, suggest that people with chronic pain are responding to situations and trying to find a balance of managing the impact of pain on themselves and others.

4.4 Reflecting on pain management: the follow-up interviews

Experience of treatment continued as a theme in the follow-up interviews, covering mostly experiences at the pain management programme and evaluation of its impact and subsequent consultations with health professionals. A second theme emerged: dealing with change following the pain management programme. Interwoven through both themes were issues of comparison, both with previous pain and ability levels and with the progress of others on the programme.

4.4.1 Experiences of (pain management) treatment

Participants assessed the treatment they had experienced in terms of the impact on their lives in the time since they left the programme. There was a range of experience from broad ranging benefits:

... if I do what I was told to do and the way I was taught to do it - that I have been virtually free of back pain since. I've had the odd twinge and things like that but not constant day and night problems. I've found that the whole quality has been better – I've been able to attempt things that

I've not been able to do for a long, long time **Anna, early 50s, pain for 33 years, BHS [5, 1]; IPQ-identity [6, 8]; IPQ-time [3.67, 3.00]; IPQ-consequences [3.43, 2.71]; IPQ-control/cure [2.33, 3.83]**

no change, and additional pain attributed to the programme:

It's been more painful than it was before I went there and I've found a lot more things a lot more difficult than they were before. **Mark, late 20s, pain for 3 years, BHS [3, 12]; IPQ-identity [11, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.14]; IPQ-control/cure [4.00, 2.17]**

A few participants who made physical gains admitted to initial scepticism about the programme. A dislike of the approach remained with one who felt that it had not made a difference:

I found it was almost like going there to be brainwashed and if you were weak minded enough – and there was a couple there that was brainwashed – fine. If you can go in a room and someone can talk to you and all of a sudden you are feeling a lot better and you can move easier, and you're not in so much pain, fine, that's what you call it – I don't know of what a polite way of putting that is [*Interviewer: Use whatever words you need*] there's nothing wrong with them in the first bloody place – they was just attention seekers. **Fiona, early 50s, pain for 20 years, BHS [12, 13]; IPQ-identity [12, 11]; IPQ-time [4.67, 4.33]; IPQ-consequences [4.14, 4.29]; IPQ-control/cure [3.17, 3.17]**

Regardless of whether there were physical benefits, the knowledge participants had gained was generally appreciated. Many also spoke of gains in psychological areas. These included increased confidence, having a better outlook on life and some ability to focus on what they still could do, rather than focusing on activities which are now more difficult. One participant described a greater ability to be open about her pain:

I don't feel ashamed of myself – because I used to be sort of ashamed that I was like it and you know, hurt by it, but it's not my fault, I can't turn the clock back – if it's happened it's happened and I'm not going to blame myself no more... **Eve, mid 40s, pain for 2 years, BHS [19, -]; IPQ-identity [7, -]; IPQ-time [4.00, -]; IPQ-consequences [4.57, -]; IPQ-control/cure [3.00, -]**

The experience of having been with others with chronic pain had been particularly important to most participants and had helped many realise that they were not the only person in this position. However, a small number of participants had preferred not to socialise with others in the evenings or had found the talk about pain at the programme unhelpful:

...too much, too much talk about people wallowing in their own pain – I didn't like that, I really did not like that because people, most people that I know that suffer chronic pain and I know three other people that suffer chronic pain, the last thing in the world they want to do is talk about it or wallow in it and I found that very, very annoying, very annoying. **Fiona, early 50s, pain for 20 years, BHS [12, 13]; IPQ-identity [12, 11]; IPQ-time [4.67, 4.33]; IPQ-consequences [4.14, 4.29]; IPQ-control/cure [3.17, 3.17]**

Several participants had had further contact with health care professionals since they had left the programme as part of their regular care. Thus one GP was reported to have read the treatment manual given to patients as the participant was his first referral to the programme. Another GP was reported as taking his patient's efforts more seriously:

to a certain extent I think that's [attending the pain management programme] made my doctor feel differently about me you know [...] you could see that I wanted to try and resolve the situation to the best of my ability **Gerry, mid 40s, pain for 7 years, BHS [13, 12]; IPQ-identity [11, 11]; IPQ-time [4.44, 5.00]; IPQ-consequences [4.29, 4.29]; IPQ-control/cure [3.00, 3.00]**

Interventions since the programme included approaches consistent with the programme such as further assistance in coming off pain-related medication, and approaches which can be seen as in parallel with it such as use of anti-depressant medication and use of counselling services. However, one participant had subsequently received conflicting advice about surgery:

I mean he wants me to have the operation, my GP [...] the fusion – he thinks it would be good for me but having spoken to the surgeon and what it entails and keeping in mind all the other operations I've had [...], I don't think it would be safe for me and I'm not going down that avenue no more. I'm having a – they're going to do a discogram shortly because he thinks that my other disc above has gone so they want to do a discogram to check on that 'cos I feel like I'm caving in more. **Eve, mid 40s, pain for 2 years, BHS [19, -]; IPQ-identity [7, -]; IPQ-time [4.00, -]; IPQ-consequences [4.57, -]; IPQ-control/cure [3.00, -]**

And for the participant who had felt considerably worse following the programme, further more conventional referrals were planned:

I've also got to go back to the [hospital] pain management clinic later this month to find out what goes on from here, what are they going to do, can anything be done or not? But other than that I've just got to keep taking the tablets and they've got to the stage where they don't work properly now so take them and keep going and just put up and shut up. **Mark, late 20s, pain for 3 years, BHS [3, 12]; IPQ-identity [11, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.14]; IPQ-control/cure [4.00, 2.17]**

Having attended the pain management programme, participants could assess their own progress against that of others in their cohort. Amongst some there was anger at the considerable time they had endured their pain prior to being referred to the pain management programme in comparison with others in the cohort, and wondering how

they might have progressed had a referral to the programme been made earlier in their pain career:

[referral in] the early stages which would really make a lot of difference, because if I'd got there in the early stages, I don't believe I would be where I am now. **Bella, early 40s, pain for 4 years, BHS [4, -]; IPQ-identity [12, -]; IPQ-time [5.00, -]; IPQ-consequences [4.29, -]; IPQ-control/cure [3.5, -]**

Looking at the progress of others was associated with a number of emotions. As well as an apparently straightforward acknowledgement of the programme having different impacts on different people, there was some evidence of the better progress of others being distressing for those who had done less well and frustration by those who felt they had done well with those who were not implementing the strategies, without an apparent consideration of their particular circumstances:

... when I came back in for my first assessment I could honestly say I was the only one out of the ten who stood up and said 'I've done all my exercises and stretches' and all of a sudden I felt a bit guilty because they was all looking at me, they was making excuses 'cos it was Christmas or they hadn't bothered or the children had been playing up, you know. [...] And I honestly feel if you come in and accept what they're trying to do for you, listen to what they're saying to you then the help is there – it's just what you want to get out of it [...] if you don't do this sort of thing, what do you expect – you won't get nothing out of it... **Leonard, mid 60s, pain for 15 years, BHS [2, 6]; IPQ-identity [10, 7]; IPQ-time [3.33, 4.67]; IPQ-consequences [4.00, 4.00]; IPQ-control/cure [3.00, 3.33]**

4.4.2 Integrating pain management strategies into everyday life

When asked what helped them keep going, some participants recalled their level of function prior to the programme, saw that they were expanding what they could do and

were keen on implementing the strategies (of which stretches seemed to be the most popular), having learned through experience that they were associated with benefits in terms of mobility and pain control:

If I don't exercise I seem to seize up – particularly the nerve mobilisation exercise, stretching exercise and that - so of course a lot more pain - can't do anything and not very happy **David, early 40s, pain for 11 years, BHS [6, 5]; IPQ-identity [10, 11]; IPQ-time [4.00, 4.00]; IPQ-consequences [4.29, 4.49]; IPQ-control/cure [4.17, 3.5]**

However, other participants spoke of the difficulty of implementing the techniques they had learned outside the environment of the pain management programme:

I thought I would have made more progress than I have had – I mean I found it quite hard to kind of you know implement everything we learned at [pain management programme] back at home, I'm doing little bits and pieces, you know, as and when I can [...] but as I say sometimes it helps me and sometimes it doesn't – i.e. the first aid plan seemed to work to a certain extent whilst I was at [pain management programme] but since I've been home I've had to resort to just laying with hot water bottles on my legs[...] with the painkillers to actually get it to the stage where I can relax. **Jack, late 30s, pain for 5 years, BHS [3, -]; IPQ-identity [12, -]; IPQ-time [4.00, -]; IPQ-consequences [4.86, -]; IPQ-control/cure [3.83, -]**

For some participants, initial progress at the pain management programme was followed by deterioration as a result of setbacks from unpredictable situations: the need to do urgent DIY work through not being able to afford to pay for it to be done, and minor accidents:

... for the first two weeks it was marvellous because, [...] health and life had improved a lot by the help I've received at [pain management programme]. When [partner] came home he had an accident and I tried to rush down the stairs, forget that you take it slowly [...], and I torn some

muscles at the back of my leg, my left leg. I'm still trying to keep up but it's really, really sore and stiff until now. **Bella, early 40s, pain for 4 years, BHS [4, -]; IPQ-identity [12, -]; IPQ-time [5.00, -]; IPQ-consequences [4.29, -]; IPQ-control/cure [3.5, -]**

More predictable was the return to the physical and psychological demands of life in a busy family and for some, work environment:

While I was in [pain management programme] it was basically all on the pain side and all you ever did each day was wash up a tea cup you know, so as soon as I came back and started to do my everyday chores and getting on with family life, I found it hit me quite badly. **Hanna, early 40s, pain for 25 years, BHS [7, 14]; IPQ-identity [10, 11]; IPQ-time [4.00, 5.00]; IPQ-consequences [4.14, 4.57]; IPQ-control/cure [3.67, 1.67]**

For some with less obvious physical benefits, dealing with change meant continued creativity in thinking how they could do things they wanted to do, delegating work tasks and realising that change is not terminal:

I just try and think it's not the end of the world, you know. You can - well, as the report [discharge letter copied to patients] said that come through, I've got to learn to rearrange my whole lifestyle, you know and it doesn't mean that because I'm rearranging it that it's the end of everything, you know. I'm learning new things now I didn't... You know, I thought there was no, no future, but I am finding that, you know, there is something and one day it might click and all fall into place. **Tom, late 40s, pain for 7 years, BHS [14, 7]; IPQ-identity [6, 9]; IPQ-time [5.00, 4.00]; IPQ-consequences [5.00, 4.00]; IPQ-control/cure [2.5, 3.17]**

In order to help maintain change, several participants suggested more follow-ups, feeling that there was too long a time between the one-month and nine-month follow ups, most having had positive perceptions of the group nature of the programme. The emphasis

here was on assistance with maintaining physical strategies and participants wondered whether local self-help groups, follow-up gym groups at the pain management programme or booster sessions might be possible.

4.5 Summary

The main themes of experiences of treatment, self-perception and comparisons, experiences of the reactions of others and attempts to manage the impact of pain on self and others have been illustrated with examples from participants at a pain management programme. Participants subsequently experienced a wide range of outcomes, as shown in the themes emerging from the follow-up interviews: experience of treatment and integrating pain management strategies into everyday life and the follow-up questionnaire data. The themes will be discussed in chapter 5 in relation to theoretical issues in the pain literature and implications for pain management programmes.

Chapter 5: Discussion

5.1 Overview

This study is based on interviews with nine men and nine women volunteers with chronic pain during their attendance at a residential pain management programme. Interviews included questions about situations in which they felt understood, or not, when talking about their pain, ways of talking about it, the impact of pain on their lives, their views of the future and suggestions for health professionals. Follow up interviews by telephone two to three months later included questions about any physical and/or emotional changes, as well as any changes in the way they spoke about their pain and viewed the future.

Interviews were processed using Interpretative Phenomenological Analysis (Smith, 1995). Four main themes were found in the first set of interviews. The first theme covers experiences of treatment, which remains as a theme in the follow-up interviews. The remaining three themes from the first set of interviews revolve around the self and identity: self-perception and comparisons, experiences of the reactions of others and attempts to manage the impact of chronic pain on self and others. The follow-up interviews also generated a final theme of integrating pain management strategies into everyday life. The themes will be considered in more detail in this chapter, with reference to relevant theoretical literature and clinical implications. Finally, the methodological limitations of the research carried out will be considered and suggestions made for further research.

5.2 Discussion of themes

Each theme will be discussed in relation to issues in the literature after a brief summary of the contents has been presented.

5.2.1 Experiences of treatment

Participants had generally arrived at the pain management programme with a considerable number of previous experiences of treatment. Although for some, progression through the medical system had been smooth, others experienced fragmentation through delays, poor co-ordination between different parts of the health service and different professional philosophies. Some had gone through a range of unsuccessful investigations and treatments and experienced doubt from medical professionals. However, there was also evidence of attempts to exert some control as a patient, which included seeking explanations from the medical profession, even though these had not always been possible to give.

The reported experience of fragmentation in treatment attempts is consistent with Osborn and Smith (1998) who found uncertainty about the causes of their pain amongst women with chronic low back pain despite frequent contact with the health services. Variety of contact rather than frequency *per se* may be a more important variable as people with chronic pain are referred to different specialists and department with different philosophies and approaches. The experience of fragmentation may occur through the application of an acute model of care to chronic illness (Charmaz, 1983). Yet this model in which a cause is located, treatment delivered and pain removed may be one in which patients themselves wish to participate. Embarking on the pain

management programme, after years of chronic pain, they find themselves faced with another approach within the health service which some have experienced as having failed them in the past. Moreover, the stated goal of the programme of managing life with pain might not correspond with their private goal of pain removal (Turk and Rudy, 1990). The pain management programme may be perceived as yet another different treatment attempt within the constellation of treatments they have tried. It is possible that a number of anxieties relating to past (failed) treatment experiences may re-emerge and affect patients' orientation and motivation.

Previous experience of treatment for some participants included having their chronic pain doubted or dismissed as 'in the head'. Pearce and Mays (1994a) state that the label of psychogenic pain when no clear cause has been identified helps neither patients nor practitioners. Although some people with chronic pain can also have a variety of emotional difficulties (see Craig, 1994 for a discussion) they do not usually conceptualise their problems in psychological terms (Pearce and Mays, 1994b). Suggestion of psychological problems when the patient has consulted for physical problems may contribute to distress as it may imply that they are not believed and that treatment for pain is being withheld. Broadening the issue, Ashmore and Contrada (1999) characterise the patient-doctor conflict in such circumstances as "not simply a disagreement about diagnosis but instead a fundamental dispute about identity" (p.250).

In situations in which the patient is not believed, the behaviour of both patient and doctor may change as one makes greater efforts to be heard and the other may respond with stereotyped judgements which make little contribution to the therapeutic

relationship (Skevington, 1995). Hydén (1997) notes that the way the doctor relates to the narrative told by the patient (both temporal aspects such as symptoms and the experience of illness itself) is crucial. Although admission to the programme implies that patients' chronic pain is believed, past experiences may affect whether they believe that this is so. Past experiences may result in suspicion of aspects of the programme which might be thought to involve techniques designed to establish whether or not the pain is real as was suggested directly or indirectly by several participants.

One participant described receiving a disclosure of pain from a doctor and this contributed to feeling understood. Whether or not it is disclosed, the experience of pain of a health care professional may be particularly significant and may decrease the likelihood of the operation of an attributional style in which the patient is held responsible for his/her pain (actor-observer effect (Jones and Nisbett, 1972)). If disclosed, it may function to alter the hierarchical relationship between doctor and patient. This alteration may be particularly significant in chronic pain as unlike in chronic illness, in which the hierarchical doctor-patient relationship becomes more of a partnership with time, a hierarchical relationship may be maintained in chronic pain as legitimacy associated with the pain patient is removed over time (Charmaz, 1999b). If not sensitively handled, however, the disclosure of experience of pain by a health professional could set an occasion for comparisons including those with someone still working and for whom life has apparently not been interrupted by pain.

The explanations participants had received of chronic pain varied and some had had to ask for them explicitly in the past. Where there was a diagnosed progressive condition, the programme message that pain did not mean damage and that pain was not progressive was difficult to reconcile with their reality. Where there was no clear causal factor, however, the uncertainty of chronic illness (Radley, 1994, Skevington, 1995) may have been attenuated somewhat at the programme as questions were welcomed and participants felt that they had learned something about chronic pain in general.

Prior to the pain management programme, some patients had made attempts at controlling aspects of their treatment by changing doctors, checking up on medication prescribed and seeking a variety of referrals. Skevington (1995) concludes that “internality is good for pain and pain coping strategies” (p.134). However, patients’ attempts to seek a variety of referrals for instance, could be argued as representing attempts to exert internal control (over treatment rather than directly over pain) within a context of belief in the external control of powerful others. This is consistent with the use of an acute pain model in which pain implies damage and a cure is sought from others who are ultimately responsible for intervention. The challenge for pain management programmes is to refocus some of the internal control expressed through seeking medical intervention into a more explicit self-management focus.

5.2.2 Self-perception and comparisons

Participants made a number of assessments of themselves during the course of the interviews. Although they were able to make positive comments about themselves, the considerable losses experienced were associated with many negative self-assessments.

Participants made a number of comparisons: with themselves before pain and how they might have been had they not had pain and made comparison with others contending with a variety of difficulties including others with chronic pain or other health problems. Although the future seemed bleak for many, the pain management programme may also have given space for a possible future self to begin to emerge, whether through resumption of their old self, or creation of something new.

The changes and losses arising from chronic pain left patients struggling with situations in which aspects of their pre-pain lives such as high levels of mobility, working life and social and leisure pursuits could no longer be taken for granted or indeed had largely disappeared. This can lead to what has been described as the ‘crumbling away’ of former self-images Charmaz (1983). For some participants, the interviews provided an opportunity to emphasise that their current state was not all there was to know about them. Having experienced many losses and adverse changes, the self-esteem of people with chronic pain may be at risk. Despite this, “mental health practitioners have been neither innovative nor outspoken concerning self-esteem as applied to illness” (Frank 1997, p.441). In chronic pain, it may be helpful to see the relationship between chronic pain and self-esteem as reciprocal. Thus the change and losses associated with chronic pain may have a negative impact on self-esteem. However, low self-esteem may also affect ability to undertake rehabilitative strategies, which rely in part on the value of spending time on oneself (e.g. exercise and relaxation) and reinforcing oneself for progress.

Participants described a number of comparisons they made with others. These included a wide consideration of the situation of others. Thus participants gave examples of considering themselves better off than others with chronic pain (for example when the financial situation of another person with chronic pain was perceived as precarious). However, being better off than someone else with chronic pain might be perceived as a temporary state before a feared future in which they would end up in a similar position and guilt at the use of this strategy.

There was also some evidence of struggling with the unwanted label of 'disabled', which may not reflect participants' own perception of disability, but which is applied to some of them by the state. This study did not explicitly investigate with which groups or labels, if any, participants identified themselves and Skevington (1995) points out the "collective identity of large and heterogeneous groups of people with painful illnesses has been entirely neglected" (p.129) in the research literature. In practice the lack of a collective identity may contribute to isolation and provide less of a clear focus for mutual-support efforts, particularly when there is no clear diagnosis. On the other hand adoption of an unwanted identity such as 'disabled' may have a negative impact on self-esteem.

Patients' comparisons with themselves in the past tended to be with themselves in a better state of health. This form of comparison may be associated with distress, as loss is further emphasised (Osborn and Smith, 1998). However, comparisons with times when symptoms were worse, have been found to be more helpful for patients with fibromyalgia than comparisons with others who may be worse off (Tennen and Affleck,

1997). It may be helpful for the distinction between helpful and unhelpful self-comparison processes to be emphasised in pain management programmes and the use of helpful forms of temporal comparison fostered. There was some evidence of more helpful temporal comparisons in the follow-up interviews.

However, encouraging comparison with times at which the pain was worse rather than with times when pain was not present may be difficult to accept as it carries with it the suggestion that return to the pre-pain self is impossible. Several participants wished to resume their 'old self', or 'real self'. The experience of chronic pain and its associated losses, as well as the passage of time itself cannot but have an impact on the self and the medical sociology literature contains many descriptions of people attempting to *reconstruct*, rather than necessarily resume their identity following accident or in chronic illness (e.g. Charmaz, 1990; Kelly, 1992; Yoshida, 1983).

It may be unrealistic for patients to resume all aspects of their pre-pain lives in the way they were handled then. Pain management programmes may help foster acceptance of chronic pain, including commitment to live a satisfying life despite pain (McCracken, 1998). Indeed, there was some evidence of participants in this study moving into 'accommodative' coping (Brandtstädter, 1992), in which personal standards were revised, unachievable goals left aside and a reorientation made to new more achievable goals (Schmitz, Saile and Nilges, 1996). However, the interaction of goals with self-esteem and comparison processes must be considered. For some patients achievements in feasible goals may be dismissed as insignificant, serving to underline the difference

between what can be achieved in the present and what could be achieved in the (pre-pain) past with potential adverse effects on self-esteem.

5.2.3 Experiences of the reactions of others

Participants identified negative judgements of them made by others in which they were not believed or not understood¹. However, as well as these negative judgements, often made on the basis of an acute pain model, participants were also believed, often by others experiencing pain or other health difficulties. Participants also experienced a range of practical responses; both those which expected little of them and also some creative responses which acknowledged their chronic pain whilst not undermining their self-esteem. This theme supports the observation of Leventhal, Idler and Leventhal (1999) that “the impact of illness on self involves social inputs, as well as personal and physical ones” (p.186).

Participants were often judged by the application of a lay model based on acute pain, which did not take variation of pain into account nor the considerable attempts of the person to live life despite pain. The variable nature of the impact of pain counted against participants as others saw them intermittently on ‘good days’ and not on days when pain was bad. The distress of not being believed may be particularly significant for patients with chronic pain as unlike a variety of other symptoms, “pain is a universal feature of the human condition” (Kleinman, Brodwin, Good and DeVecchio Good, 1992, p.1).

¹ One participant specifically asked for a copy of the tape because he wanted to play it to his family so that they would understand.

Thus others may be expected to use their own experience of pain as an aid to imagination and understanding of chronic pain and its impact.

There was an element of overlap between judgements based on acute pain in this theme and responses from the medical profession in the theme of experiences of treatment. This suggests an interaction of professional and lay understandings in a field where the certainty of diagnosis can be denied and in which doctors may feel increasingly powerless as efforts to address pain are unsuccessful. Disbelief or the minimising of pain by doctors may be particularly memorable and distressing for the patient as unlike judgements from others who might not be expected to understand, patients approach doctors expecting both understanding and relief from symptoms. Although the behaviour of people with pain has been extensively studied, Skevington (1995) points out that there has been little attention to the behaviour of staff providing treatment.

Participants tended to feel understood by others with chronic pain. This suggests that a shared identity as someone with chronic pain may be salient during some encounters and that experiences of pain, treatment and the impact of pain could be validated if shared. Meeting others with chronic pain on the programme provided an opportunity for this to occur. Participants also described feeling understood by people with other health or other life problems suggesting a broad common identity as someone suffering. They also described being understood by family or close friends who had maintained contact and who had witnessed their deterioration over time. This is a validation of what may be invisible by witnesses who will have seen the previous active life the participants have led. Such validation may become more important as the number of witnesses decreases

as it becomes difficult to maintain social relationships and new relationships begin with the current situation and limitations of the person with chronic pain.

Participants also identified a number of strategies others (colleagues, family and friends) used in attempts to protect them, and the impacts these strategies had on them. Many were attempts to limit activity which was thought to lead to greater harm (arising from the lay confusion between 'hurt' and harm' (Fordyce, 1986)). Although appropriate in some situations where the participants had a tendency to push themselves, in other situations this may have contributed to passivity and lack of control over everyday matters and a consequent adverse impact on self-esteem. This multiple effect of others' responses is consistent with the finding of Neuling and Winefield (1988) in the area of breast cancer where encouragement from others influenced compliance with treatment regimen positively but mood negatively. Others' responses suggest that they may operate using a dualistic model in which the physical aspects of chronic pain for the individual are considered but the potentially less visible psychological implications are neglected or about which they simply do not know what to do. Distinguishing between positive support and problematic support (which is perceived as unsupportive regardless of the intentions of the provider) Revenson, Schiaffino, Majerovitz and Gibofsky (1991) conclude that different kinds of support and the balance between them should be considered in the development of interventions for patients.

Although Charmaz (1983) suggests that in chronic illness "past reciprocity becomes altered and the chronically ill are left behind" (p. 176), participants in this study also described a number of creative responses of others in which this did not occur. Some of

these acknowledged chronic pain and maintained self-esteem and are encouraging in a literature which paints a bleak picture of social loss and growing isolation as chronicity of pain develops. The factors contributing to such esteem-maintaining reactions from others would be important to determine. This is an area with considerable theoretical and practical research potential, De Ridder and Schreurs (1996) commenting that the study of social support in chronic illness lacks a theoretical framework and that “it is not clear under what conditions which contacts are experienced as supportive” (p.79).

5.2.4 Attempts to manage the impact of pain on self and others

Participants made a variety of attempts to manage the impact of pain on both self and others, with varying degrees of success.

Participants used a number of psychological and physical strategies in attempts to manage the impact of chronic pain on themselves. Whereas Charmaz (1983) wrote that while people with chronic illness aim to protect their lives, “they may do so at great costs to their self-images” (p.174), some of the descriptions here involved what might be seen as the reverse of this: attempts to protect their self-image at the cost of increased pain. Examples included physical activity regardless of high levels of pain and refusal of help to gain the satisfaction of accomplishing a heavy task alone and maintenance of work despite considerable pain (often as their income was essential for the family and there appeared to be no choice). Some of these examples can be seen as consistent with the ‘super-normal identity’ characterised by a fierce independence identified by Yoshida (1983) in a study of people following spinal cord injury. Alternatively, there were examples of attempts to avoid thinking and talking about the pain and take one day at a

time, which can be seen as attempts to manage its psychological impact. The emphasis on functions of strategies has parallels with the work of Ferguson and Cox (1997).

Different strategies were not only applied to the individual him/herself but also with respect to interactions with others. Most of the participants in this study mentioned family and/or friends, even though their social networks may have decreased. Their comments suggest that some 'social reciprocity' (Charmaz, 1993) remains despite pain, and that there may be an imperative to minimise the amount others worry. This is achieved by attempts to fulfil the rules of social encounters in which others are judged as not wanting to hear about distress and considering the situation of others before communicating about pain and its impact. The attempt to minimise the impact on others in this way is potentially an area which the person with chronic pain can still try to control. However, this may not be possible in all situations and the worry of some participants about the impact of their pain on their children is not groundless as children of chronic pain patients are at risk (e.g. for maladjustment problems (Chun, Turner and Romano, 1993)).

The descriptions of the participants support the flexible use of several strategies which has been found to be helpful (c.f. Haythornthwaite, Menefee, Heinberg and Clark, 1998) and assessment of what might be better in any situation – a focus on the psychological, social and/or physical ramifications of chronic pain for self and others. There is some overlap here between the model of adjustment to illness proposed by Radley and Green (1985), in which an individual's adjustment is a combination of accommodation, secondary gain, active-denial and resignation used in different ways at different times

and situations. It also has parallels with the perspective taken by Alonzo (1984) who argues that the individual with health problems is “a social psychological actor attempting to construct a response to a changing and emerging environment” (p.501). Alonzo (1984) describes the individual with health problems considering the impact of participation in different types of situation on his/her psychological, social or physical well-being. He argues that the individual’s capacity to contain signs and symptoms of illness (or adjust to them in the case of chronic illness) is influenced by factors including commitment to situations, others’ responses and the individual’s assessment of others’ responses to their containment/adjustment attempts, power relations and social propriety, and resources which assist the management of signs and symptoms.

This is a useful framework but it can be argued that it could be extended by the findings in the research reported here. Extension would include the individual considering the impact of varying degrees of his/her own participation in situations: a) on others in terms of *their* psychological, social and physical well-being (beyond the demands of social propriety), b) the use of both short and long term time-frames in which potential impacts on self and others are considered, and c) the locating of any situation in the context of past and possible future situations in which participation has had/might have had significance.

Although attempts to manage the impact of pain may also be affected by a range of cognitive and emotional factors, such an extended framework can be argued to go some way to acknowledging the complex interrelationships involved in managing life with chronic pain. It can help contextualise what might appear to be superficially

inappropriate strategies used in situations by people with chronic pain to manage their changed lives and indeed locate responses such as overactivity and social withdrawal, and a variety of possible secondary gains within a single framework. It could also be of potential use with people with chronic pain, assisting them to consider situations and potential actions (or inactions) more explicitly, to identify the short and long-term consequences of their responses and the interrelationships between them.

5.2.5 Experiences of (pain management) treatment

Telephone interviews with participants two to three months after the pain management programme identified a range of physical outcomes. Despite the occurrence of welcome physical change in some participants, this did not occur in all participants, indeed one in particular regarded his pain and resulting limitations as considerably worse. As Skevington (1995 p.111) points out a 'one dose fits all' approach to the treatment of chronic pain may be less successful than promised. Despite the variation in physical gains, most participants had something positive to say about the psychological impact of the programme. This is consistent with change occurring not just on objective grounds but also in how people subjectively measure their health status and the meaning they attach to health (Norman and Parker, 1996).

The group environment of the pain management programme was one in which experiences of life with chronic pain could be shared and explicit comparisons of progress could be made. Although discouraged by programme staff, social comparisons are still likely to occur, and it may be distressing for patients to watch the physical progress of others if they feel they are not making much progress themselves. Although

the programme emphasised that change could occur at a number of different levels, progress in psychological terms may be less available for comparison and physical progress serves as a more obvious measure to adopt. This resulted in some critical judgement of others, in which personal experience of variation of levels of pain and knowledge of differences in individual pain thresholds was overridden when others were considered.

Although subsequent contact with the medical profession generally functioned to support positive changes, for some participants there was a return to situations in which the fragmentation of attempts at treatment appeared to be starting again (c.f. Charmaz, 1983). This may be a particularly difficult experience for patients where so much hope may have been vested in the programme. It underlines the challenge chronic pain poses to medicine, but also the difficult experiences of being a patient with chronic pain in the health care system.

5.2.6 Integrating pain management strategies into everyday life

Progress whether physically and/or psychologically provided an opportunity for different comparisons to be made. There was evidence of participants saying that they now focussed on what they could do rather on what they could not do which is more likely to be helpful (c.f. Tennen and Affleck, 1997). However, participants also indicated that maintaining pain management strategies was difficult in their home environment. Maintenance and generalisation are difficult issues in much of the behavioural literature and there is no reason to believe this is any less of an issue in the field of chronic pain.

The model proposed of the individual attempting to manage the impact of his/her chronic pain on self and others could contribute to an understanding of the difficulty of maintenance of change following pain management programmes. It may be that perceived short and long term consequences of creating and maintaining a lifestyle in which pain management techniques have a regular part interact with the perceived short and long term demands and responses of others in the environment. The non-inclusion of pain management strategies may thus be seen as the result of a series of responses following consideration of self and others, short and long term individual, social, physical and financial consequences, rather than as a discrete decision. It takes a non-blaming approach to the individual and sees him/her within the context of his/her particular environment.

5.3 Overview of the themes

The four main themes (experiences of treatment, self-perception and comparisons, experiences of the reactions of others and attempts to manage the impact of chronic pain on self and others) can be seen as falling into two even broader themes. The first is that of the individual with chronic pain as a patient within a therapeutic environment. The second is that of the individual with chronic pain as a social being dealing with the social and material world outside the therapeutic environment. Indeed, as Charmaz (1999b) points out, people who have chronic illnesses are neither patients, nor occupants of the sick role, much of the time. Whether the therapeutic world/social and material world distinction is artificial is open for discussion, but part of the difficulty of living with chronic pain may be that staff in therapeutic environments (particularly in brief medical consultations) may see little of how the individual with chronic pain operates in

the rest of his/her social and material world; and others in the social and material world of the individual with chronic pain may see little of what happens in the therapeutic environment and the inapplicability of an acute pain model sequence of pain—diagnosis—treatment—cure to chronic pain. This may lead to the patient straddling two cultures of which the key players may see them as having failed. The patient may be seen as having failed the medical staff as their attempts at intervention have come to nothing; and as having failed significant others insofar as relationships, reciprocities and responsibilities have to be renegotiated to take account of changed physical and psychological function. In turn, the patient may also experience that he/she has been failed by medicine and by others.

The model of the patient with chronic pain as involved in managing the impact of chronic pain on self and others seems to provide a useful way of conceptualising a number of possible reactions without the need to invoke blame. It also allows for considerable variation in responses as different situations with different implications for self and others are encountered. This is consistent with impression management being a crucial activity for those in pain: “people must constantly decide which expressions to use, and who to address, to reveal their pain” (Brodwin, 1992, p.92), early ethnographic work in chronic illness in which the management of ‘spoiled identity’ was a theme (Goffman, 1963) as well as more recent work integrating social and health psychology on the potential beneficial implications of strategic self-presentation for the adjustment to chronic illness (Leake, Friend and Wadhwa, 1999). It is also consistent with the dynamic aspects implicit in the suggested relabelling of chronic pain as ‘persistent pain’

defined as a “continuing process extending beyond an initial acute episode, *rather than a static state* that has been reached” [my emphasis] (Notcutt, 1998, p.211).

5.4 Clinical implications

The themes emerging from this study have a number of potential clinical implications for pain management programmes. Given the experience of treatment and the variety of messages which patients might have received in the past, it would be appropriate for there to be particular attention to those who are experiencing difficulties adjusting to the emphasis of a programme. It might also be appropriate for some flexibility to exist in programme messages about pain to take into account participants with chronic pain from progressive conditions. This might help participants to understand the potential relevance of the programme for them, rather than creating a potential division between them and other patients present.

The theme of self perception and comparisons suggests that it may be important to include explicit attention to those with low self-esteem in pain management programmes. A cognitive behavioural framework on self-esteem (e.g. Fennell, 1999) is a way of integrating this focus into the existing theoretical framework of a pain management programme. Where pain management programmes teach communication skills which include asking for help where appropriate, this may interact with the self-esteem maintaining concept of independence despite pain and not giving others cause to worry. Alterations to this pattern may need to be sensitively tackled, perhaps looking for an alternative source of self-esteem by those who view making requests for help in a negative light.

The theme of experiences of the reactions of others emphasises the importance of work beyond the individual with chronic pain. Turk, Flor and Rudy (1987) stress that chronic pain should be seen in the context of its social network, in which the family is particularly important. Work with family and friends is a component of many pain management programmes and can offer the opportunity for them to understand the impact of chronic pain and its consequences on the mind as well as the body. It can also help them to understand the potential consequences of their own responses to the individual with chronic pain and the impact on them of overactivity and underactivity. However, changing responses may be a challenge for families after extended periods of adapting to the limitations of the individual with chronic pain, particularly if frightened by flare ups of pain in which previous patterns of responses may resume. As chronic pain may mean that family income and time are limited, it may be difficult to include family members directly and the challenge for pain management programmes is to develop alternative means by which to reach them.

Finally, the model of the individual with chronic pain managing the impact of pain on self and others could serve as an explicit framework around which to structure some discussions about managing life with chronic pain in terms of self and others. It can also serve as a heuristic device in which to consider the maintenance and generalisation of change.

5.5 Methodological issues

Attention to quality issues in qualitative research is essential in order to have confidence that research findings are derived from a reasonable treatment of the data rather than

from an idiosyncratic and tangential treatment, and confidence that qualitative methods are not a cover for the propagation of theories and ideas without a relationship to the data (see Johnson, 1999). However, the issue of quality control in qualitative research is a 'difficult' one and the relative novelty of qualitative methods in psychological research and plurality of approaches and underlying philosophies of different qualitative methods contribute to a "lack of well-defined and universally agreed criteria for quality" (Yardley, 2000, p.217). As Cutcliffe and McKenna (1999) point out, some critics of qualitative research attempt to import the (more established) techniques and terminology of quantitative methods into the debate over credibility. Yet these are not consistent with the aims of qualitative research and indeed, Yardley (2000) argues that the approach to the construction of meaning taken by qualitative approaches would also imply that "there can be no fixed criteria for establishing truth and knowledge, since to limit the criteria for truth would mean restricting the possibilities for knowledge" (p.217).

Yet if any form of credibility checking is discounted, for example on the basis of links with a positivist paradigm, the acceptability and utility of qualitative methods risk being compromised and a largely 'unhelpful' qualitative-quantitative distinction reinforced which "does not accurately map the differences in practical method or in philosophical position that are actually to be found" (Hammersley, 1996:172). Thus Yardley (2000) calls for a provisional agreement on open-ended and flexible ways of assessing quality and "wider appreciation of the inherent complexities and ambiguities associated with evaluating qualitative studies" (p.224) and Elliott, Fischer and Rennie (1999) make the pragmatic point that "the value of any scientific method must be evaluated in the light of its ability to provide meaningful and useful answers to the questions that motivated the

research in the first place". Quality issues in this study were addressed using many of the suggested guidelines of Elliott, Fischer and Rennie (1999) which were developed using multiple peer-revision and with a focus on qualitative research².

The research was carried out by an author sympathetic to the aims and methods of the pain management programme who had chosen a specialist placement in chronic pain. However, being on placement may have located the researcher as part of the staff group at the programme, with an associated impact on the balance of power, which may have affected how freely participants spoke. In consideration of this, an attempt was made to explain that the research was part of clinical training and not part of the standard programme content and interviews were conducted outside programme hours.

The research participants have been described, as was the context in which the research was conducted and the study included a variety of people with chronic pain of different duration and in different sites. However, participants were volunteers who may have felt able to explore their chronic pain in a research interview context. No claim is made for the participants being representative of chronic pain patients at the pain management programme, indeed this was not a specific focus of inclusion. Everyone who volunteered and was eligible to take part did take part in the first stage (except one person who was

2

1. Owning one's perspective – statement of the values/assumptions of the researcher(s)
2. Situating the sample – description of the research participants and their life situation
3. Grounding in examples – illustration of data analysis/data understanding by examples
4. Providing credibility checks – attention to the credibility of accounts
5. Coherence – structured presentation of the central understanding and any nuances
6. Accomplishing general vs. specific research tasks – use of an appropriate range of participants
7. Resonating with readers – achievement of an increase in reader understanding

ill) so there was no selection by the researcher from within the patient cohorts. The interviews were of varied depth and content suggesting that a range of perspectives was included.

Guidelines for credibility checks include checking out interpretations with participants or others like them; using several researchers, an additional 'auditor' or the original analyst for a 'verification step' so that data are reviewed for discrepancies; and triangulation with external factors or quantitative data (Elliott, Fischer and Rennie, 1999). In this study, confidence in the face validity of the themes derived was achieved by regular discussion of emerging themes with an experienced researcher and practitioner in the field of chronic pain management during data analysis. However, this process does not claim to represent statistical agreement across readers nor to imply a single reality about which observers can agree. The inclusion of a transcript in the appendix with associated working is an attempt to be transparent about the method used (Yardley, 2000). It offers the interested reader an opportunity to follow something of the route by which data were processed towards the final write up, although (Smith, 1996b) points out there can be more than one reading. There were also discussions with two experienced qualitative researchers during the data analysis, one of whom made comments on an initial interview transcript. The results chapter includes many quotations from the interviews as examples of the themes and sub-themes derived. It is left for the reader to judge whether or not an increase in understanding has resulted.

Generalisability in qualitative research is more a matter of generalisability of concepts, rather than of samples or data (Conrad, 1990). Considering research on chronic pain

conducted at specialist centres, Crombie and Davies (1998) argue that although the patients are a highly selected group, this does not necessarily compromise issues of generalisability. It is possible though, that the themes which emerged may not have done so in interviews with people with chronic pain who have not been referred to specialist intervention, or if they did, that they would be played out in a different way. However, questions such as those used in this study, which focused on occurrence rather than frequency are arguably more amenable to the generalisation of findings. The broad nature of the themes can also encompass a wide variety of individual experience, which can contribute to the generalisability and utility of the research.

Follow-up interviews may have been richer had they been conducted face-to-face as it was more difficult to prompt on the telephone. However, face-to-face follow-ups would have been impractical given the broad geographical area to which patients returned and the funding constraints of the project. Similarly, the time-constraints of the project limited the longitudinal aspect of the research.

The longitudinal aspect of the research focused on life following pain management intervention. As Charmaz (1999b) points out, different stories may be developed at different times in the illness trajectory, a point also made by Hydén (1999) who states that “illness narratives are constantly changing and being renegotiated, depending on changing perspectives and other changes in the illness process” (p.61). It would be of interest to follow-up this group of participants a year or further following the intervention in which many of them had invested so much.

5.6 Suggestions for further research

Hydén (1997) comments that there is not much research on illness narratives in different social contexts. Expanding the general focus here of talking about pain, it would be of interest to explore what people do and say in situations where demands are made on them for action or explanations and what variables they consider when deciding how to respond and to study accounts given to different people. Ashmore and Contrada (1999) suggest that “examination of such variation and its relation to coping with stress, patient compliance, and disease progression would be an important contribution to the self and identity perspective” (p.250). Whereas talking about significant life experiences has been found to be beneficial, particularly for those constantly living with their experiences (Pennebaker and Susman, 1988), this area can be developed following Ashmore and Contrada (1999) who suggest that research could focus on the conditions under which stories about chronic pain foster or hinder physical and mental health.

Further research could be directed at the contexts in which comparisons are made by patients with chronic pain, the dimensions on which comparisons are made and the perceived moral implications of the comparison process. Research could also contribute further to an understanding of what constellations of internal locus of control, external locus of control (powerful others) and external locus of control (chance) are used in what situations with what results by those with chronic pain.

Finally, much remains to be done in the area of social support. Leventhal, Idler and Leventhal (1999) “suspect that a patient’s self-concept and how others view him or her

influence the operation of social networks in chronic disease” (p.202) but point out that this awaits empirical test. The finding in this research that there are supportive, self-esteem maintaining responses from the social networks of individuals with chronic pain (as well as the negative ones frequently reported in the literature) adds to the call for research to help understand when such particularly helpful responses occur.

5.7 Summary

Starting from the accounts of patients with chronic pain about being understood, or not, when talking about chronic pain, a suggested model of the patient with chronic pain attempting to manage the impact of chronic pain on self and others in a variety of contexts and timeframes was derived. This can be seen as representing a link back to the main assumptions of cognitive-behaviour therapy, in which interpretations and anticipated consequences of actions are significant and which forms a key part of pain management interventions (Bradley, 1996). It is also consistent with Skevington (1995) who argues that the recognition that socio-cognitive factors affect the behaviour of pain patients “advances the case for a social psychology of pain” (p.88) and locates the person with chronic pain not as an isolated individual but as part of an interactive world.

References

Alonzo, A. A. (1984) An illness behaviour paradigm: a conceptual exploration of a situational-adaptation perspective. *Social Science and Medicine*, **19**; 499 – 510.

Ashmore, R. D. and Contrada, R. J. (1999) Self, social identity, and the analysis of social and behavioural aspects of physical health and disease. In R. J. Contrada and R.D. Ashmore (Eds.) *Self, Social Identity and Physical Health: Interdisciplinary Explorations*. New York: Oxford University Press.

Bandura, A. (1977) *Social Learning Theory*. Englewood Cliffs, NJ: Prentice-Hall Inc.

Banks, S. M., and Kerns, R. D. (1996) Explaining high rates of depression in chronic pain: a diathesis-stress framework. *Psychological Bulletin*, **119**; 95 - 110.

Beck, A. T., Steer, R. A., Kovacs, M. and Garrison, B. (1985) Hopelessness and eventual suicide: a 10 year prospective study of patients hospitalized with suicidal ideation. *American Journal of Psychiatry*, **142**; 559 – 563.

Beck, A. T., Weissman, A., Lester, D. and Trexler, L. (1974) The measurement of pessimism: the hopelessness scale. *Journal of Consulting and Clinical Psychology*, **42**; 861 – 865.

Borkan, J., Reis, S., Hermon, D. and Biderman, A. (1995) Talking about the pain: a patient-centred study of low back pain in primary care. *Social Science and Medicine*, **40**; 977 - 988.

Bradley, L. A. (1996) Cognitive-behavioral therapy for chronic pain. In R. J. Gatchel and D. C. Turk (Eds.) *Psychological Approaches to Pain Management. A Practitioners' Handbook*. New York: Guilford Press.

Bransdtstädter, J. (1992) Personal control over development: some developmental implications of self-efficacy. In R. Schwarzer (Ed.) *Self-efficacy: Thought Control of Action*. Washington, DC: Hemisphere.

Brodwin, P. E. (1992) Symptoms and social performance: the case of Diane Reden. In A. Kleinman, P. E. Brodwin, B. J. Good and M. J. DeVecchio Good (Eds.) *Pain as Human Experience*. Berkeley: University of California Press.

Burton, H.J., Kline, S., Hagadon, R., Schik, R., Ong, M. and Cooper, B. (1998) Chronic pain patients' quality of life improves with increased life control. *The Pain Clinic*, **11**; 33 - 42.

Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, **4**; 167 – 182.

Chamberlain, K., Stephens, C. and Lyons, A. C. (1997) Encompassing experience: meanings and methods in health psychology. *Psychology and Health*, **12**; 691 – 709.

Chapman, C. R. and Gavrin, J. (1999) Suffering: the contributions of persistent pain. *Lancet*, **353**; 2233 - 2237.

- Charmaz, K. (1983) Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, **5**; 168 – 195.
- Charmaz, K. (1990) ‘Discovering’ chronic illness: using grounded theory. *Social Science and Medicine*, **30**; 1161 - 1172.
- Charmaz, K. (1999a) Stories of suffering: subjective tales and research narratives. *Qualitative Health Research*, **9**; 362 – 382.
- Charmaz, K. (1999b) From the sick role to stories of self: understanding the self in illness. In R. J. Contrada and R.D. Ashmore (Eds.) *Self, Social Identity and Physical Health: Interdisciplinary Explorations*. New York: Oxford University Press.
- Chun, D. Y., Turner, J. A. and Romano, J. M. (1993) Children of chronic pain patients: risk factors for maladjustment. *Pain*, **52**; 311 – 317.
- Clinical Standards Advisory Group (2000) *Services for Patients with Pain. A summary of the CSAG report on services for NHS patients with acute and chronic pain*. London: HMSO.
- Conrad, P. (1990) Qualitative research on chronic illness: a commentary on method and conceptual development. *Social Science and Medicine*, **30**; 1257 - 1263.
- Cornwell, J. (1984) *Hard-Earned Lives: Accounts of Health and Illness from East London*. London: Tavistock.
- Craig, K. D. (1994) Emotional aspects of pain In P. D. Wall and R. Melzack (Eds.) *Textbook of Pain*. Edinburgh: Churchill Livingstone.
- Crombie, I. K. and Davies H. T. O. (1998) Selection bias in pain research. *Pain*, **74**; 1 – 3.
- DeRidder, D. and Schreurs, K. (1996) Coping, social support and chronic disease: a research agenda. *Psychology, Health and Medicine*, **1**; 71 - 82.
- Eccleston, C., Williams, A. C. de C. and Stainton Rogers, W. (1997) Patients’ and professionals’ understandings of the causes of chronic pain: blame, responsibility and identity protection. *Social Science and Medicine*, **45**; 699 - 709.
- Elliott, R., Fischer, C. T. and Rennie, D. L. (1999) Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, **38**; 215 – 229.
- Fennell, M. (1999) *Overcoming Low Self-esteem: A self-help guide using cognitive behavioural techniques*. London: Robinson
- Ferguson, E. and Cox, T. (1997) The Functional Dimensions of Coping scale: theory, reliability and validity. *British Journal of Health Psychology*, **2**; 109 - 129.
- Festinger, L. (1954) A theory of social comparison processes. *Human Relations*, **1**; 117 - 140.
- Flor, H. Fydich, T. and Turk, D. C. (1992) Efficacy of multidisciplinary pain treatment centers: a meta-analytic review. *Pain*, **49**; 221 – 230.
- Fordyce, W.E. (1986) Learning processes in pain. In R. A. Sternbach (Ed.) *The Psychology of Pain*. Second Edition. New York: Raven Press.

Frank M. R. (1997) Chronic Physical Illness and self-esteem: understandings and interventions. In L. VandeCreek, S. Knapp and T. L. Jackson (Eds.) *Innovations in Clinical Practice: A sourcebook*. Volume 15. Sarasota, FL, USA: Professional Resource Press.

Goffman, E. (1963) *Stigma. Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall Inc.

Greene Bush, E. and Pargament, K. I. (1997) Family coping with chronic pain. *Families, Systems and Health*, **15**; 147 - 160.

Greenhalgh, T (1998) Narrative based medicine in an evidence based world. In T. Greenhalgh and B. Hurwitz (Eds.) *Narrative Based Medicine: dialogue and discourse in clinical practice*. London: BMJ Books.

Greenhalgh, T. and Hurwitz, B. (1998) *Narrative Based Medicine: dialogue and discourse in clinical practice*. London: BMJ Books.

Hallberg, L. R.-M. and Carlsson, S. G. (1998) Psychosocial vulnerability and maintaining forces related to fibromyalgia. *Scandinavian Journal of Caring Sciences*, **12**; 95 - 103.

Härkäpää, K. Järvikoski, A. and Estlander, A.-M. (1996) Health optimism and control beliefs as predictors for treatment outcome of a multimodal back treatment programme. *Psychology and Health*, **12**; 123 - 134.

Haythornthwaite, J. A., Menefee, L. A., Heinberg, L. J. and Clark, M. R. (1998) Pain coping strategies predict perceived control over pain. *Pain*, **77**; 33 - 39.

Hydén, L.-C. (1997) Illness and narrative. *Sociology of Health and Illness*, **19**; 48 - 69.

International Association for the Study of Pain (1979) Pain terms. *Pain*, **6**; 249 - 252.

James, P. T. (1992) Cognitive therapies. In S. P. Tyrer (Ed.) *Psychology, Psychiatry and Chronic Pain*. Oxford: Butterworth-Heinemann

Jensen, M. P., Turner, J. A., Romano, J. M. and Karoly, P. (1991) Coping with chronic pain: a critical review of the literature. *Pain*, **47**; 249 - 283.

Johnson, M. (1999) Observations on positivism and pseudoscience in qualitative nursing research. *Journal of Advanced Nursing*, **30**; 67 - 73.

Jones, E. E. and Nisbett, R. E. (1972) The actor and the observer: divergent perceptions of the causes of behaviour. In E. E. Jones, D. E. Kanouse, H. H. Kelley, R. E. Nisbett, S. Valins and B. Weiner (Eds.) *Attribution: Perceiving the Causes of Behaviour*. Morristown, NJ: General Learning Press.

Kelly, M. (1992) Self, identity and radical surgery. *Sociology of Health and Illness*, **14**; 390 - 415.

Kelly, M. P. and Field, D. (1996) Medical sociology, chronic illness and the body. *Sociology of Health and Illness*, **18**; 241 - 257.

Kleinman A (1988) *The illness narratives: suffering, healing and the human condition*. Basic Books: New York

- Kleinman, A., Brodwin, P. E., Good, B. J. and DelVecchio Good, M. J. (1992) Pain as human experience: an introduction. In A. Kleinman, P. E. Brodwin, B. J. Good and M. J. DelVecchio Good (Eds.) *Pain as Human Experience*. Berkeley: University of California Press.
- Lackner, J. M., Carosella, A. M. and Feuerstein, M. (1996) Pain expectancies, and functional self-efficacy expectancies as determinants of disability in patients with chronic low back disorders. *Journal of Consulting and Clinical Psychology*, **64**; 212 - 220.
- Lazarus, R. and Folkman, S. (1984) *Stress, Appraisal and Coping*. New York: Springer Publishing.
- Leake, R., Friend, R. and Wadhwa, N. (1999) Improving adjustment to chronic illness through strategic self-presentation: an experimental study on a renal dialysis unit. *Health Psychology*, **18**; 54 - 62.
- Leventhal, H., Idler, E. L. and Leventhal, E. A. (1999) The impact of chronic illness on the self-system. In R. J. Contrada and R.D. Ashmore (Eds.) *Self, Social Identity and Physical Health: Interdisciplinary Explorations*. New York: Oxford University Press.
- Magni, G., Caldieroni, C., Rigatti-Luchini, S. and Merskey, H. (1990) Chronic musculo-skeletal pain and depressive symptoms in the general population. An analysis of the 1st National Health and Nutrition Examination survey data. *Pain*, **43**; 299 - 307.
- Mathieson, C. M. and Barrie, C. M. (1998) Probing the primary narrative: illness, interviewing and identity. *Qualitative Health Research*, **8**; 581 – 601
- Maxwell, K., Streetly, A. and Bevan, D. (1999) Experiences of hospital care and treatment seeking for pain from sickle cell disease: qualitative study. *British Medical Journal*, **318**; 1585 – 1590.
- McCracken, L. M. (1998) Learning to live with the pain: acceptance of pain predicts adjustment in persons with chronic pain. *Pain*, **74**; 21 – 27.
- Meichenbaum, D. (1993) Changing conceptions of cognitive behavior modification: retrospect and prospect. *Journal of Consulting and Clinical Psychology*, **61**; 202 - 204.
- Melzack, R. and Wall, P. D. (1965) Pain mechanisms: a new theory. *Science*, **150**; 971- 979.
- Melzack, R. and Wall, P. D. (1982) *The Challenge of Pain*. New York: Basic Books.
- Mikulincer, M. and Florian, V. (1996) Coping and adaptation to trauma and loss. In M. Zeidner and N. S. Endler (Eds.) *Handbook of Coping. Theory, Research, Applications*. New York: John Wiley and Sons Inc.
- Morley, S. J., Eccleston, C. and Williams, A. C. de C. (1999) Systematic review and meta-analysis of randomised controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain*, **80**; 1 - 13.
- Neuling, S. J. and Winefeld, H. R. (1988) Social support and recovery after surgery for breast cancer: frequency and correlates of supportive behaviors by family, friends and surgeon. *Social Science and Medicine*, **27**; 385 - 392.

- Norman, P. and Parker, S. (1996) The interpretation of change in verbal reports: implications for health psychology. *Psychology and Health*, **11**; 304 - 314.
- Notcutt, W. (1998) The Tao of pain. *Pain Reviews*, **5**; 203 - 215.
- Osborn, M. & Smith, J. A. (1998) The personal experience of chronic benign lower back pain: an interpretative phenomenological analysis. *British Journal of Health Psychology*, **3**; 65 - 84.
- Pearce, S. and Mays, J. (1994a) Chronic pain: assessment. In S. J. E. Lindsay and G. E. Powell (Eds.) *The Handbook of Clinical Adult Psychology. Second Edition*. London: Routledge.
- Pearce, S. and Mays, J. (1994b) Chronic pain: psychological approaches to management. In S. J. E. Lindsay and G. E. Powell (Eds.) *The Handbook of Clinical Adult Psychology. Second Edition*. London: Routledge.
- Pennebaker, J. W. and Susman, J. R. (1988) Disclosure of trauma and psychosomatic process. *Social Science and Medicine*, **26**; 327 - 332.
- Potter, J. and Wetherell, M. (1995) Discourse analysis. In J. A. Smith, R. Harré and L. Van Langenhove (Eds.) *Rethinking Methods in Psychology*. London: Sage.
- Radley, A. (1994) *Making Sense of Illness: The Social Psychology of Health and Disease*. London: Sage Publications.
- Radley, A. and Green, R. (1985) Styles of adjustment to coronary graft surgery. *Social Science and Medicine*, **20**; 461 - 472.
- Register C (1987) *Living with chronic illness: days of patience and passion*. Free Press: New York
- Revenson, T. A., Schiaffino, K. M., Majerovitz, D. and Gobowsky, A. (1991) Social support as a double-edged sword: the relation of positive and problematic support to depression among rheumatoid arthritis patients. *Social Science and Medicine*, **33**; 807 - 813.
- Romano, J. M., Turner, J. A., Friedman, L. S., Bulcroft, R. A., Jensen, M. P. and Hops, H. (1991) Observational assessment of chronic pain patient-spouse behavioral interactions, *Behavior Therapy*, **22**; 549 - 567.
- Rosentiel, A. K. and Keefe, F. J. (1983) The use of coping strategies in chronic low back pain patients: relationship to patient characteristics and current adjustment. *Pain*, **17**; 33 - 44.
- Rowat, Jeans and LeFort (1994) A collaborative model of care: patient, family and health professionals. In P. D. Wall, and R. Melzack, R. (Eds.) *Textbook of Pain*. Edinburgh: Churchill Livingstone.
- Schmitz, U. Saile, H. and Nilges, P. (1996) Coping with chronic pain: flexible goal adjustment as an interactive buffer against pain-related distress. *Pain*, **67**; 41 - 51.
- Shapiro, A. P. and Teasell, R. W. (1997) Misdiagnosis of chronic pain as hysterical. *NeuroRehabilitation*, **8**; 201 - 222.
- Skevington, S. (1995) *Psychology of Pain*. Chichester: John Wiley and Sons.

- Skevington, S. (1998) Investigating the relationship between pain and discomfort and quality of life, using the WHOQOL, *Pain*, **76**; 395 – 406.
- Skinner, J.B., Erskine, A., Pearce, S., Rubenstein, I., Taylor, M. and Foster, C. (1990) The evaluation of a cognitive behavioural treatment programme in outpatients with chronic pain. *Journal of Psychosomatic Research*, **34**; 13 - 19.
- Smith, J. A. (1995) Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harré and L. Van Langenhove (Eds.) *Rethinking Methods in Psychology*. London: Sage.
- Smith, J. A. (1996a) Evolving issues for qualitative psychology. In J. T. E. Richardson (Ed.) *Handbook of Qualitative Methods for Psychology and the Social Sciences*. Leicester: BPS Books.
- Smith, J. A. (1996b) Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health*, **11**; 261 – 271.
- Smith, J. A., Jarman, M. and Osborn, M. (1999) Doing interpretative phenomenological analysis. In M. Murray and K. Chamberlain (Eds.) *Qualitative Health Psychology: theories and methods*. London: Sage Publications.
- Snow-Turek, A. L., Norris, M. P. and Tan, G. (1996) Active and passive coping strategies in chronic pain patients. *Pain*, **64**; 455 - 462.
- Söderberg, S, Lundman, B. and Norberg, A. (1999) Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research*, **9**; 575 – 587.
- Strong, J. and Large, R. G. (1995) Coping with chronic low back pain: an idiographic exploration through focus groups. *International Journal of Psychiatry in Medicine*, **25**; 371 - 387.
- Strong, J. and Large, R. G. (1997) The personal constructs of coping with chronic low back pain: is coping a necessary evil? *Pain*, **73**; 245 - 252.
- Tennen and Affleck (1997) Social comparison as a coping process: a critical review and application to chronic pain disorders. In B. P. Buunk, F. X. Gibbons and M. Reis-Bergan (Eds.) *Health, Coping and Well-Being: Perspectives from Social Comparison Theory*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Turk, D. C., Flor, H. and Rudy, T. E. (1987) Pain and families: I. Etiology, maintenance and psychosocial impact. *Pain*, **30**; 3 - 27.
- Turk, D. C. and Okifuji, A. (1999) Assessment of patients' reporting of pain: an integrated perspective. *Lancet*, **353**; 1784 - 1788.
- Turk, D. C. and Rudy, T. E. (1990) Neglected factors in chronic pain treatment outcome studies – referral patterns, failure to enter treatment, and attrition. *Pain*, **43**; 7 - 25.
- Van Houdenhove, B. and Onghena, P. (1997) Pain and depression. In *Depression and Physical Illness: Perspectives in Psychiatry. Volume 6*. In M. M. Robertson and C. L. E. Katona (Eds.) Chichester: John Wiley and Sons.

Verhaak, P. F. M., Kerssens, J. J., Dekker, J., Sorbi, M. J. and Bensing, J. M. (1998) Prevalence of chronic benign pain disorder among adults: a review of the literature. *Pain*, **77**; 231 - 239.

Weinman, J., Petrie, K. J., Moss-Morris, R. and Horne, R. (1996) The Illness Perception Questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and Health*, **11**; 431 - 445.

Weisenberg M. (1994) Cognitive aspects of pain In P. D. Wall and R. Melzack (Eds.) *Textbook of Pain*. Edinburgh: Churchill Livingstone.

Williams A. C. de C. (1998) Depression in chronic pain: mistaken models, missed opportunities. *Scandinavian Journal of Behaviour Therapy*, **27**; 61 - 80.

Williams A. C. de C., Nicholas M. K., Richardson P. H., Pither C. E., Justins D. M., Chamberlain J. H., Harding V. R., Ralphs J. A., Jones S. C., Dieudonne I., Featherstone J. D., Hodgson D. R., Ridout K. L. and Shannon E. M. (1993), Evaluation of a cognitive behavioural programme for rehabilitating patients with chronic pain. *British Journal of General Practice*, **43**; 513 – 518.

Wills, T. A. (1981) Downward comparison principles in social psychology. *Psychological Bulletin*, **90**; 245 - 271.

Yardley, L. (2000) Dilemmas in qualitative health research. *Psychology and Health*, **15**; 215 – 228.

Yoshida, K. K. (1993) Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health and Illness*, **15**; 217 - 245.

Presentations

Orlowska D (2000) *Talking about chronic pain*. Presentation to Clinical Psychologists working in pain in London and the South East. Royal National Hospital, London, March 2000.

Orlowska D (2000) *Patients' experiences of being understood*. Presentation at the Annual Meeting of the Pain Society. University of Warwick, April 2000.

APPENDIX 1: Ethics Committee approval letter

ST THOMAS' HOSPITAL RESEARCH ETHICS COMMITTEE

Medical Committee Office
Block 5, South Wing

Ext 2097

Fax 0171 922 8163

stella.hirsch@gstt.sthames.nhs.uk

Chairman - Dr G du Mont
Administrator - Ms S Hirsch

23/09/1999

Dr D Orłowska
65 Roderick Road
London
NW3 2NP

Dear Dr Orłowska

**EC99/148 Accounting for pain: identity and audience-dependent descriptions
of non-malignant chronic pain by patients at a multi-disciplinary
pain management programme**

Thank you for your correspondence dated 17/9/99 and for submitting a revised consent form and addressing the queries raised by the Research Ethics Committee. This is satisfactory and I am happy for the study to commence.

Please note that this project carries a reference number, noted above, which must be quoted in any future correspondence.

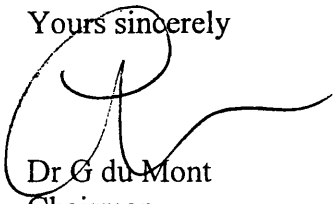
The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

In the case of research on patients, a copy of the consent form must be placed in the patient's medical records, together with a note of the date of commencement of his/her participation in the research. A label must appear on the outside cover of the records when the patient is participating in the research.

The investigators must adhere to the published Guidelines of the Committee and provide the Chairman with annual progress reports and an end of study report. The research should start within 12 months of the date of approval.

The St Thomas' Hospital LREC is compliant with the ICH GCP requirements.

Yours sincerely



Dr G du Mont
Chairman
Research Ethics Committee

APPENDIX 2: Participant information and consent form

CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS & CLINICAL TRIALS

Title of Project: Accounting for pain: identity and audience-dependent descriptions of chronic pain by patients at a multi-disciplinary pain management programme.

Principal Investigator: Dr. Danuta Orłowska **Ethics Committee**
Other Investigator/s Dr. Amanda C de C **Code No:** EC99/148
enrolling patients: Williams

Outline explanation:

We would like to invite you to take part in a research study about the impact of chronic pain. Participation is entirely voluntary and your treatment at INPUT will not be affected if you do not choose to take part.

The study will involve two interviews with Danuta Orłowska, clinical psychologist in training. The first interview will be a face to face one while you are at INPUT and last about an hour. You would be asked about the impact chronic pain has had on you and about how you talk to others about your pain. You would also be asked to complete two questionnaires – one about how you perceive your condition (this would take approximately 20 minutes) and the second about your expectations for the future (this would take approximately 10 minutes). The second interview would take place by telephone about a month after you leave INPUT and will last about 20 minutes. You would also be sent a copy of the two questionnaires to complete again and return by pre-paid envelope. With your agreement, we would like to tape record these interviews. You would be asked to sign a separate written consent form if you agree to the tape recording being made. Tapes will be securely held without names and destroyed when they are no longer required for the research. Participants will be able to have a copy of their tape, if they wish. Any material arising from the research, for example, reports, articles in journals or teaching materials will not identify participants. It is hoped that talking about your experience of pain will be helpful rather than distressing. However, if you find yourself distressed by the discussion, your keyworker and other INPUT staff are available.

We hope that this study will increase our understanding of what it is like to live with chronic pain, and to continue to adapt the pain management programme to be even more responsive to the needs of patients.

Again, we would like to stress that participation in the study is entirely voluntary. If you do not wish to take part this will not affect your care in any way. You would also be free to change your mind about taking part, at any time, without giving a reason.

I (name) _____

of (address) _____

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care I receive as a patient

SIGNED (Volunteer) _____ **Date** _____

(Doctor) _____ **Date** _____

(Witness, where appropriate) _____ **Date** _____

3 copies required:- one for researcher, one for patient/volunteer, one for patient's notes

APPENDIX 3: Audio-taping consent form

CONSENT FORM FOR AUDIO TAPING OF RESEARCH INTERVIEW
--

Project title Accounting for pain

Principal investigator: Dr. Danuta Orłowska

Other investigators: Dr. Amanda C de C Williams

Ethics Committee Code: EC99/148

I agree to a tape recording being made of the research interview. I understand that the tape will be securely stored without my name and will be destroyed once it is no longer needed for research.

I would like a copy of the tape YES NO
(please circle one)

NAME _____ Date _____

SIGNED (volunteer) _____ Date _____

 (researcher) _____ Date _____

APPENDIX 4: Main interview schedule

INTERVIEW GUIDE

PART I: Talking about the pain

1. In what situations do you talk about your pain?
2. Does it make a difference who's asking?
3. Could you tell me about a situation in which you felt really listened to and understood when talking about your pain?
who, when, what was helpful about the situation, anything else?
(If at pain management programme, what was it that made a difference, also another example apart from this)
4. Could you tell me about a situation in which you did not feel listened to and understood when talking about your pain?
Who, when, what was unhelpful, anything else?
5. When you are in pain, do you ever
 - a) Not talk about it example
 - b) Play it down “
 - c) Play it up “
 - d) Tell it like it really is “
 - e) Anything else “

PART 2: The impact of pain on your life

1. To what extent has pain changed the way you see yourself as a person?
2. To what extent has pain affected the way others see you?
3. What impact would you say pain has had on your life?
4. What impact has pain had on the following areas:
 - Family
 - How you get on with your partner
 - Work/training and housework
 - Leisure and sports
 - Social life
 - Looking after yourself
 - Your personal qualities
 - What you think is important in life
 - Any other areas

5. Where has the impact been the greatest?
6. What parts of you or your life have stayed the same despite the pain?

PART 3: The future

1. How do you see the future?
2. What about the future short medium and long term on the areas above?
What might be the same/different

PART 4: What medical professionals need to understand

1. What would you tell medical staff like doctors, nurses and physiotherapists to help them when they are seeing people who are in chronic pain?

PART 5: Questionnaires (in own time)

APPENDIX 5: Patient guide for main interview

Part 1: Talking about the pain

Not talk about it?
Play it down?
Play it up?
Tell it how it really is?
Deal with it any other way?

Part 2: The impact of pain on your life

Family
How you get on with your partner
Work/training and housework
Leisure and sports
Social life
Looking after yourself
Your personal qualities
What you think is important in life
Any other areas

Part 3: The future

Short term (next few months)
Medium term (next year or two)
Long term (the rest of your life)

Part 4: What medical professionals need to know

Part 5: 2 Questionnaires to complete (in your own time)

THANK YOU FOR TAKING PART

APPENDIX 6: Follow-up interview

Follow-up interview

1. What have the last few months been like since leaving INPUT?
2. How would you compare yourself now with yourself before you came to INPUT (physically and emotionally)?
3. How would you say you see the future now compared with how you saw it before you came to INPUT?
4. Has INPUT made a difference to how or when you talk about your chronic pain?
5. What helps you keep going now that you have left INPUT?
6. What else would help you keep going?
7. Anything else – like comments about being at INPUT or about the few months since you left INPUT?

THANK YOU
REMIND ABOUT QUESTIONNAIRES – REPLY PAID ENVELOPES

APPENDIX 7: Illness Perception Questionnaire

YOUR VIEWS ABOUT YOUR CHRONIC PAIN

Please tick how often you experience the following symptoms as part of your chronic pain

SYMPTOM	ALL THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Pain				
Nausea				
Breathlessness				
Weight loss				
Fatigue				
Stiff joints				
Sore eyes				
Headaches				
Upset stomach				
Sleep difficulties				
Dizziness				
Loss of strength				

We are interested in your own personal views of how you now see your chronic pain. Please indicate how much you agree or disagree with the following statements about your chronic pain.

	VIEWS ABOUT YOUR CHRONIC PAIN	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
1	A germ or virus caused my chronic pain					
2	Diet played a major role in causing my chronic pain					
3	Pollution of the environment caused my chronic pain					
4	My chronic pain is hereditary – it runs in my family					
5	It was just by chance that I got my chronic pain					
6	Stress was a major factor in causing my chronic pain					
7	My chronic pain is largely due to my own behaviour					
8	Other people played a large role in causing my chronic pain					
9	My chronic pain was caused by poor medical care in the past					
10	My state of mind played a major part in causing my chronic pain					

	VIEWS ABOUT YOUR CHRONIC PAIN	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
11	My chronic pain will last a short time					
12	My chronic pain is likely to be permanent rather than temporary					
13	My chronic pain will last for a long time					
14	My chronic pain is a serious condition					
15	My chronic pain has had major consequences on my life					
16	My chronic pain has become easier to live with					
17	My chronic pain has not had much effect on my life					
18	My chronic pain has strongly affected the way others see me					
19	My chronic pain has serious economic and financial consequences					
20	My chronic pain has strongly affected the way I see myself as a person					
21	My chronic pain will improve in time					
22	There is a lot which I can do to control my symptoms					
23	There is very little that can be done to improve my chronic pain					
24	My treatment will be effective in curing my chronic pain					
25	Recovery from my chronic pain is largely dependent on chance or fate					
26	What I do can determine whether my chronic pain gets better or worse					

Date **Initials**

THANK YOU VERY MUCH FOR COMPLETING THESE QUESTIONNAIRES

APPENDIX 8: Beck Hopelessness Scale

YOUR VIEWS ABOUT THE FUTURE

This questionnaire consists of 20 statements. Please read the statements carefully one by one. If the statement describes your attitude for the **past week including today**, circle the TRUE in the column next to the statement. If the statement does not describe your attitude, circle FALSE in the column next to this statement. **Please be sure to read each statement carefully.**

- | | | |
|---|------|-------|
| 1. I look forward to the future with hope and enthusiasm | TRUE | FALSE |
| 2. I might as well give up because there is nothing I can do about making things better for myself | TRUE | FALSE |
| 3. When things are going badly, I am helped by knowing that they cannot stay that way forever. | TRUE | FALSE |
| 4. I can't imagine what my life would be like in ten years. | TRUE | FALSE |
| 5. I have enough time to accomplish the things I want to do. | TRUE | FALSE |
| 6. In the future, I expect to succeed in what concerns me most. | TRUE | FALSE |
| 7. My future seems dark to me. | TRUE | FALSE |
| 8. I happen to be particularly lucky, and I expect to get more of the good things in life than the average person | TRUE | FALSE |
| 9. I just can't get the breaks, and there's no reason I will in the future. | TRUE | FALSE |
| 10. My past experiences have prepared me well for the future. | TRUE | FALSE |
| 11. All I can see ahead of me is unpleasantness rather than pleasantness. | TRUE | FALSE |
| 12. I don't expect to get what I really want. | TRUE | FALSE |
| 13. When I look ahead to the future, I expect that I will be happier than I am now. | TRUE | FALSE |
| 14. Things just won't work out the way I want them to. | TRUE | FALSE |
| 15. I have great faith in the future. | TRUE | FALSE |
| 16. I never get what I want, so it's foolish to want anything. | TRUE | FALSE |
| 17. It's very unlikely that I will get any real satisfaction in the future. | TRUE | FALSE |
| 18. The future seems vague and uncertain to me. | TRUE | FALSE |
| 19. I can look forward to more good times than bad times. | TRUE | FALSE |
| 20. There's no use in really trying to get anything I want because I probably won't get it. | TRUE | FALSE |

APPENDIX 9: Worked transcript

Side A

	I	My first question is, in what situations do you talk about your pain?	
<ul style="list-style-type: none"> •Pain talk: in few situations •Pain talk with others in INPUT group •Avoids talk as repetition •I'm OK is easier than expln •Explanation as a taped message •Length of time with pain •Pain talk lowers mood 	A1	Very very few. I find I have difficulties in expressing my pain, in fact I've found more advantages within this group since I've been here. I find that to people outside, I'm tending on, I've got to a stage now where I say, they ask me how I am and I say I'm OK, because it's just been repeated over and over again, I feel like carrying a tape recording of a message around and anybody ask me and I can just play them a tape message because it's you know obviously been going on for a long period of time – it's a long period of time to me and my mood deepens when I talk about it – that's the experience I had before I came here.	<p>Self-presentation: hard to talk about pain 10A1</p> <p>Self-presentation: wants to carry tape message of how he is 10A1</p> <p>Self-presentation: OK is easier 10A1</p> <p>Self-presentation: avoids pain talk as makes him low 10A1</p> <p>Time issues: long time of pain 10A1</p>
	I	[...]	
	A2	Being with people em, that obviously each person's an individual with individual problems but you know we're all here for the same reason, chronic pain and you know it helps to you know find out how similar it's affecting other people's lives not just my own	<p>Listeners situation: helpful to find others have chronic pain 10A2</p>
<ul style="list-style-type: none"> •Helps to find how pain has affected others' lives 	I	You said in very few situations do you talk about your pain [...] situations in which you might do	
<ul style="list-style-type: none"> •Wife notices pt goes quiet •Wife wants to know •Tells when pain gets too much for him 	A3	Errr, generally close, well obviously my wife, em, I tend to go very quiet and she's a talker and she you know obviously wants to know how I'm feeling and when things get too much I'll you know eventually come out with it but I'm, it's not one of my main plus points, I've always been quite a quiet person and I find it hard to talk. In fact before I came here I was dreading the group sessions thinking that I wouldn't be able to, I mean I've got in situations before where I've opened my mouth and nothing came out whereas you know as I say as the week's gone on, I've become, I've gained a	<p>Self-presentation: talks to wife 10A3</p> <p>Getting treatmt: gained confidence to speak out at INPUT 10A3</p>
<ul style="list-style-type: none"> •Confidence in speaking as others in same boat 			

<ul style="list-style-type: none"> •Professional training not the same as own experience of pain 		<p>bit of confidence in speaking out in front of the group because as I said they are in the same position. If it was just on a situation where it was a group of say professionals, yeah OK they've done their training but they've not actually experienced or are experiencing what I'm going through and I would have felt less comfortable.</p>	<p>Listeners situation: more comfortable with others with pain than health professionals 10A3</p>
	I	<p>Could you tell me about a situation in which you felt really listened to and understood when talking about your pain?</p>	
	A4	<p>Since I've been here or before</p>	
	I	<p>[..] situation [...]</p>	
<ul style="list-style-type: none"> •Little understanding pre-INPUT •Feels more of a person at INPUT •Health profs experience of others in pain helps them relay information 	A5	<p>Again, this really is I've not had that much understanding, I didn't feel I had that much understanding until I came here. The way that the different specialists here kind of approach the way they think or the way they say things to you makes you get, you know, it makes you feel more of a person, emmm, you know it's just the fact that they're kind of, although they've not actually probably been through it they've seen so many people that have, they know the correct ways, you know, to relay information</p>	<p>Others judgements: little understanding pre-INPUT Getting treatmt: more of a person at INPUT 10A5 Getting treatmt – information at INPUT 10A5</p>
	I	<p>What were those ways - what is it that's made a [...]</p>	
<ul style="list-style-type: none"> •Length of time with pain •Knock on effects of pain 	A6	<p>Well as I say I mean, I've said for a long time it's a vicious circle I mean I know life is as such but emmm, you know one thing triggers off another and that triggers off another and it you know as I say it's like a never ending merry-go-round that you know you just can't seem to get any peace from or any understanding from.</p>	<p>Description of pain: never ending merry go round 10A6</p>
	I	<p>What about before INPUT, a situation in which you felt really listened to and understood</p>	
<ul style="list-style-type: none"> •Family get frustrated •Consideration of impact on carers 	A7	<p>Err, not really to the extent, I mean obviously I've got a very, I like to think a close relationship with my wife and family but they get frustrated because, I mean I'm the first to admit that I would if I had a choice of being a sufferer or a say carer with a sufferer I'd choose to be a sufferer because I, I don't know how you know somebody</p>	<p>Reponses of others: frustration 10A7 Listener's situation: rather be a sufferer as hard to live with s'one in pain 10A7</p>

<ul style="list-style-type: none"> •Prefers to suffer than care •Impact of pain: guilt that letting family down •Impact of pain on concentration 		<p>can put up with, I mean I try my hardest you know with relationship and I've got 2 children but there's times when I you know would rather walk away because I, I'm feeling that I'm getting them down all the time. I feel very mixed up very confused and there's one thing I've picked up on, I'm becoming slowly less confused since I've come here. I'm finding the days long and tiring, certain aspects I can take in certain aspects I can't but my concentration level's poor anyway so, never used to be you know, but as the years have gone on emmm, you know, I find the concentration side very hard</p>	<p>Self-perception: letting family down, confused 10A7 Impact of pain: concentration 10A7</p>
<ul style="list-style-type: none"> •Mind-body link as new to pt 	A8	<p>The way that, the mechanics of it, the way that emmm, i.e. the body affects the mind and vice versa</p>	<p>Mind-body links: learning that one affects the other 10A8</p>
<ul style="list-style-type: none"> •Doctors only interested in location of pain •Fragmentation: pt passed between departments •Years to get correct test done •Anger and dread of going to hospital •Records mixed up •Lack of confidence in NHS 	A9	<p>I hadn't because all the specialists and doctors I've seen in the past have, they're only interested in where the pain is and emmm, i.e. they'll treat an acute pain but you know, when that damage has been healed, they you know, no longer want to know. I found myself being passed from one department to another I mean one of my problems took four years to get the correct test done and errr, you know I began to dread making a visit to a hospital because I didn't know whether or not I could keep my temper when I finally got to see somebody and I mean there's one incidence I got transferred – there's two hospitals in Southampton I was under – I got transferred from one to the other – I turned up at the other hospital Mrs [own surname] and I was a single mother – my records, so at that point I lost practically all confidence , you know, the little confidence I had in the system, I, you know, I just completely lost</p>	<p>Getting treatmt: pain site as focus in past 10A9 Getting treatmt: passed between depts, years to get correct test 10A9 Getting treatmt: records mixed up 10A9 Getting treatmt: lost confidence in system 10A9</p>
<ul style="list-style-type: none"> •Not understood in a hospital context 	A10	<p>Emmm, again I feel that it would probably be in a hospital environment</p>	
	I	<p>So what is it that [...]</p>	
	I	<p>To what extent is that something you've come across before?</p>	
	I	<p>Could you tell me about a situation in which you did not feel listened to and understood when talking about your pain?</p>	

	I	Is there Any particular situations [...]	
<ul style="list-style-type: none"> ●Blanking out medical encounters to help cope ●Pt sees check-ups as perfunctory ●Discharge to other specialists ●Medics not looking in a multidisciplinary way 	A11	Difficult one. I've been, where it's kind of is, it's not been a happy experience, I've, I tend to black me or blank out you know the un you know the healthy things I've gone through I suppose. Emmm, generally, as I say it's been if I've had a procedure done emmm, and I've been back for a check up, they want to get you in and out of the room in a couple of minutes and they want to discharge you from one specialist and right, I can't do no more, you go to another specialist in another field and it's just the fact that they you know, won't take the time to look at all aspects, really.	Adaptation: blanks out medical encounters 10A11 Getting treatmt: check ups feel perfunctory 10A11 Getting treatmt: referred on to other specialists, doctors not looking at all aspects 10A11
	I	OK [refer to patient's interview guide] When you are in pain, do you ever not talk about it?	
●Pain talk: avoids	A12	All the time	
	I	I was going to ask you to give me an example but you've already answered that	
	I	What about talk about it but play it down?	
<ul style="list-style-type: none"> ●Plays down to protect son from impact ●Children expect a cure ●Difficult to explain pain mgmt approach to kids 	A13	Emmm, generally when I'm with my son at either football training or at a match, I manage my son's football team, or co-manage and he's very sensitive and he'll pick up when I'm trying to hide my own problems and emmm, it then affects his performance so that's not a very you know, happy, happy time. I feel that I, I mean children are kind of, they're very black and white, they, I mean he's expecting me to come out after a month cured. I've told him that you know I'm only expecting an improved quality of life but to get that through a child isn't easy.	Self-presentation: hide problems to decrease impact on family 10A13 Others judgements – children expect cure 10A13 Getting treatmt: hard to describe management of pain aim to child 10A13
	I	How old is he?	
	A14	He's twelve, emmm, you know fairly intelligent but as I say he's very you know heart on a sleeve and as I said, obviously the	

•Difficult to explain pain mgmt approach to kids

feedback I get from him, I don't want to go home and you know have him disappointed if you see what I mean, I, I've, you know that's an aspect I'm not looking forward to, I mean, as trying to tell him you know it's going to take time, you know, it's not a, you know a 5 minute job.

I How do you think you'll tackle that?

•Wife will help explain to kids

A15 Mmmm, well hopefully you know if he doesn't emmm, get what he wants in the way of a clear answer from me because sometimes I have trouble getting over exactly what I want to say, my wife's very good at that so she will you know relay it in perhaps a term that he will you know take in more.

I What about [...] play it up?

A16 What do you mean, make it seem worse than it is? No.

I What about telling how it really is [...]

•Tries to hide pain from wife but difficult to do so
•Variation in experiences of talking to wife: needing to talk and snapping
•Wife would prefer him to talk before he snapped

A17 Yeah, generally emmm, with emmm, my wife as I say, emmm you know the last five years I've been with her 24 hours a day emmm, I, you know, I try, it's, you know, I try to hide it from her at times but I found that I can't, emmm, there's times like I feel I need to talk to her and she's always there, emmm, but then there's times when I'm snapping her head off and she said if only you would tell me beforehand I mean, if I start snapping at her she'll start snapping at me but she expects, obviously it's right you know, if only I would come out with you know exactly how I'm feeling before I you know, lose my temper or you know get snappy

Maintaining normality: but can't pain from wife 10A17

Impact: emotional impacts 10A17

Others judgements: wife would prefer him to talk before snaps 10A17

I And do you tell her about what the pain is really like?

•Pt and wife trying to read up on the problem

A18 Yeah, yeah, I mean she's got a fairly good knowledge of certain aspects of medical, she was an auxiliary nurse when I met her you know so she's pretty cued up, emmm, you know whilst, the early days whilst they were trying to sort me out we were getting books

Getting treatmt + reading up on problem with wife 10A18

<ul style="list-style-type: none"> •Impact of painkillers •Choice: normality with pain over zombie state with pills 		<p>from the library and trying to you know gen up on exactly what was going on so you know, as I say she's, she's a great source of support to me but I've got a very low esteem on myself, I mean I've got to a stage where I've cut quite a bit of medication out before I came in because I got to a stage where they were just saying take a bit more of this, take a bit more of that and it affected me emmm, it affected the way I was in the family unit and it was getting to the stage where you either go through life as a zombie or you , you know take a higher level of pain and try and keep a bit of normality and I've chosen to take more pain, take, take lower dosage or lower forms of medication to enable me to cling on to a bit of you know normality really.</p>	<p>Getting treatmt – choice of normality with pain instead of zombie state without 10A18 Adaptation - choice of normality with pain instead of zombie state without 10A18</p>
<ul style="list-style-type: none"> •Short answers about pain •Talking about pain makes him low 	<p>I</p> <p>A19</p>	<p>Is there any other way you might talk about your pain [people may take a humorous aspect at times, is there any other way? Generally you don't talk about it, when you do, you play it down, [...]] occasionally tell it how it really is to your wife, any other way?</p> <p>I mean I tend to give short sharp answers i.e. a football match, obviously the parents of the children I've got in my team, I mean, they're, we're quite a close knit unit and they're always asking me and as I say sometimes I'll be truthful but with short sharp answers – no, I'm not having a good day but you know I won't sit there and go into it because I find the more I talked about it, the more low I became</p>	<p>Self-presentation: short answers about pain 10A19 Self-presentation: pain talk makes him feel low 10A19</p>
<ul style="list-style-type: none"> •Pain shattered confidence •Less positive thinking •Harder to get motivated 	<p>I</p> <p>A20</p> <p>I</p>	<p>Onto my next section [...] To what extent do you think pain has changed the way that you see yourself as a person?</p> <p>It's shattered my confidence, emmm I used to be a totally positive thinker now it's more intermittent. I can still think positive but not to the same degree and less often, so you know in general things in life that are a lot harder to become motivated to do.</p> <p>What things in particular?</p>	<p>Impact of pain: on confidence, on motivation 10A20</p>

<ul style="list-style-type: none"> •Everyday things harder to motivate self with •Possible impact on daughter? 	A21	<p>Everyday things, emmm i.e. taking the children to school, joining the wife when the dogs go out, especially helping my daughter with her homework, emmm, she's, well she's recovering now but she had a nervous breakdown at Christmas emmm, and we found notes in her room saying that she couldn't go on, that she wanted to end it. I mean she's fourteen, emmm, she was referred to a child psychologist and has been on very high doses of I suppose antidepressants. She's finally cut right down and she's you know come off and she's currently in a steadyish relationship for the first time which has helped so you know things haven't been rosy really</p>	<p>Impact of pain: everyday things harder 10A21</p> <p>Impact of pain: possible impact on mental health of family 10A21</p>
<ul style="list-style-type: none"> •Missing out due to pain •Others exclude pt •Pain means pt can't join in with some activities •Importance of mind-body link •INPUT – looking at mind-body not just pain site 	A22	<p>Sometimes I feel that I miss out say for instance emmm, a few of my friends decide to go out and perhaps I'm not going through a good stage, they, either they won't bother to ring me or through mainly the pain I can't participate so it's obviously restricting what I do as I said it's just a vicious cycle. This is why I can relate to what we're being taught downstairs, you know you can't have, you can't mend the mind without the body and vice versa – there's that strong link and this is the first time that you know that anybody's been interested in treating more than the actual site of pain</p>	<p>Others judgements – don't include pt socially 10A22</p> <p>Impact of pain: restricting 10A22</p> <p>Mind-body link – appreciates health pros at INPUT interested in more than pain site 10A22</p>
<ul style="list-style-type: none"> •Devastating effect of pain – active and proud to a wreck •Might hit self to snap out of suicidal thoughts •Description of pain: wants to do violence to self 	A23	<p>Emmm, for want of a better word devastating. I've gone from an active happy, hmmm, proud man really to emmm, a physical wreck, at times a mental wreck, emmm lost, at times I've lost the will to go on but then I'll, I won't actually hurt myself, I mean, perhaps I might you know hit myself or do things to make myself snap out of it emmm, it's you know, I'm not a violent man but there's times I could rip myself limb from limb (laughs)</p>	<p>Comparison with previous self 10A23</p> <p>Adaptation: hits self to distract from depressive thoughts 10A23</p> <p>Description of pain: wants to do violence to self 10A23</p>
	I	<p>To what extent do you think the pain has affected the way other people see you?</p>	
	I	<p>What impact would you say the pain has had on your life?</p>	
	I	<p>What effect do you think the pain has had on your family</p>	

<ul style="list-style-type: none"> ●Feels has held family back ●Financial struggle 	A24	<p>Emmm, again if that question was put to my family that would be a different answer to what I could probably give you but from my own personal view I think I've held them back, emmm, obviously not being able to work we struggle financially. The school where my two children go to is a emmm, privately run school and the trips, they're always going on trips and I don't get any financial help to pay for these trips and I'm afraid I'm old fashioned and I'll put my children first and you know, i.e. my daughter's fourteen and she's taking some GCSEs year early and she needed to go on a three day field trip for geography and they want £150 for three days because it's private tuition and you know I will struggle and make sacrifices so that she can go so that she's not actually isolated because a lot of the people out the area where we live are financially you know well off and the children can have this that and the other and you know obviously that affects me because I'm you know if I was working, fit and working emmm, perhaps then the wife could go back to work. Both my children are 14 and 12 so they're at an age where you know they can actually you know come in and out you know responsibly and then obviously then we would be able to give them a better standard of life that what we can</p>	<p>Self-perception: holding family back 10A24</p>
<ul style="list-style-type: none"> ●Prioritises childrens education 	I	<p>What sort of impact would you say the pain has had on how you get on with your wife?</p>	
<ul style="list-style-type: none"> ●Impact on relationship ●Wife insists they talk 	A25	<p>It's put a massive strain. I'm 37 now, I married at 20 and I'll be honest it's only the way that she is and the way she approaches me that's kept us together especially over the past 5 years. Emmm, she'll force me to sit down and talk, emmm, she'll force me, I don't mean physically force emmm, for instance if there's something I have to do, I must, I found out this week that I'm not alone, that the majority of people in the class, a slightly better day do too much and end up three or four days can't do bugger all, nothing. So you know that's basically it.</p>	<p>Impact of pain: on marriage 10A25 Others judgement: wife insists they talk 10A25 Self-perception – not the only one with pain 10A25</p>
<ul style="list-style-type: none"> ●Self-perception: not alone going through over/underactivity 	I	<p>What about work and housework? What impact has the pain had?</p>	

<ul style="list-style-type: none"> •Adaptations in kitchen so can do something •Hoovering impossible •Unable to provide for family as would wish •Feels he's failed his family •Multiple visits to experts got him nowhere 	A26	<p>Well obviously the situation I've got I can't work, I can do very little emmm, around the home. I've got emmm, you know aids within the home to, I've got you know especially made seating in the kitchen where I can you know, what I do, I do wipe up the dishes for the wife. I've tried on better days to say, do a bit of hoovering and that's not, that ends up as a disaster, generally laid up and bad for days after, emmm, yeah, I'm not an actual great help around the home and I feel a lot of hate you know really for what's happened because you know as I say I'm not able to provide a decent, you know we get by because I put my priorities – I put a roof over their heads and food on the table but you know there's no spare money, there's no money for treats and things and as I say it just keeps coming back to you know at times I feel I've failed through obviously I know through no fault of my own but it, you're fighting all the time to get these answers and as I say up until now, we've been, you go from one expert or so-called expert to another and it's just like a merry go round that doesn't get anywhere really</p>	<p>Adaptation: in kitchen 10A26 Impact of pain: can't Hoover 10A26</p> <p>Self-perception: unable to provide for family as would wish 10A26</p> <p>Getting treatment – sceptical of experts, got nowhere 10A26</p>
<ul style="list-style-type: none"> •Impact of pain – on active sport life •Maintaining normality – son's football team work •Other parents suggested he manage football team •Frustrated that can't implement dreams for house and garden 	I	<p>What about leisure, sport and hobbies?</p> <p>A27 Emmm, totally changed, I used to like playing football, cricket, golf especially, I was a county league player at darts. All of those have stopped. It's only been the last year that I've got involved with my son's football team and it was the management's decision to kind of have me on board to give me something to help occupy, so I do like the decision making, I attend the meetings and I've got a trainer, co-manager cum trainer that does all the physical side. Emmm, you know that's been a massive help, without that you know it would have been even worse than what it is, so you know as I say, that is the only activity I've got now. Emmm, I mean I love gardening, again that's been severely restricted. We just moved eight weeks ago emmm, we've now got a house with a 220 foot back garden that hadn't been touched for 20 years emmm, contractors came and got it manageable emmm, and I can lay awake at night and dream what I want to do – it brings on frustration because my present state I can't do it. It's there for me – it's one of my main goals is to be able to get out there and do a day's work in the garden. At the moment I do 10,</p>	<p>Impact of pain: on sporting life 10A27</p> <p>Maintaining normality: involved in sport team management 10A27</p> <p>Others responses: sport management to occupy him 10A27</p> <p>Impact of pain: can't work in garden 10A27</p>

15 minutes weeding on a stool. I mean I'm trying to get the pacing part right before I came here, knowing how important you know that is, but I was still overdoing it

	I	What about friends and social life, how has the pain affected that?	
•Limited social life	A28	The friends I've got I see really only when there's something to do with my son's football club. I mean that's through my son's football club. I don't go out socially for a drink or anything. The old thing money comes into. Both myself and my wife like to go out for a meal more often but every time we think we've got a little bit left over the children decide to go through their clothes so you know it ends up being put on the back burner so yeah, as I say it has a poor effect on it really and that's	Impact of pain: finances and limited social life 10A28
•Prioritises money for children			
	I	What about looking after yourself [...]	Impact of pain: lazy with self-care 10A29
•Laziness in looking after self	A29	I'd say I've become lazy and I have to be prompted at times, especially where shaving's concerned. I've been very good here [INPUT] errr, but as I said I'm amongst strangers. It was strangers, they're not so much of a stranger now and I've found actually that I'm in more of a routine now than I was at home emmm, the day starts at half eight down there. My alarm goes off at six or just before. I need two hours to get myself up and going and in a state actually to take anything in. Emmm, as I say I was, that was one thing I was thinking – when I go home tonight do I have a lay in, in the morning or do I continue this routine of getting up at six	Time issues: two hours to get ready 10A29
•Time taken to get self ready			
	I	So what are you going to do	
	A30	I was speaking to [name] the physiotherapist and she said that at least allow yourself an hour, an hour's extra rest. As I say I've got a long journey ahead of me and as I say it's not very pleasurable I mean I've worked my train times out to not coincide with the rush hour but as I say it's still quite a long trip, different forms of transport, as I say when I came up for one of my pre-assessments a friend brought me up in the car and it took three and a half hours and	Impact of pain: travel more difficult 10A30
•Planning journey not to be in rush hour			

I was in agony when I got here because I sat in one position. At least you know by using public transport the train especially I can move around to a certain extent so obviously that helps

I Find out on Monday

A31 Yeah, yeah

I What about your personality, how has pain affected your personality or personal qualities?

•More withdrawn, don't laugh, don't show feelings

A32 I've become more withdrawn, emmm, children especially have noticed that I don't laugh as much, emmm, I have great difficulty showing my feelings I mean this is all on a, it's been on a downward spiral. When I get upset I can't cry. I've been seventeen years, no, hang on, nineteen, we got married in the September, October my dad, I think last time I cried was October 1980 at my father's funeral. I get there but I can't release.

Impact of pain: withdrawn, don't show feelings and can't cry
10A32

I So that was before the pain?

•Wants to release feelings but can't cry

A33 That was before the pain but it's become, I mean I yearn to be able to release, you know I get all dry, clogged up and it's there but it just won't come. I feel that I need to, I you know I've got a lot of pent up anger and all the other feelings inside that perhaps would benefit from a good cry. I'm not embarrassed to cry, I'm just, you know, for some reason I just can't let go.

Self-perception: thinks could benefit from crying
10A33

I What about things you think are important in life. What impact has the pain had on what you think is important in life?

A34 Well, again I mean I put the family at the top of the list and to be able to provide

I So that's been the same – was that the priority before?

A35 That was my priority before and it still is, but obviously as I said

		that's with my situation changing and I'm able less, to do able to do less and provide less	
	I	But the fact that that's important hasn't changed	
•Tries to compare with others worse off eg worldwide on news	A36	yeah, yeah. It's been hard to keep it, I mean at times I've wanted to go into a self pity mode, emmm, I tend to try and put other people's problems that are worse than my own to the forefront. As I say you watch the news for instance and you see people all around the world that are having a lot worse problems than what we've got so you know I tend to try and do that all the time to make, to pull myself up you know	Comparison: with those worse off in the world 10A36
	I	Does that work?	
	A37	Sometimes, sometimes. I'm not half as positive as I used to be	
	I	OK, is there anything else apart from that list of family, social life, leisure, relationship, personality - are there [...] affected your life	
•Impact on sex life	A38	It's obviously affected emmm, the physical relationship i.e. I've lost a lot of interest, emmm, my wife had lost quite a bit of interest beforehand but it's now getting to stage where it's over 5 months and we're both not bothered. I mean we've got a strong relationship on the fact that we're friends and we always have been and that's to me a very important base to have but obviously you know the physical side is as, is important as well and it's you know as I say it's a bit of a worry that, you know we're not able to kind of sort that out. Again, I'm hopeful that perhaps with increased mobility from here and also the more positive thinking that things will help carry on at home, it's a hope I'm clinging to	Impact of pain: on sex life 10A38
•hopes to regain sex life			Future: regain sex life 10A38
	I	On what part of your life would you say the impact of pain has been the greatest?	
	A39	Emmm, difficult because obviously I, I used to love my work and I can't work	

	I	What was your work?	
Reflects on past active life 10A40	A40	Well there were various jobs but it was physical work, emmm, I used to enjoy you know coming home at the end of the week, going to work, coming home at the end of the week, obviously with a reasonable amount of pay. Being able to you know go out for treats, things, so obviously the family suffered. Sorry I keep on going back to them.	Comparison: with past work life and money 10A40
	I	No, if that's where it's most important. What about what parts of you or your life have stayed the same despite the pain?	
•General health is good despite pain	A41	Emmm, if you can separate it I'd say health. If could separate, you know the parts of me that are suffering through the pain, take the rest, my general health, i.e. errr, picking up flu, things like that has actually you know been improved so that's one thing I have noticed. Whether or not that's due to you know being pumped full o pain killers but I mean we had a very, very vicious flu bug going around 3 weeks before I came in and people were still led in bed three and four weeks after they contracted it. I mean I picked it up and within three days, I wasn't laid up because of it and within three days it'd gone so I would say that I am less susceptible to infections	Self-perception: apart from pain in good health 10A41
	I	Is there anything else that you think has stayed the same about your life [...]	
•Pain affected almost everzthing	A42	As I say, it's had a, the pain has had a you know effect on practically every aspect	Impact of pain: on almost everything 10A42
	I	OK, next section, how do you see the future?	
•Hopeful about future	A43	Emmm, I'd say my feelings at this present moment in time are hopeful. Emmm, actually more hopeful before I got videoed this afternoon and I was able to see exactly how immobile and unconfident I'd become on my legs, emmm and it's interesting that's the first time I've able, been able to see myself actually you	Future: hopeful 10A43

<ul style="list-style-type: none"> •Self-perception - didn't realise how bad his walking was 		<p>know moving 'cos obviously you don't walk along in front of mirrors all the time and you don't see behind you, so you know, that aspect</p>	<p>Self-perception: deterioration in walking 10A43</p>
	I	<p>If I break the future down into short term medium and long and short term is the next couple of months, medium the next year or two and long term the rest how do you see the next few months</p>	
<ul style="list-style-type: none"> •Hopes for increased mobility 	A44	<p>Short term hopefully an increase in mobility, emmm, and also a better awareness of how the pain can affect other parts i.e. the mind and being able to put into practice what we are being taught here. Long, middle term I mean I, I've set goals out and they're all linked to more mobility and being able to participate more in everyday life. Emmm, i.e. I yearn to have a round of golf. I've put 2 years down as a – I'm under no illusions, it's not going to be a 5 minute task, I think I put one year down for being able to join in say a 3 mile walk with the dogs, emmm, and also I'd like to, I used to run a line, be a linesman at football matches, I've put about 18 months down for that. I'm, it's to say I'm not expecting miracles because I don't want to get my hopes up too high and then dashed but I'm clinging to some hope and what I've experienced this week is more encouraging than discouraging you know, as, you know carry on</p>	<p>Future: more mobile, golf, walk dogs 10A44</p>
<ul style="list-style-type: none"> •Future: play golf 			
<ul style="list-style-type: none"> •Future: walk dogs 			
<ul style="list-style-type: none"> •Protecting self by trying to have realistic goals 			<p>Self-perception: set achievable goals 10A44</p>
	I	<p>And what about beyond two years, the longer term?</p>	
<ul style="list-style-type: none"> •Experience of hopes being dashed in the past •Difficulty of planning things + living day to day now 	A45	<p>I've learned that over the past few years long term planning hasn't - although I can think and imagine what it might be like, I've tended to, I've had so many things I used to look forward to and over the past few years I've had dashed. I mean I couldn't tell you tomorrow whether I was able to do anything. You see what I mean it's gone from planning ahead to living purely on a day to day basis. If somebody asked me out for a meal next Friday I'd have to say I'll ring you Thursday night or Friday morning – I couldn't give a definite I can do this on that day</p>	<p>Time issues: difficulty of planning things in case of pain 10A45</p>
	I	<p>My last question is what medical professionals need to understand so if I was to say what advice, what would you say to medical staff</p>	

		like doctors nurses and phsyios to help them when they are seeing people with chronic pain what would you advise?	
	A46	Personally they need to move with the times, it needs to	
	I	What does that mean	
●Doctors as stuck in their ways	A47	For want of a better word I find a lot of the specialists to be dinosaurs with their heads stuck in the sand, They're not, they're only saying right this is how it used to be and this is how it's going to be. They're not kind of you can't actually make them realise there's another way	Expectations of doctors – keep up with new approaches 10A47
	I	And what is this other way?	
●Doctors to realise importance of mind-body	A48	As I say I wasn't aware of how important the mind and body interacting was. Perhaps if they were not forced, although some specialists I'd like to force emmm, that they as part of their kind of retraining were to you know come observe or even take part in a course similar to this to make them more aware of there is another option rather than just ruling it out and you know as I say just treating the site and when the site's cleared up, you know, off you go	Expectation of doctor – realise mind-body link in helpful way 10A48
●Doctors to be more aware of pain mgmt			Expectation of doctor – consider more than initial site 10A48
	I	Anything else [...] if they said [...] we want to learn from chronic pain patients what we can do better	
●Doctors to treat more than initial site	A49	If they said that, I would, as I said, I would try and help them be a link between the two because it's ignorance, as I say they've how I got referred here was through a pain specialist but she was at the last port of call and you know you're getting shoved from pillar to post and they go through every possible medical or so-called progressive problems emmm, although the problems I've got are progressive they can be made to progress perhaps at a slighter slower pace and you know doctors and that will just say you've got this, take some pills, out your feet up, that's it, whereas I'm already learning that you have to, yes you have to rest, you've also got to exercise and as	Experience of treatmt – multiple attempts with different specialties 10A49 Experience of treatmt – pills and take it easy 10A49 Adaptation: need mix of rest and action 10A49
●Pts experiences of multiple treatment attempts with different specialties			
●Hopes that progression of condition can be slower			

- Doctors resort to pills and 'take it easy' – not helpful long-term
- Pt learning that need mix of rest and activity
- Anger at years wasted before pain mgmt approach

I say coming here has made me more angry at the years wasted and you know I think that's really covered it

Time issues – angry at time wasted before pain mgmt 10A49

I Anything else you want to say [...]

A50 No, I think that's been pretty thorough,

I OK Thanks a lot