AN INVESTIGATION INTO PSYCHOLOGICAL ASPECTS OF CHRONIC PAIN

Thesis submitted to the University of London
for the degree of Doctor of Philosophy

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ABSTRACT

This thesis studied the role of schema and meaning in chronic pain. Four studies, using a range of different methods, were used to assess pain schema and pain meanings, and two aspects of pain schema were considered: schema function and schema content.

Study 1 adopted an information processing approach and explored the role of retrieval inhibition in the pain-related recall bias, previously demonstrated in chronic pain sufferers. Whilst no evidence was found to support the role of retrieval inhibition in the pain-related recall bias, both this study and Study 2, on group differences in perceived word meaning, provided evidence consistent with the view that categorization processes may play an important role in the pain-related recall bias and that interpretative biases may be a key function of pain schema.

Study 3 investigated the role of specific types of schema content/ pain meanings (understandings of pain and perceptions of loss accompanying pain experience) in pain adjustment, exploring evidence for both 1) Lacroix *et al.*'s assertion that symptom understanding is an important predictor of pain-adjustment, and 2) Schmitz *et al.*'s claim that chronic pain adjustment is moderated by the flexible adjustment coping style. Little evidence was found to support either of these models, although this could have been due to insufficient power in the analysis. However there was evidence that factors such as levels of involvement in a pre-pain hobby may be important predictors of depression. Study 4 used an unconstrained method to explore broader aspects of pain meanings and their relation to pain adjustment, developing a grounded theory based on interviews with chronic pain sufferers. The concept of constraint emerged as an important aspect of schema content in understanding pain-adjustment. Furthermore, the analogy between having pain and the ageing process emerged and the parallels between the two were found to be worthy of further exploration.

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Chapter 1

1.1 INTRODUCTION

There is widespread evidence that pain cannot be considered solely in terms of level of tissue damage or peripheral input, and that psychological factors play a crucial role in pain experience (Melzack and Wall, 1996). Cognitive psychological approaches to pain propose that the meaning of pain is embodied in mental representations, such as pain schema and pain beliefs, and that these play a central role in both the continuation of chronic pain and the impact it has on people's lives.

The aim of this thesis was to study the role of cognitive representations (principally schema and the meanings embodied in them) in chronic pain. This aim was addressed through four studies which use a range of different methods to assess pain schema and pain meanings, and which consider two aspects of pain schema: schema function and schema content. The first two studies in the thesis address schema and meaning within the context of *how* pain meanings might dominate information processing in chronic pain sufferers, and hence focus on schema *function* in chronic pain; and the second two studies address schema and meaning within the context of *what types* of pain meanings appear to be associated with poor adjustment to chronic pain, and hence focus on schema *content*. As noted above, the studies use a range of different methods to assess schema and meaning: directed forgetting and card sort methodologies are used to assess schema function, and questionnaire and interview methodologies are used to assess schema content. However two key themes are evident throughout the thesis.

A central theme of this thesis is the meaning of pain, and this is considered in all four studies: Study 1 aimed to explore a potential mechanism responsible for the domination of pain schema (and hence pain meanings) in the processing of information in chronic pain sufferers. Study 2 examined differences in the perception of word

meanings, and the function of pain schema in biasing interpretation. Study 3 investigated the role of specific types of schema content/ pain meanings (understandings of pain and perceptions of loss accompanying pain experience) in pain adjustment, and Study 4 used an unconstrained method to explore broader aspects of pain meanings and their relation to pain adjustment.

A second key theme of the thesis concerns the ability of the different methods used to tap different types of cognitive representation (unconscious and consciously accessible forms), and levels of meaning (prepositional and implicational). This issue is discussed throughout the thesis within the context of Leventhal and Everhart's (1979) 3-systems model of pain and Teasdale and Barnard's (1993) Interacting Cognitive Subsystems framework, and forms a central part in the choice of methods which are used to assess schema in the thesis.

Previous research into cognitive representations of pain and pain meanings have used a variety of approaches. These include examining the way in which pain-related information is 'processed' and inferring the presence and function of cognitive pain-related representations, such as pain schema, from such findings (see Williams, Watts, MacLeod and Mathews, 1997, for a review of work using this approach in emotional disorders, and Chapter 2 for a review of findings as they relate to chronic pain); questionnaire methodology to assess conscious beliefs about pain and their role in pain and pain-adjustment (see Jensen, Turner, Romano and Karoly, 1991; and section 1.4.4.2 of this thesis); and qualitative methods which are used to explore both beliefs about pain and the broader socio-cultural meanings which surround pain (see Chapter 6 for a summary of this research). However, in this thesis all of the above approaches are used to examine cognitive representations of pain and pain meanings, and there are benefits and drawbacks to using this range of methods. The benefits include procedural knowledge of both quantitative and qualitative methodologies and an understanding of

different underlying assumptions and strengths and weaknesses inherent in these, along with an understanding of the strengths and weakness of specific techniques for assessing schema and meaning. The problems centre on the potentially large literature that surrounds the use of such different methods. The methods and research questions which are considered in the different studies in this thesis are situated within particular theories and research findings which mean that the individual studies draw on potentially very large literatures. For example, the method of directed forgetting draws on a considerable body of work related to information processing biases in emotional disorders (see Williams *et al.*, 1997) and it is clearly beyond the scope of this thesis to document the literature surrounding the approaches used in each study in full. Hence the thesis is structured such that fundamental issues in pain and pain-adjustment are outlined in Chapter 1, and more detailed and focused literature reviews, which draw on key findings specific to the individual studies, precede the four empirical studies. Hence previous findings relating to information processing biases in pain and emotion and previous directed forgetting studies are discussed in Chapter 2, findings relating to interpretative biases in chronic pain sufferers and card sort methodologies are discussed in Chapter 3, beliefs relating to symptom understanding, role/goal loss and depression are discussed in Chapter 5 and qualitative work which explores broader pain meanings are discussed in Chapter 6. Hence rather than provide a literature review of the main topic or topics of the empirical studies in the thesis, this introductory chapter aims, instead, to provide a background to the central themes of the thesis and cover the crucial issues in pain and pain-adjustment. This first chapter therefore begins by illustrating why meaning is considered important in pain experience, through presenting an outline of past and present theories of pain (affect, pattern and specificity theories of pain, and the Gate Control Theory of pain). It then discusses how meaning is thought to be represented cognitively through a discussion of the cognitive models of pain and emotion offered by Leventhal and Everhart (1979), and Teasdale and Barnard (1993) respectively, and

following Leventhal and Everhart's 3-systems model of pain, which suggests that meaning is represented in two ways (unconscious-schematic and conscious-verbal), it presents evidence for the role of these two types of representation in both pain-intensity and pain-adjustment. The chapter then goes on to discuss other models of chronic pain and pain-related adjustment, and concludes with a discussion of the distinction between acute versus chronic pain, and issues in pain measurement.

1.2 UNDERSTANDING CHRONIC PAIN

1.2.1 What is chronic pain?

How chronic pain is understood determines crucial issues such as how it is measured and how it is treated. Over the last century there has been a change in the dominant model used to understand pain, and other medical problems in general, which has been broadly summarized as a shift from a biomedical to a biopsychosocial model (Kugelmann, 1997). This change has meant a general movement away from explanations based solely on disease processes to ones based on the interaction of biological, psychological and social factors. As a result pain is no longer viewed as determined solely by peripheral input but as something influenced by multiple factors: physiological, psychological and social.

In their section on chronic pain, the Association of Anaesthetists of Great Britain and Ireland and The Pain Society (1997) are explicit about adopting a biopsychosocial model in their statement that chronic pain is:

> "pain following an episode of tissue damage which persists past the time when healing is expected to be complete, usually nominated as three months. Chronic pain is a complex biopsychosocial problem."

However, they also highlight the difficulties associated with attempting to define chronic pain in that, although they initially appear to link chronic pain with the presence of tissue damage, they go on to qualify this with the statement that:

> "A single pathophysiological explanation is not available for many chronic non malignant pain states. Up to one third of chronic pain patients will have no objective findings of organic disease."

Whilst this definition reflects a biopsychosocial framework, this way of understanding pain is a relatively recent development. A number of different models of pain have developed over the centuries. The three basic theories at the beginning of the 20th century were affect theories, specificity theories and pattern theories. These varied not only in terms of their understanding of the physiological basis of pain but in terms of whether psychological factors were considered central to pain experience or secondary to it (see Dallenbach, 1939, for a review). Aspects of each of these three theories have been incorporated into the currently accepted theory of pain: the Gate Control Theory, which argues that the meaning of pain is a central feature to understanding individual differences in pain experience.

1.3 OVERVIEW OF THEORIES OF PAIN

1.3.1 Affect, pattern and specificity theories of pain

As noted above, previous theories of pain differed in terms of which factors they considered to be central to the experience of pain. Affect theories placed a primary emphasis on the negative affective qualities of pain; pattern theories placed a primary emphasis on levels of stimulation; and specificity theories placed a primary emphasis on the particular type of sensory stimulation being experienced.

Affect theories viewed pain as an emotion rather than a sensation, emphasizing its negative affective qualities and the role such qualities played in stimulating action, such as doing something to stop the pain (e.g. Marshall, 1894). As a result, such theories link pain with motivation and emotion, however they did not disregard its sensory qualities, as both the sensory and affective elements of pain were considered to be proposed in parallel (Marshall, 1894). Whilst this latter point is something which is

accepted in current theories of pain (see section 1.3.2), its failure to fully consider physiological factors has led to such theories being considered incomplete.

Pattern theories (sometimes referred to as intensive theories), typically argue that whether or not pain is experienced critically depends upon both stimulus intensity and central summation (i.e. summation of input from the periphery in the central nervous system). Pattern theories argue that pain is not a specific *type* of sensation but one of a certain *intensity*, and that any sensory stimulus is therefore capable of producing pain if it is sufficiently strong. (Weddell, 1955; Sinclair, 1955; Livingston, 1943). Hence they reject the notion that pain is the result of stimulation occurring to specific receptors. Whilst pattern theories have been criticized for not incorporating the facts of physiological specialization (Melzack and Wall, 1996), aspects of these theories have received fairly widespread empirical support and are able to account for some of the more puzzling aspects of pain, including phantom limb pains, causalgia and neuralgic pain.

Specificity theories propose that pain is the direct and inevitable result of encountering a particular stimulus and that this stimulus is dealt with by a specialized 'pain system'. The pain system, as conceptualised by a specificity theorist, is one in which specific pain receptors transmit pain signals down specialized pain fibres to a pain system in the spinal cord and up to a pain centre in the brain (e.g. von Frey, 1985). This type of theory therefore proposes that there is a direct link between sensory input and the experience of pain. As a result, pain is viewed primarily as a sensation, and psychological factors are considered secondary, with motivational and cognitive processes seen as reactions to the pain rather than as core features of the pain itself. Whilst theories of this type dominated ideas about pain, its cause and its treatment for much of the 20th century, they have been widely criticised and have been largely replaced by the Gate Control Theory (Melzack and Wall, 1996). Whilst there is strong evidence to support the idea that there are specialised receptors in the skin

(physiological specificity), the idea that there is a direct link between the stimulation of such receptors and the experience of pain has been challenged. Receptor specialisation has been defined in terms of the lowest threshold it takes for a particular stimulus to fire a particular receptor (Sherrington, 1900; cited by Melzack and Wall, 1996), with different receptors exhibiting different thresholds. Melzack and Wall (1996) state that:

> "This concept of 'adequate stimulus' is so generally accepted that it is rightfully considered to be a biological principle or law" (p. 154).

However it is the assumption that the firing of certain receptors is both necessary and sufficient for pain to be experienced that Melzack and Wall find problematic. The link between injury and pain is extremely variable and evidence of this comes from a number of sources.

- Pain can depend on the meaning of the situation in which it has occurred, for example, both Beecher (1959) and Carlen, Wall, Nadvorna and Steinbach (1978) have shown that the complaints of pain are lower in soldiers injured in combat in comparison with injured civilians. This suggests that the more positive meanings the pain has for the soldiers (e.g. removal from immediate danger) moderates pain experience.
- Pain can exist without any clear physical cause, for example, lower back pain is often accompanied by an absence of organic pathology (Melzack and Wall, 1996).
- Pain can persist beyond the expected healing time, such as phantom limb pain which continues despite the healing of an injury. In a study of a hundred consecutive cases of people with damage to the brachial plexus (the network of nerves connecting the arm to the body), Wynn Parry (1980) found that 95 were in severe pain, reporting painful phantoms.
- Pain can be disproportionate to the level of injury, such as neuralgic pain, which is often described as being triggered by stimuli that are usually considered very mild such as gentle touch or puffs of air. And,

- People born without the ability to feel pain show widely differing physiological abnormalities (Comings and Amromin, 1974) and no clear abnormality can be definitively linked to their inability to feel pain.

1.3.2 The Gate Control Theory of Pain

The Gate Control Theory (GCT) represents a major theoretical development in the field of pain and currently dominates understandings of pain. Its innovation lies in its linking the physiological and the psychological together, rather than according primary roles to either sensation or affect. As such it is able to account for many more empirical findings and clinical reports than any of the other theories upon which it is based. However it retains elements from all three theories noted above:

- from affect theories of pain it retains the idea of parallel processing of different dimensions of pain (sensory and affective) and the appreciation that negative affect or unpleasantness is a central aspect of pain experience;
- from pattern theories it retains the idea of summation of input as crucial to a complete understanding of pain, and
- from specificity theories it retains the idea of specialized receptors that respond and transmit different sensory qualities.

The GCT argues that pain is a phenomenon that cannot be reduced to sensory input or affective experience alone. Instead it proposes that pain is the product of a complex interaction between afferent sensory activity and central processes (cognition). Neither sensory nor cognitive processes are regarded as dominating the experience of pain. Furthermore, these physiological and psychological factors are thought to interact in a complex way.

The central role of psychological factors is clear in the following quote:

> "It is now becoming increasingly evident that virtually all of the brain plays a role in pain. Even seemingly unrelated brain activities such as seeing, hearing and thinking are important. Seeing the source of injury, hearing the

> sounds that accompany a rifle shot or a falling beam, and thinking about the consequences of an injury all contribute to pain. Any satisfactory understanding of pain must include all of these processes which interact with inputs from the injured area or from deafferented neurons that produce pain signals when injury is absent" (Melzack and Wall, 1996; p. 132).

This theory makes it clear that psychological factors such as expectation, attention and memory are considered critical to understanding pain perception.

The physiological details of the GCT are documented in full elsewhere (Melzack and Wall, 1996). In brief, the theory proposes that there are broadly two types of fibre important to the dynamic processing of pain: the small diameter fibres (A-delta and C fibres) and the large diameter sensory fibres (A-beta fibres). These fibres connect in the dorsal horns of the spinal cord and it is at this point that mutual activity in these two types of fibres can interact, affecting the activity of central transmission cells, or T-cells, which reside in the dorsal horns and send messages up to the brain. Small nerve fibre activity increases T-cell activity 'opening the gate' and sending signals up to the brain which lead to pain perception. In contrast, large fibre activity inhibits T-cell activity and 'closes the gate'. The spinal cord is therefore seen as the key transmission site and is the place where ascending and descending nerve fibres interact. However, afferent nerve activity in large diameter cells is not the only type of activity that can inhibit T-cell transmission. Descending fibres from the brain to the spinal cord can also act to inhibit T-cell activity. Initially there was only thought to be one type of descending pathway from the brain to the spinal cord but there are now thought to be two; one from the cerebral cortex and one from the brainstem.

Melzack and Wall propose that pain consists of three broad dimensions: a sensory-discriminative and a motivational-affective dimension (which are both processed in parallel), and an evaluative dimension. The latter:

> "reflects the capacity of the brain to evaluate the importance or urgency of the overall situation.... based not only on sensory and affective qualities, but

also upon previous experiences, capacity to judge outcome, and the meaning of the situation" (Melzack and Wall, 1983; p. 71).

Empirical evidence for dimensions of pain tend to centre on the distinction between sensory and affective dimensions. For an example, in a review of the sensory and affective dimensions of pain Fernandez and Turk (1992) cite numerous studies which have supported this distinction between affective and sensory pain qualities. These studies have tested the validity of this distinction using a variety of methods such as factor analytic and multidimensional scaling techniques, signal detection analyses and paired scaling methods. However high collinearity among these two components of pain was also demonstrated, arguably supporting the view that these two dimensions, whilst distinct, are part of the same phenomenon. Nevertheless, there is evidence that the two dimensions can be differentially affected by therapeutic interventions. Leventhal has argued that therapies can reduce overall pain by affecting one or other dimension. For example, manipulations such as hypnotherapy or the use of narcotic drugs are interpreted as differentially affecting sensory and affective components of pain (Hilgard, Morgan and MacDonald, 1975; Kupers, Konings, Adriaensen and Gybels, 1991, respectively). In both cases, these interventions typically led to sufferers reporting continued sensory experience of pain but reduced affective response to pain. That is, such interventions appeared to differentially affect the sensory and affective-distress aspects of pain. Precisely what constitutes the affective dimension of pain is, however, unclear. Melzack and Wall themselves argue that affect may relate to level of arousal or qualitatively different emotions such as anger, fear or sadness. However, emotions such as sadness are not synonymous with pain, and in a study looking at what factors predicted ratings of the emotional unpleasantness of pain, Wade, Price, Hamer, Schwartz and Hart (1990) found that, controlling for pain intensity, significant predictors of the unpleasantness of the pain were anxiety, frustration and anger, but not depressed mood.

From a psychological viewpoint the Gate Control Theory is critical in legitimising psychological approaches to study pain. The meaning of the pain is considered central to its experience and psychological process, such as attention and memory, conscious appraisals and beliefs, are considered central to its experience. Whilst details of how these factors might contribute to pain are sketched out in the GCT, they are arguably developed more fully in Leventhal and Everhart's (1979) 3-systems model, which outlines how pain might be represented cognitively and this is discussed in more detail in section 1.4.1.

1.4 COGNITIVE REPRESENTATIONS OF PAIN AND EMOTION

The ability of different methods to tap pain schema or pain meanings is a key issue behind the choice of methods used in the thesis, and this in turn centres on how pain and meaning is thought to be represented cognitively. The two theories/frameworks outlined below (the ICS framework and Leventhal and Everhart's 3-systems model) present differing models as to how meaning is represented. The models also differ in terms of their conception of schema: Leventhal and Everthart propose a holistic structure, Williams *et al.* a more limited structure and Teasdale and Barnard a more dynamic schematic structure. However, they both posit two levels of representation, and both argue that only one level of representation is involved in the experience of pain/emotion (i.e. hot cognition). For example, Leventhal proposes that meaning is embodied either in form of conditioned emotional responses (the 'schematic' level of representation) or hypotheses about what symptoms signify (the 'conceptual' level of representation), and Teasdale and Barnard, in their discussion of depression, offer a similar distinction between two levels at which meaning can be represented: the 'implicational' level and 'propositional' level. Both of these theories therefore assume that not all representational levels play a role in eliciting emotion/ pain and the ability of

different methods to access different levels of representation is discussed more fully in Chapter 4.

1.4.1 Leventhal and Everhart's 3-systems model of pain

The 3-systems model provides a more explicit psychological framework for viewing pain experience, particularly chronic pain. Whilst it appears to draw extensively on the GCT, it seems to flesh out the concept of the evaluative dimension of pain.

In brief, the 3-systems model assumes that pain experience has two dimensions:

a) a sensory-perceptual dimension which relates information about the location, duration and intensity of the pain, and

b) an emotional/affective dimension which relates information about the distressing aspect of the experience.

This model proposes that these two dimensions of pain are processed in parallel and enter consciousness (subjective awareness) as a unified experience. As already discussed, this aspect of the model is not new, dating from Marshall's affect theory of pain (1894) and re-appearing in the Gate Control Theory. However the 3-systems model proposes that the products of this parallel processing are then further processed by a hierarchical system containing three levels:

1) The perceptual-motor system

The perceptual motor system is responsible for carrying out the earliest stage of processing. This type of processing is regarded as automatic and innate and gives rise to involuntary, unlearned responses to pain, such as cries of pain.

2) The schematic system

In general, schema are considered to be abstract mental representations which are built up through experience. For example, English and English (1958; cited by Beck,

1976; p. 282) define schema as:

> "the complex pattern, inferred as having been imprinted in the organismic structure by experience, that combines with the properties of the presented stimulus object or of the presented idea to determine how the object or idea is to be perceived and conceptualized"

Schema are thought to represent typical actions, attributes and relationships and serve to integrate incoming information. As a result they guide the encoding, interpretation and retrieval of information. They impose structure on incoming information, help to resolve any ambiguities and also fill in any 'gaps' with stereotypical information. For example, Leventhal has argued that phantom limb pain reflects the activation of an entire pain schema on the basis of only certain features of pain experience actually present (Leventhal and Everhart, 1979; Leventhal, 1984), as it has been suggested that such pain cannot be explained by continuing stimulation from remaining peripheral nerve roots (Morgenstern, 1970).

In Leventhal and Everhart's model the schematic level is indeed seen as derived from, and as embodying, previous pain experience. Incoming stimuli are integrated into pain-related memory systems (pain schema) which embody the meaning of these previous pain experiences. This stage of information processing reflects the way in which previous pain experience can affect current pain perception and influence response to future pain events. The schematic level is conceptualised as operating outside of conscious awareness and is considered to be the stage at which the bulk of pain processing occurs.

In contrast to other conceptions of schema (e.g. Beck, 1970), Leventhal (1984) conceptualises schema as non-verbal entities which are analogue versions of past experience, embodying subjective feelings and expressive-motor reactions. He views the schematic representation of something as an analogue representation, linking external objects to subjective feelings in terms of a record of a conditioning history. Schema embody the relationship between the subject (person) and the object, which is one of

meaning at an emotional level. That is, the meaning of the object becomes linked to a subjective feeling within the schematic representation (in the case of pain this link might be between pain and feelings of depression or fear). Once schematised, the appraisal, or personalized meaning of the object and associated feelings are automatically invoked on presentation of the object, and hence the appraisal of the object occurs outside of awareness.

3) The conceptual level

The conceptual level is considered to be consciously accessible, verbal in content, and hence available to verbal report. This level reflects the individual's beliefs about pain. The 3-systems model proposes that all three systems, perceptual, schematic and conceptual, mutually interact and that each can activate the other. Within this model, activation at the conceptual level can produce activation at both the perceptual-motor level and schematic level and can therefore, in theory, produce a 'physical' response. It is this model which has formed the basis for previous work done into information processing biases in chronic pain sufferers and hence will be discussed in more detail through the thesis.

1.4.2 Integrated model

Williams *et al.* (1997) Integrated Model is based on the concepts of integration and elaboration taken from Graf and Mandler (1984). Integration or 'priming' is defined as the automatic activation of the mental representation of a stimulus. Activation of this representation is hypothesized as causing the internal organization of it to be strengthened. This increases the *accessibility* of the representation, so, for example, the word will be more likely to come to mind when only partial cues are presented, e.g. some of the initial letters of a word as occurs in an implicit memory task such as stem completion. Elaboration occurs when activation spreads from the representation of the

stimulus to other associated representations, forming new links and re-activating old ones. The consequence of elaboration is increased *retrievability* of the word, as these new and old links offer up pathways to aid retrieval of the target word. Graf and Mandler (1984) argue that elaboration also involves priming and hence whilst integration makes the word more accessible, elaboration makes the word both more accessible and more retrievable. In contrast, Williams *et al.* propose that the two processes of elaboration and priming are distinct. Hence they argue that priming and elaboration can be affected be independently affected by different mood states. However, like other schema theories it does not appear to offer an account of the flexible nature of information processing biases. Inflexibility is considered to be a problem with theories that invoke the concept of static structures such as schema, as Williams *et al.*'s model does. For example, once a pain or depressive schema has built up through experience there should be evidence that it biases information processing towards thematically-related concerns on a permanent basis. However there is evidence that these effects disappear once the chronic pain or mood state has resolved (e.g. Edwards, Pearce and Beard, 1995). Concerns about conceptual inflexibility inherent in accounts based on the notion of schema have been sufficient to prompt the development of a new framework in the field of depression: Interacting Cognitive Subsystems (ICS).

1.4.3 Teasdale and Barnard Interacting Cognitive Subsystems

The Interacting Cognitive Subsystems (ICS) framework developed by Teasdale and Barnard (1993) offers an account of the effect of depression on information processing. It is relevant to this thesis through its discussion of the representation of emotion and how this level might be accessed.

The ICS framework

In its treatment of some of the issues directly relevant to the effect of memory on depression, the ICS framework could be described as a more sophisticated version of schema theory. However it is more comprehensive than this in that it deals with different types of 'information code' and their inter-relationships, and can accommodate a much wider range of the data relating to depression than schema theory, through its proposition of a dynamic information processing system.

In brief, ICS was put forward to explain the cognitive processes which may lead to prolonged depressed status in the apparent absence of continued depressive events. It rests on the assumption that information-processing can become "interlocked" in vicious cycles. This means that processing can occur which only relates to a limited range of themes. In the case of depression these themes are predominantly negative.

This framework describes a number of subsystems and their mutual interaction. It recognizes different types of information which it suggests are encoded in different mental codes. It proposes three subsystems which deal with sensory information (Visual, Acoustic and Body State), two subsystems which deal with "intermediate structural level descriptions, capturing recurring regularities in the sensory code patterns encountered" (Morphonolexical and Object) (Teasdale and Barnard, 1993; p. 51), two subsystems which deal with meaning at two different levels: one dealing with specific level meaning (Propositional) and one with abstract holistic meaning (Implicational), and two subsystems which deal with action (Articulatory and Limb).

Within this framework 'information processing' consists of two processes;

i) information storage, and

ii) information transformation (from one type of code into another).

The storage of information in a particular code, and the translation of information from one code into that particular code can only be done by the subsystem specialized for dealing with that type of mental code. A given subsystem can perform

simultaneous (parallel) transformation operations on patterns of information it receives as input, and its output can be fed to more than one subsystem at a time. Information regarding one particular topic can be represented in more than one code but one code can have "functional relationships that are quite different to those of related representations in other codes" (p. 50). For example, they argue that only patterns in one type of code (Implicational) are directly related to affect and its production.

As noted earlier, of relevance to the studies in this thesis is the distinction Teasdale and Barnard draw between Propositional and Implicational codes, both of which represent different types of meaning:

Propositional - meaning at this level refers to the specific meaning of words and concepts, and prepositional meanings assert specific relations and hence this type of meaning can be assessed with relation to truth, i.e. whether it is true or false. Propositional code is usually derived from the correspondence between Morphonolexical and Object codes; for example:

> "the relational concept "above" will be derived from repeated experiences of seeing a certain spatial relationship between two objects in conjunction with speech code patterns such as "above" or "over" or "on top of"" (p. 53).

Implicational - meaning at this level is of a higher order. It is a more holistic, generic level of meaning. In contrast to prepositional meaning, meaning at this level has no relationship to truth and embodies regularities across all codes, representational and sensory. That is, meaning is extracted beyond the level of explicit meaning (propositional), for example, the context of what is being said and how it is being said are taken into account. It is proposed that sensory contributions play an important role in the generation of such schematic models.

Teasdale and Barnard argue that it is when meaning is 'generated' at this level, i.e. schematic models of this type are processed (that is, information of other types e.g. PROPOSITIONAL, are translated into IMPLICATIONAL code) that emotion is produced.

Teasdale and Barnard describe the distinction between these two levels of meaning as one between 'knowing with the head' and 'knowing with the heart', i.e. as representing a distinction between 'intellectual belief' and 'emotional belief', and hence is able to account for the fact that talking about emotions does not necessarily lead to them being experienced.

This framework differs from traditional schema theories in that regular patterns of events are not embodied by structured schema but lead to the generation of a schematic model on the spot. That is, rather than leading to the retrieval/activation of a schema from long-term memory, these regularities cause such schema to be constructed 'on-line'. As a result, this framework side-steps some of the criticisms of conceptual inflexibility often directed at schema theory.

Teasdale and Barnard contrast their framework for viewing depressive thought principally against Beck's cognitive model of depression. The latter proposes that negative schema produce affect, and that certain individuals are vulnerable to depression (i.e. vulnerable to interpreting events as negative) as the result of relatively stable underlying assumptions/beliefs such as the belief: 'I must achieve great things or I will be a failure in life' which form the basis of negative schema. Beck's model proposes that depressive recall biases reflect the operation of depressive schema and that depressed mood is also the product of this schema. ICS similarly proposes that the depressive recall bias and depressive mood are the product of the same thing, but in this case the 'thing' is not a structure but a process: a process of interaction between depressive schema. This schema interaction gives rise to models which produce specific outputs (e.g. negative thoughts, pessimistic beliefs etc.). These specific outputs can in turn contribute to the synthesis of further models. Such a reciprocal cycle (called a Propositional-Implicational cycle) is said to be principal to "controlled tasks" such as the execution of complex or novel tasks. This theory therefore explicitly states that the

prolonged state of depression is associated with, and can in turn be caused by, a ruminative, self-perpetuating cycle which takes up a so-called "central engine" of cognition. Although this framework has been developed to understand depression rather than pain it is relevant to the first study in the thesis through its placing an emphasis on process as well as structure.

1.4.4 Evidence for schematic and conceptual processing in chronic pain

1.4.4.1 Schematic processing

The majority of research into chronic pain has tended to focus on conscious conceptual-verbal representations of pain. Studies exploring the role of schematic processing in pain has been scant in comparison.

The most powerful evidence for such schematic processing comes from phantom limb pains. In their review, Katz and Melzack (1990) present evidence which suggests that the majority of phantom limb pains are similar in quality to pre-amputation pain: pain which is experienced before, or at the time of, the amputation. Hence they do not appear to be pains arising simply from the new lesion of the amputation itself. In addition, Katz and Melzack found no relationship between measures of anxiety and depression, and the report of phantom pains which were similar to pre-amputation pains. They therefore argue that emotional disturbance does not appear to play role in the development of phantom pains. However they argue that the intensity and duration of pain experience prior to amputation does play a role because pains of a short duration but high intensity, and pains of a longer duration and lower intensity were both associated with the development of phantom pains. Because of this, and because the phantom limb pain continues in the absence of the painful 'limb', Katz and Melzack argue such evidence suggests that the pain is represented centrally (i.e. in the brain), and that emotional and cognitive states combine with somato-sensory 'memories' or 'pain

schema' to produce a unified lived experience of phantom limb pain. That is, that phantom pains are arguably the result of schema activation alone.

Other work on schematic representations of pain has looked for evidence of pain schema indirectly, through the effects of such schema on the processing of pain-related information. Schema-consistent information is thought to be processed more efficiently than schema-inconsistent information. The preferential recall of certain material is therefore considered to be evidence for the presence of a schema containing the material that is preferentially recalled. Research exploring recall biases towards pain-related material in chronic pain groups is discussed in more detail in Chapter 2.

1.4.4.2 Evidence for conceptual level processing in pain

The role of consciously accessible thoughts and beliefs in relation to pain have been widely studied, however, they tend to be explored in relation to pain-adjustment rather than pain-intensity. Definitions of 'adjustment' have varied. Disability is often viewed as a key outcome variable in chronic pain research and whilst it has been defined in a variety of ways, in an effort to standardize the meaning of the term the World Health Organization (WHO, 1980) have offered the following definition. They define disability as:

> "Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being"

where impairment refers to:

> "Any loss or abnormality of psychological, physiological or anatomical structure or function"

The term 'handicap' is defined as:

> "A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex and social and cultural factors) for the individual."

The definition of disability offered by the WHO centres on people's ability to perform activities, and hence, as Johnson (1997) points out, defines disability in behavioural terms, i.e. in terms of what people can do. However, disability, or what people can do, is not necessarily the only outcome variable of interest in pain research. Jensen *et al.* (1991), for example, use the term 'adjustment' and define it as an "ability to carry out normal physical and psychosocial activities" (Jensen *et al.*, 1991; p. 250). Included under this term are people's psychological wellbeing, including feelings of depression, and not just people's ability to carry out particular activities.

Banks and Kerns (1996) offer a more detailed list of factors which could constitute adjustment outcomes. In their discussion of the relationship between chronic pain and depression, they outline the difficulties that may accompany pain. They argue that whilst the losses associated with chronic pain can be those of loss of actual bodily function ('impairment') and/or those of an inability to carry out certain activities ('disability'), there are also what they term 'secondary losses' associated with pain. Under these they list difficulties in relationships such as martial, family and social relationships, financial difficulties and uncertainty about the future. They also list: "body integrity, youth and vitality, self-concept, self-esteem, and family role", and argue that: "Pain may also inflict psychophysical loss in terms of sleep deprivation and accompanying mood disturbances." (Banks and Kerns, 1996; p.104). Whilst some of these clearly relate to roles and hence would appear to fit under the term 'handicap', Banks and Kerns do not categorize them as such, and hence they do not appear to categorize roles and mood disturbances as coming under any of the distinctions outlined by the WHO.

Within cognitive psychological models, the relationship between impairment and adjustment is seen as mediated by factors such as attitudes, beliefs, control cognitions, coping strategies and emotions (Johnson, 1997). For example, distorted

beliefs about one's ability to do things (self-efficacy beliefs), and/or beliefs about pain causing further damage or impairment (e.g. McCracken, Zayfert and Gross, 1992) have been seen as contributing to disability.

In their review of coping with chronic pain, Jensen, *et al.* (1991) point out that chronic pain:

"is not synonymous with disability and depression"(p. 249),

and point to a need to identity factors which promote adaptive functioning.

However, there are a wide variety of ways to conceptualize and hence measure beliefs and thoughts about chronic pain (Gamsa, 1994b; Jensen *et al.*, 1991). In their extensive review of the role of beliefs in adjustment to pain, Jensen *et al.* (1991) classify beliefs into seven categories: beliefs about general locus of control, beliefs specifically about control over pain, attributional style, cognitive errors, self-efficacy beliefs, outcome expectancies and other pain appraisals. Jensen *et al.* (1991) do not explicitly use the term 'illness representations', or 'illness schema' (terms which are used in this thesis and discussed in more detail in Chapter 5) although such terms refer to beliefs about illness *per se*, as opposed to more general beliefs, unrelated to a specific illness. Illness schema therefore include beliefs such as beliefs about one's ability to control the pain, attributions about the cause of pain, and pain appraisals which relate to its cause, possible cure, its time-line and its consequences. Whilst some of these beliefs have been linked with pain severity, such as self-efficacy beliefs and cognitive distortion, (Jensen *et al.*, 1991) the majority relate to measures of pain-adjustment.

Jensen *et al.* define 'beliefs' as cognitions (thoughts) patients have about their pain problem. Beliefs are thought to influence adjustment to pain in two ways. Firstly through their direct influence on mood, for example, thoughts which focus on the negative aspects of pain and one's inability to control aspects of pain are thought to lead

to depression (e.g. Beck, 1970; Seligman, 1975; 1992). Also thoughts about pain are thought to influence adjustment indirectly through their effect on coping (Lazarus and Folkman, 1984). For example, one's belief in the ability to do something may lead to it being done (e.g. exercise) and thereby aid the process of coping with and hence adjusting to pain. One of the more consistent findings in the literature appears to relate to feelings of control both over the pain specifically and over life more generally. High levels of belief that one has control either over one's health or one's pain has been associated with lower levels of pain intensity (Skevington, 1983), lower levels of depression (Rudy, Kerns and Turk, 1988), higher reported use of 'active' coping strategies (Harkapaa, Jaervikoski and Vakkari, 1996; Gibson and Helme, 2000) and higher levels of compliance with treatment (Harkapaa, Jaervikoski, Mellin, Hurri and Luoma, 1991). For example, Crisson and Keefe (1988) demonstrated that a belief that one's pain severity was due to chance was associated with greater psychological distress and feelings of helplessness. In addition, Rudy *et al.* (1988) found that higher perceived life control mediated the relationship between pain intensity and depression, such that those pain sufferers with higher feelings of life control were less likely to feel depressed in the face of having chronic pain. The concept of control also appears to be one which has validity across the age spectrum. In their study examining the concept of control in older pain patients, Gibson and Helme (2000) found that higher levels of belief in the ability to control pain was associated with the use of active pain coping strategies and higher levels of pain and depression. However, other evidence suggests that the role of beliefs in pain adjustment may be moderated by levels of pain severity. For example, Jensen and Karoly (1991) showed that belief in control over the pain was associated positively with *activity* levels but only for those patients reporting relatively low pain levels; however, the link between belief in control over the pain was found to be positively associated with good *psychological* functioning *regardless* of pain levels.

Following the theories of Abramson, Seligman and Teasdale (1978) and Beck respectively, evidence of attributional style and cognitive errors/distortions have been linked to depression in chronic pain suffers and evidence for these are discussed more fully in Chapter 5. Self-efficacy beliefs, which refer to a person's belief in their ability to perform a specific behaviour, have also been associated with adjustment. For example, a significant relationship has been demonstrated between high self-efficacy and enhanced work status, increased exercise level and reduced medication usage following cognitive-behavioural psychological therapy (Dolce, Crocker and Doleys, 1986). Self-efficacy beliefs have also been associated with the use of coping strategies such that higher beliefs in the ability to do use different coping strategies has been positively associated with the use of such strategies to cope with the pain (Jensen, Turner and Romano, 1991).

Outcome expectancies refer to expectancies about the consequences of engaging in specific actions. Following the principles of learning theory, behaviours which are typically followed by positive outcomes are thought to be more likely to be executed than behaviours which are typically followed by negative outcomes. Research conducted on this relationship has provided evidence of a weak association between outcome expectancies and behaviours. For example, Council, Ahern, Follick, and Kline (1988) found that beliefs about the effects of performing certain actions on pain severity were associated with performance of those actions such that people expecting more pain to arise from a particular action were less likely to perform it. Jensen *et al.* (1991) suggest that this relationship falls to non-significant when self-efficacy is entered into the equation. Council *et al.* (1988) have suggested that outcome expectancies affect self-efficacy beliefs which predict activity, hence self-efficacy the belief in one's ability to perform certain actions mediates the relationship between outcome expectancies and behaviour.

Cognitive psychological treatments for chronic pain have focused on altering cognitive mediators, such as beliefs and thoughts about the pain, and provide some test of the causal relationship between psychological factors and pain. However, whilst Leventhal and Everhart (1979) propose that change at the conceptual level should alter pain intensity, the evidence in support of this relationship is mixed.

Many outcome studies into psychological treatments for pain point to the role of thoughts and beliefs in pain sufferer's *adjustment* to pain, rather than as altering pain per se, as reflected in improved measures of mood, activity levels and subjective reports as to the extent pain interferes with daily life (e.g. Skinner, Erskine, Pearce, Rubenstein, Taylor and Foster, 1990). However, some studies have demonstrated reductions in pain intensity as well (e.g. Flor, Fydrich and Turk, 1992) and in a recent systematic review and meta-analysis of randomised controlled trials of cognitive-behavioural and behavioural treatments Morley, Eccleston and Williams (1999) argue that there is evidence that cognitive-behavioural therapies are effective in producing changes in pain intensity, along with changes in negative mood and cognitive coping strategies in comparison with a waiting list control.

1.5 OTHER CAUSAL MODELS OF CHRONIC PAIN

The Gate Control Theory of pain appears to lend itself to cognitive theoretical models of pain, however there are a number of psychological models of pain which have been forwarded to account for the role of psychological factors in chronic pain and these include psychodynamic, biochemical and behavioural (Gamsa, 1994a; 1994b). These models vary in terms of whether they offer an understanding of the continuation of pain *per se* or pain-related disability, and suggest different types of treatment for pain. As it is the cognitive approach to understanding pain which is adopted in the present thesis, the other theoretical approaches will only be discussed briefly.

1.5.1 Psychodynamic models

Psychodynamic models consider pain which has no apparent physical basis to be a physical expression of 'emotional pain'. In models of this type, pain is thought to indicate the presence of unresolved, unconscious, emotional conflict. Consistent with this view, the presence of pain has been attributed to a variety of problems such as masked depression, guilt and resentment (see Gamsa 1994a). Two of the principal theorists offering psychodynamic accounts of pain are Szasz (1957) and Engel (1959). Szasz (1957) proposed that feelings are projected onto the body in the same way that they are projected onto other people. This projection of emotions onto the body was seen as serving a variety of possible functions such as denying or minimizing the experience of loss through the substitution of pain for feelings of grief.

Engel (1959) similarly viewed pain as serving an emotional function but his unique contribution was the suggestion that the early childhood experiences of pain lead to the development of a 'pain-prone personality'. The early experience of pain determines the meaning that pain comes to have for the individual sufferer. However, later on, these meanings can come to trigger pain in the absence of peripheral stimulation. Whilst this has clear parallels with cognitive models of pain such as Leventhal and Everhart's, it is the function those meanings serve which distinguish the two approaches. In Engle's theory pain is seen to serve a psychodynamic function, whereby pain comes to have meanings such as atonement for one's guilt, or as a substitute for feelings of aggression or loss, and hence plays a role in dealing with psychic conflict, whereas the functions served by pain within cognitive models of pain do not posit such unconscious conflict.

Evidence to support psychodynamic models has been evaluated elsewhere (Gamsa, 1994a) and will not be discussed in detail here. However in summary, Gamsa argues that there is little systematic evidence to support psychodynamic theories of pain. For example, Gamsa concludes:

> "A critical analysis of the published literature shows that attempts to distinguish pain of psychological origin from pain due to physical causes have not been successful" (p. 21).

Whilst Gamsa concedes that Engle's theory receives some support in explaining pain, this evidence is viewed as extending only to a subgroup of pain sufferers (Adler, Zlot, Hurny and Minder, 1989), and she argues that there is little evidence that it applies to the general population of pain patients. Despite this, Gamsa points out that psychodynamic theories spawned a variety of work which explored the role of psychosocial variables in the etiology of chronic pain, including factors such as the role of depression, problem in family relationships and as such raised the profile of the role of psychological factors in chronic pain.

However, psychodynamic models promote the distinction between pain which is caused by psychological factors and that caused by physical factors and hence the distinction between psychogenic *vs.* organic pain. The current dominance of models which allow for the possibility that both organic and psychogenic factors can mutually interact to produce 'pain' renders the distinction between organic and psychogenic pain largely redundant. For example, Melzack and Wall (1996) state:

> "It is clear that we must recognize the psychological contribution to pain, but we must maintain a balanced view of it. The term 'psychogenic' assumes that medical diagnosis is perfect, that all organic causes of pain can be detected; regrettably, we are far from such infallibility" (p. 31).

Although there are still some researchers willing to attribute primary status to psychological factors in the etiology of chronic pain, there is considerable evidence that psychological disturbances such as hysteria, depression, anxiety and hypochondriasis are a consequence rather than a cause of chronic pain. For example, Sternbach (1974), and Sternbach and Timmermans (1975), reported a reduction in the subscale scores of the MMPI measuring psychological disturbance, following relief from chronic pain. In addition, Sternbach, Wolf, Murphy, and Akeson (1973) found that scores on these scales

were raised in chronic pain sufferers but not in acute pain sufferers, suggesting such factors do not play an etiological role. A number of studies have also demonstrated that pain is more likely to precede depression rather than follow it (e.g. Romano and Turner, 1985). In addition, Guest and Drummond (1992) have argued that emotional disturbance in chronic pain sufferers is influenced by a complex interaction of factors including lack of employment, financial insecurity and the psychosocial consequences of pain which might include isolation, activity limitation and lowered self-esteem.

1.5.2 Psychophysiological models

Psychophysical models assume that pain arises from physical changes that accompany psychological processes, such as emotions. Psychological states, such as stress, are thought to cause physiological changes which then give rise to pain. The physiological changes which have been explored within the pain field include muscle tension and vascular changes. For example, muscle tension has been suggested as a cause of tension headaches, low back pain and temporomandibular (TMJ) pain. Headache, low back and TMJ pain are all considered to be muscularskeltal and hence muscle activity via EMG has been recorded. Tension headaches have been associated with elevated frontalis electromyography (EMG), and low back pain with elevated paraspinal EMG. Migraine headaches, on the other hand, have been viewed as having either muscular or vascular cause (e.g. temporal artery blood flow).

Evidence for psychophysical models has been reviewed by Flor and Turk (1989). In brief, the results of such studies have produced mixed support for models of this kind. Some studies have found evidence that stress-related responding in headache patients was higher than that of controls, supporting the view that people with headaches showed more marked physiological reactions to stress than those without pain, whilst other studies have failed to find such a relationship. In addition, high variability in psychophysical response is a frequent finding in research of this kind and so theories

positing higher stress-related physiological responding in chronic pain patients may apply only to a subset of those with pain (Flor and Turk, 1989).

In general, this type of model has been criticized because it reduces the understanding of pain to physical processes alone, and, as outlined above in section 1.2, current theorizing argues for the role of cognitive, affective and behavioural components in understanding pain (Melzack and Wall, 1965).

1.5.3 Behavioural models of pain

The behavioural model of chronic pain developed by Fordyce (1976) follows from the work of Skinner (1953). Fordyce's model is based on the premise that pain is only knowable by an observer through the behaviours emitted by the person with pain. The term 'behaviour' is used to refer to any actions which are observable, in contrast to cognitive events which may have no observable correlates. However, under the term 'behaviours', Fordyce cites not only facial expressions, posture and autonomic responses, but scores that pain sufferers give on visual analogue scales to indicate the amount of pain they are in (Fordyce, Roberts and Sternbach, 1985).

Fordyce argues that, because private experience is something which is not accessible to another person, research needs to focus only on that which is observable and therefore measurable. Furthermore he argues that a central reason for studying behaviours is that they are subject to reinforcement, such that behaviours which are reinforced (lead to some positive benefit) will continue, whilst behaviours which are either negatively reinforced or not reinforced either way will extinguish. This focus on the effects of emitting certain behaviours forms the basis of behavioural therapies which aim to reduce the amount to which pain behaviours are positively reinforced and thereby reduce pain behaviours.

Whilst Fordyce views acute pain as the automatic response to a stimulus (e.g. tissue damage) he considers that chronic pain may continue for a number of reasons, one

of which may be operant conditioning. Operant conditioning refers to the process whereby behaviours are shaped by the rewards (or punishment) that follow them. Pain behaviours which are followed by a reward are thought to continue by virtue of the reward they elicit, and discontinue by virtue of the punishment or lack of reinforcement that follows. Hence pain behaviours are thought to continue because of the secondary gain they afford, for example, relief from unpleasant chores and attention from family members.

In support of this model, there is evidence that pain behaviours do increase and decrease depending on the amount of positive and negative reinforcement respectively, and treatment programmes based on the principles of operant conditioning have shown decreases in pain behaviours following the reduction of positive reinforcement (Fordyce *et al.*, 1985). However for Fordyce, pain is not synonymous with pain behaviours. Hence behavioural therapies do not aim to reduce pain *per se*, which he refers to as having antecedents in "noxious stimuli generating injury signals" (Fordyce *et al.*, 1985; p. 115), but rather aims to reduce "excess disability and expressions of suffering" (Fordyce *et al.*, 1985; p. 115). Behavioural therapies therefore aim primarily to improve function (disability) and whilst pain reduction may follow behavioural modification, such a change is considered incidental and as occurring through factors such as the strengthening of muscle and other body parts. Hence this approach aims to reduce the gap between impairment and disability (see section 1.4.4.2 for definitions of these terms).

In summary, Fordyce argues that the cause of pain behaviours is multifactorial. He argues that pain is primarily the result of nociception, but that adverse effects arise through the non-use of muscle/body parts, and from environmental reinforcers which reinforce pain behaviours. However, whilst there is evidence that behavioural programmes can be effective in reducing medication and increasing exercise levels, there is debate about which aspects of treatment are efficacious and whether it is really

the behavioural aspects which lead to positive changes (see Linton, 1982). Furthermore such approaches have been criticized for not reducing pain behaviours so much as making people more stoical about their pain.

1.6 ACUTE VERSUS CHRONIC PAIN

The definition of chronic pain currently rests primarily upon its duration: pain lasting for less than three months is considered acute, and pain lasting for more than three months, chronic. However, medical professionals often use greater flexibility in their diagnosis of pain as chronic, with some categorizing chronic pain as 'any pain that has lasted for longer than it should have' (Allan, personal communication). This ad hoc definition allows for context specific judgements to be made which take into account the nature, location and cause of the pain and the typical time-line that that sort of pain usually displays.

The distinction between acute and chronic pain has sometimes been understood as reflecting qualitatively different types of pain and it has certainly been used as a basis for offering different types of intervention. Typically, acute pain has been viewed as pain which is most appropriately treated within a biomedical framework (e.g. with medication and bed-rest) whilst chronic pain has been viewed as a more complex problem than acute pain and more suited to psychological intervention. Karoly (1985), for example, notes that:

> "The complex, interactive processes that modulate pain appear less likely to be invoked in discussions of acute pain (which is, therefore, left to be dealt with in more or less traditional, "medicalistic" ways)" (p. 467).

In the case of chronic pain there has often been a similar omission of understanding psychological factors as central to the experience of pain; rather psychological factors have been hypothesized as producing 'overlay' on top of the pain. For example, Fordyce (1976) conceptualises chronic pain within a behavioural

framework whereby much of the disability associated with the pain (e.g. reduced activity levels, loss of work) is viewed as the result of learned pain behaviours which have been reinforced over time.

Qualitative differences between acute pain and chronic pain sufferers have been explored, for example, by Keefe, Block and Williams (1980). They examined chronic pain sufferers following their first two months of treatment for pain through to two years later. They characterized the acute phase (0-2 months) as being one where patients were typically anxious, showing signs of heightened autonomic arousal, temporary decreases in activity levels and a reliance on medication and medical treatment. However, as time passed (2-6 months), whilst pain sufferers' autonomic arousal levels were still high, they were beginning to realize that their pain could not be controlled by medication. At this point some attempted to return to work. In what they described as the chronic phase (6-24 months), Keefe *et al.* (1980) found that autonomic arousal was typically reduced, and instead of being anxious, pain sufferers often became depressed. At this point, activities had often decreased permanently, including work loss, and the pain sufferers were characterized as preoccupied with bodily complaints. Hence Keefe *et al.* proposed that acute pain is characterized as associated with anxiety and active treatment seeking, whereas chronic pain is characterized as associated with depression and inactivity.

The transition from acute to chronic pain

Given the lack of understanding about why pain continues beyond the recognized healing time of three months, some research has begun to focus more on the development of chronic pain from an acute pain state.

The proportion of acute pain sufferers who continue to experience pain beyond the recognized healing time of 3 months has been reported as being between 20 and 40% (Radanov, Di Stefano, Schnidrig and Sturzenegger, 1993; Philips and Grant, 1991). Being able to identify those who will continue to suffer pain and the evaluation

of early interventions to prevent developing chronicity is clearly of clinical and economic value. Gervais, Dupuis, Veronneau and Bergeron (1991), for example, estimated that identification of and intervention for patients at risk from continued work disability following one episode of compensated low back pain could save up to 396 Canadian dollars per patient per year.

In a longitudinal study, Philips, Grant and Berkowitz (1991) identified several measures at baseline (i.e. taken an average of 15 days after an initial attack of pain), which predicted the presence of pain at 3 months. These included pain located in the upper back, higher baseline levels of pain, more negative cognitive reactions to pain and higher anxiety. However, the only baseline variable predicting the presence of pain at 6 months was pain intensity at baseline.

Whilst considerable changes may take place over the initial three month period following pain onset, Philips and Grant (1991) conclude that the pattern of change over longer periods, e.g. six months, reflected the persistence of an acute pain state that fails to extinguish, rather than the growth and development of a chronic pain state (as hypothesized by Fordyce and presented by Keefe *et al.*, 1980). Indeed Philips and Grant argued that many of the changes observed over the first three months represented adaption to the pain. For example, they found that the *highest* degree of discordance between measures of perceived disability and pain intensity were recorded at baseline, with the lowest degree of discordance occurring at 3 months, reflecting positive adjustment to the pain over this time with relative stability in measures taken between 3 and 6 months.

This result could be interpreted as suggesting that the development of chronicity critically depends on the pain sufferer's initial response to the pain, rather than the development of maladaptive coping strategies occurring over subsequent weeks. An equally viable interpretation could be that maladaptive changes take longer to develop

and emerge after 6 months, taking a major role in the chronic pain disorder once it has become established rather than playing a role in its development *per se*.

Hellsing, Linton and Kalvemark (1994) conducted a community based investigation into people reporting acute back and/or neck pain and conducted a prospective study to examine which factors predicted development of chronicity. They found that there was no difference between those who went on to develop chronic pain and those who did not, in terms of age, amount of pain or functional impairment. However they did demonstrate that the risk of developing chronic pain was fives times higher:

> "for those patients whose pain was provoked by trunk movements in several directions at the first clinical examination" (p. 116).

which suggests that the type and extent of initial damage might be crucial.

Whilst there are likely to be factors involved in long-term pain which are irrelevant for acute pain, particularly in terms of life-impact, it is not necessarily the case that chronic pain is in need of greater explanation than acute pain. It seems that the reasons why pain continues beyond the recognized healing time of three months is as much a mystery as why pain disappears *before* three months. Hence a deeper understanding of pains of all types and duration could be valuable in understanding chronic pain.

1.7 MEASURING PAIN

Following the Gate Control Theory, pain is now widely considered to be a multidimensional phenomenon. Karoly (1985) has argued that the Gate Control Theory permits pain to be viewed as a multidimensional experience involving sensation, emotion, cognitive evaluation, and behavioural response. As such, the potential for measuring aspects of pain is to some extent unlimited, potentially involving physiological measures, sensory, affective, behavioural, cognitive and lifestyle impact

measures (see Williams and Erskine, 1995 for a review of some of the available measures).

Melzack and Wall (1996) themselves state that:

> "Pain in man comprises two components - behaviour and conscious experience - which can both be measured with appropriate tools" (p. 124).

Whilst this distinction appears reasonable to some extent, it cannot be considered a clear-cut one. What might count as the *beginning* of behaviour and the *end* of conscious experience is debatable and implies a mind-body dualism that certain researchers attempt to transcend (e.g. Turner, 1992).

In addition to a sensory and affective component, Melzack and Wall argue that there is a third 'evaluative' dimension to pain, and the McGill Pain Questionnaire (MPQ; Melzack, 1975) has been developed to measure these three facets of the subjective pain experience. This questionnaire contains groups of pain descriptors of increasing intensity, which fall into three broad categories: those reflecting the sensory qualities of pain (e.g. stabbing, sharp); those reflecting the affective qualities of pain (e.g. fearful, cruel); and those reflecting the evaluative response to pain (e.g. miserable, troublesome).

Whilst this three-way distinction makes theoretical sense, in factor-analytic studies of people's word selection from the MPQ, the sensory- affective distinction has been supported more than the idea of a third distinct evaluative dimension. Although this sensory-affective distinction may be supported, it is hypothesized to reflect pre-conscious dimensions of pain reflecting the fact that pain is an inherently unpleasant sensation. However, it is unclear to what extent people's responses on the McGill reflect more of a sensory-evaluative distinction, in that people select the sensory words to describe their pain (a unitary phenomenon, e.g. throbbing, scalding) and the affective words to describe their evaluation of that pain, i.e. how it feels to experience pain (e.g. distressing, horrible etc.).

1.7.1 Measuring subjective pain intensity.

The models of both Melzack and Wall, and Leventhal and Everhart propose that pain comprises numerous dimensions but that it is consciously experienced as a unitary phenomenon. It is frequently this experience of pain that is measured in research, and usually the intensity of this experience which is of interest. Whilst pain measurements can include verbal and numeric self-rating scales, behavioural observations, and measures of physiological response, because pain is primarily considered to be a subjective experience, self-report scales are considered to be the most valid (Katz and Melzack, 1999) .

There are a variety of measures that can be used to measure subjective pain intensity, ranging from numeric rating scales to verbal rating scales. The numerical rating scales are typically 11 or 101 point scales anchored at two extremes of pain intensity. The most commonly used verbal rating scale (included on the McGill Pain Questionnaire) consists of five descriptors: mild, discomforting, distressing, horrible, excruciating.

Jensen, Karoly and Braver (1986) compared six different methods for measuring subjective pain intensity, including both Visual Analogue Scales and Verbal Rating Scales. They concluded that in terms of both utility and validity all six methods were comparable. More recently, Jensen and McFarland (1993) conducted a study into the reliability and validity of pain intensity measurements in chronic pain patients and concluded that multiple pain measures should be used in studies being conducted on pain treatment, where changes in pain scores are important, but argued that:

> "the coefficients obtained (a stability coefficient of 0.63 and a validity coefficient of 0.74) indicate that a single (pain) measure may be useful in 'basic research' (i.e., examining the relationship between pain intensity ratings and other variables among large groups of patients)" (p. 200).

The measurement of pain is, however, far from straight forward, and some of the difficulties inherent in its measurement have been discussed recently by Williams, Davies and Chadury (2000). In a study examining the use of visual rating and numerical

rating scales, Williams *et al.* found considerable variability in how pain patients interpreted and responded to the task of providing ratings of their pain. For example, in providing ratings of pain, patients often placed a primary emphasis on the extent to which the pain upset their ability to do things, although there was lack of consistency both within and between patients in how they set about providing a rating of pain. On the basis of their findings Williams *et al.* argue that pain ratings cannot be seen as a simple mapping of an internal stimulus to a rating scale but rather as "an attempt to construct meaning" (p. 457) as the patient interprets the end points of the scale in relation to a range of factors which included understandings of their own pain and other people's perception of the pain rating they were about to give. Williams *et al.* have also questioned the psychometric properties of pain scales such as the VAS as their findings suggest that the VAS may not be used by patients as though it is a uniformly linear scale. However, whilst their paper points to potential sources of error in pain measurement, no clear solutions to this problem are provided, although a call for further research in this area is made. Clearly caution must be used in interpreting findings based on VAS assessments of pain intensity, although, with the exception of Study 3 (Chapter 5), pain measures are only used in this thesis to confirm the group status of the participants (i.e. whether they are pain patients or non-pain controls) and so this issue will not be discussed further in the thesis.

1.7.2 Memory and measurement

A key issue in the measurement of pain and pain-related constructs, is the role of memory and its affect on measurement accuracy. This issue has been reviewed in detail elsewhere (Erskine, Morley and Pearce, 1990). In brief, findings are mixed as to the role of pain intensity and mood on recall accuracy of previous pain experiences. For example, it has been demonstrated that chronic pain sufferers frequently over-estimate their pain when asked to recall it (e.g. Linton and Melin, 1982). However, other

evidence suggests that, rather than a general tendency to overestimate previous pain, it is present pain intensity levels that affects recall accuracy in chronic pain sufferers. For example, Eich, Reeves, Jaeger and Graff-Radford (1985) showed that high present pain intensity was associated with overestimation of pain whereas low present pain intensity was associated with underestimation of pain. There is also mixed evidence as to the role of mood on recall accuracy. Although anxiety has been linked to poor recall of pain intensity in dental patients (Kent, 1989), Linton (1991) demonstrated that there was no evidence of a relationship between depression and accuracy of pain intensity recall in chronic pain sufferers.

Erskine *et al.* (1990) point to a number of factors which may affect recall accuracy, and these include whether the pain is intermittent or continuous, the particular mood state being experienced at the time (anxiety or depression), and the aspect of pain experience being examined, pain intensity or pain-distress. What seems clear is that recall for pain intensity is frequently inaccurate, and hence reliance on memory in pain measurement should be reduced and present pain intensity measures used wherever possible.

Chapter 2

An Exploration of the Role of Retrieval Inhibition in the Pain Related Recall Bias Demonstrated in Chronic Pain Sufferers.

2.1 INTRODUCTION

The first study in the thesis aimed at exploring schematic levels of processing in chronic pain sufferers. In particular it aimed to explore why pain schema might dominate cognitive processing in chronic pain sufferers through the exploration of a possible mechanism responsible for the preferential selection of pain schema and hence pain meanings: failure of retrieval inhibition.

The preferential interpretation and recall of pain-related material has been viewed by previous researchers as demonstrating the presence of a pain-related schema. However, the presence of an elaborate schema relating to a particular topic is not necessarily sufficient to explain the role that same schema might take in dominating information processing. The concept of 'dormant schema', for example, has been invoked to explain the absence of information processing biases in recovered depressives. This concept refers to the idea that schema exist but are not playing an active role in the processing of information. The first study in this thesis therefore aimed to explore a potential candidate responsible for the preferential activation of pain schema in chronic pain sufferers.

As noted in Chapter 1 (section 1.4), the role of cognitive processes in chronic pain has tended to focus on what Leventhal and Everhart refer to as the conceptual level, whilst research aimed at exploring the schematic level of processing in chronic pain has been scant in comparison. However, the study of the schematic level in emotion has been considerable and it is a body of work that pain research aimed explicitly at addressing the schematic level has drawn on. This chapter therefore outlines the

information processing biases that have been associated with pain, depression and anxiety, examines theoretical accounts of these findings, and then presents the rationale for the first study.

2.1.1 Information processing biases in chronic pain sufferers

Schema are thought to influence the perception, interpretation and recall of information (e.g. Neisser, 1966). As noted in Chapter 1, Leventhal and Everhart (1979) argue that pain schema can act to continue the experience of pain *per se* through their interpretation of sensations as painful and the activation of pain memories. Because schema-consistent information is thought to be preferentially processed in comparison with non-schema consistent information, evidence for an elaborate pain schema in chronic pain sufferers has been sought through an analysis of their attention to, interpretation of and memory for pain-related information, and the degree to which pain-related material is preferentially processed. To date, research suggests that pain schema may act to bias the interpretation of, and memory for, pain-related material.

2.1.1.1 Pain and memory

Pain schema are typically viewed as abstract representations of prior pain experience which are used in the processing of information, such as physical sensations and verbal material. At present, the research that has been carried out on information processing biases in chronic pain patients points to the existence of recall biases which are specific to sensory pain information and which typically occur only on explicit memory tasks. Importantly, these recall biases seem to exist independently of the depressive and anxiety states that frequently accompany the experience of pain.

The preferential recall of sensory-pain words has been demonstrated in non-depressed chronic pain patients in comparison to pain-free controls (Edwards, Pearce, Collette and Pugh, 1992; Pincus, Fraser and Pearce, 1998). In addition these recall biases have been demonstrated in competition with different word types. For example,

Edwards *et al.* (1992) found that chronic pain patients preferentially recalled sensory pain words above two other word types: affective-pain words and neutral words, and Pincus *et al.*, (1998) found that chronic pain sufferers preferentially recalled sensory-pain words above three other word types: affective-pain, positive and neutral words. In chronic pain sufferers who were classified as depressed on the basis of their Beck Depression Inventory (BDI) scores (Beck, Rush, Shaw and Emery, 1979), a recall bias was not demonstrated toward any of three word types (sensory-pain, affective-pain and neutral), although the pattern of results suggested a tendency for them to recall both more sensory-pain and more affective-pain words than neutral words, although this was not significant (Edwards *et al.*, 1992). However, depression-related recall biases towards depressive, rather than affective-pain, words have been demonstrated in depressed chronic pain sufferers. These studies show some evidence that depressive-related recall biases in chronic pain patients may differ from those demonstrated in non-pain depressives. For example, Pincus, Pearce, McClelland and Isenberg (1995) found that depressed chronic pain sufferers preferentially recalled negative material that was pain-related (e.g. words such as 'disabled' and 'vulnerable') in contrast to negative material unrelated to pain, and they interpreted this as evidence that depression in chronic pain patients may be qualitatively different from that in depressed patients who are pain free. Clemmey and Nicassio (1997) found similar evidence for negative illness self-schema in depressed rheumatoid arthritis (RA) patients in comparison with non-depressed RA patients. They found that depressed RA patients used negative self-descriptions and demonstrated recall biases towards negative health-related words such as 'ill' and 'weak'. In contrast, the non-depressed RA patients demonstrated biases towards positive self-description and enhanced processing of positive illness-related information (such as 'healthy' and 'strong'). Clemmey and Nicassio (1997) argue that the presence of such negative illness self-schema could result in the biased processing of bodily sensations

which are interpreted as disabling and thereby contribute to illness-related disability and hence argue that schematic processing may contribute to pain-adjustment.

In a study looking at recall biases in osteoarthritis patients, Calfas Ingram and Kaplam (1997) examined information processing biases in relation to affective distress in chronic pain (measured using the BDI). Because they were examining patients who they thought would be subclinically depressed, they chose words they thought would access the self-relevant schema were meant to reflect this. Hence they used words such as 'troubled' and 'unhappy'. Using three word types: state depressed (e.g. 'sad'), trait depressed (e.g. 'inferior') and non-depressed (e.g. 'pleasant'), they found those with high levels of affective distress recalled more state-depressed and trait-depressed words than the non-affective distress group. However this difference between the groups only emerged when the 'distressed' pain group were defined on the basis of their scores on the BDI omitting the somatic items. They therefore concluded that "depressive cognitive structures appear to be better differentiated by a nonsomatic measure of depressive symptomatology for pain patients." (p. 580). The content of depressive schema in pain patients therefore appears to vary and in particular appears to relate more to concerns about disability and illness rather than feelings of failure and hopelessness.

Although neither study explicitly manipulated self-referential encoding, the studies by Clemmey and Nicassio (1997) and Calfas *et al.* (1997) have also demonstrated that recall biases are often specific to information which is self-relevant. In research which has explicitly manipulated self-referential encoding, evidence has been found that both pain and depression-related recall biases in chronic pain sufferers may be specific to self-relevant material, and such results have been interpreted as supporting the presence of pain-related self-schema. In a study looking at self-referential encoding, Pincus, Pearce and McClelland (1993) asked participants to encode three different word types (sensory-pain, affective-pain, neutral), one set with reference to

themselves and one set with reference to another well-known fictional character. They found a recall bias in pain sufferers for sensory-pain words but only when the words were encoded with reference to themselves and not when they were encoded with reference to someone else. A self-referential encoding bias was also demonstrated by Pincus *et al.* (1995) towards negative pain words in depressed pain sufferers but again only when a 'self' and not an 'other person' encoding strategy was used.

Such self-referential encoding biases suggest that encoding pain and depression words with reference to oneself (when one is a pain sufferer) has particular salience and mnemonic power. However, specific explanations for the self-referential encoding effect have varied. Some researchers, such as those noted above, have interpreted it as evidence for a self-schema which enhances the encoding and retrieval of self-schema congruent information, whilst others have argued that the advantage in the self-referent condition is due to the high constraint on encoding processes obtained by asking people to encode with reference to themselves. Evidence to support this latter interpretation comes from studies which have shown that if the encoding process is similarly constrained, for example, by asking people to make the judgement "A part of the body?", recall for such material is enhanced to comparable levels as in the self-reference condition (Klein and Kihlstrom, 1986). Regardless of the specific interpretation, however, these findings suggest that not all pain-related material is easier to access and that encoding strategies may influence whether pain-related material is preferentially retrieved or not. These studies also provide evidence for the view that the recall bias cannot be explained solely in terms of a frequency effect, (i.e. arising from the fact that pain sufferers use pain-related words and concepts more frequently than non-pain sufferers) as a pain-related recall bias should be demonstrated regardless of the way in which the material is encoded.

In addition to recall biases on explicit memory tasks, a tendency for pain sufferers to interpret ambiguous homophones as pain-related has also been demonstrated (Pincus, Pearce and Perrott, 1996). However, no preferential recall bias towards pain words has been demonstrated in chronic pain sufferers using cued recall, or using a stem completion task. The latter is usually consider as a task that taps implicit memory (Williams *et al.*, 1997; Pincus, 1993). Implicit memory tasks require the participant to undergo a procedure which does not require them to explicitly remember material previously presented to them. Instead, their demonstration of having remembered words lies in their performance on completing a stem with the first word that comes to mind. Implicit memory is indexed by the tendency to complete stems with words they have already seen, over and above a random level. Furthermore, no evidence has been found for a recognition bias towards pain-related words in chronic pain patients (Edwards *et al.*, 1992) and possible explanations for this are discussed in section 2.1.2.

2.1.1.2 Pain and attention

Studies on the effect of chronic pain on information processing biases in attention have, to date, used two types of attentional paradigms: the visual-dot probe paradigm and the emotional Stroop. Results have been mixed and there is some debate as to whether the attentional biases that have been found in chronic pain patients towards pain-related stimuli relate to the presence of pain or the presence of anxiety which may be linked to pain. In the emotional Stroop task, participants are presented with a variety of word types (e.g. pain and non-pain words) which are printed in different coloured inks. The task is to name the colour ink. Attentional distraction or interference caused by the words *per se* is indexed by the delay in naming the colour ink. Hence slower colour naming for pain-related words compared with non pain-related words is interpreted as evidence for a selective attentional bias towards pain words. The Stroop paradigm has been used to study whether attentional biases towards pain-related words are evident in pain patients. Pearce and Morley (1989) found that pain patients

showed increased interference in the colour naming of pain-related words compared with non-pain controls, and not for general negative words. Whilst Pincus *et al.* (1998) have argued that this attentional bias may only relate to pain patients who are anxious, more recently, Crombez, Hermans and Adriaensen (2000) have demonstrated a pain-related attentional bias on a Stroop task whereby pain patients were found to have an attentional bias towards sensory-pain words which in regression analyses was related to current pain intensity rather than pain-related fear, pain catastrophizing or negative affect. However, the ability of the Stroop paradigm to tap attentional rather than response biases has been questioned (Williams *et al.*, 1997) and the Visual Dot Probe task has been argued to be a purer measure of attentional biases. In this task two words are presented simultaneously in two fixed positions on the screen. One of these is followed by the presentation of a dot and the participant has to indicate which side of the screen (left or right) the dot has appeared. If attention has been attracted by a particular word then, if the dot follows that word, the response will be relatively quick, whereas if the dot follows the other word the response will be relatively slow. Attentional distraction specific to pain words in chronic pain patients is therefore indexed by the speed with which participants correctly identify which side of the screen the dot has appeared and whether this is speeded up when the dot follows a pain word or slowed down when the dot follows a non-pain word and a pain word has appeared on the opposite side of the screen. Studies using this paradigm suggest that attentional biases in pain may relate to degree of fear about pain rather than the presence of pain *per se*. For example, Asmundson, Kuperos and Norton (1997) examined the role of fear of anxiety symptoms in patients with chronic pain and found an attentional bias towards pain-related words using the visual dot probe task. Similarly, Keogh, Ellery, Hunt and Hannent (2001) demonstrated an attentional bias toward pain-related stimuli among pain fearful individuals, although this was among a normal population rather than a chronic pain group, they argue their results suggest that preferential attention towards

pain-related material is not just associated with chronic pain states but occurs in healthy individuals. This attentional bias might be one which predisposes healthy individuals to react more negatively to pain and represent a vulnerability factor in the development of a chronic pain state.

Studies examining attentional processes and pain have tended to use external (word) stimuli which may be more relevant to anxiety (and where perceptual biases for threat-related words have been found), rather than internal (physical) stimuli which may be more relevant to chronic pain and where attentional biases may yet be found. In addition, the concept of 'attention' is clearly a very broad one. Attentional processes vary in terms of whether they relate to automatic or controlled processes. For example, orientation towards a particular spatial location is a relatively automatic, and hence non-resource demanding process, whereas sustaining attention on a given task is more of a controlled process requiring attentional resources. Furthermore, attention can play a role in the selection of thoughts and actions, as, for example, in the model of attentional control put forward by Norman and Shallice (1986), and yet the role of attention in thought selection in pain has not been addressed, and attentional biases of this kind may well exist.

Research on attention and mood has tended to focus on automatic effects on attention, rather than on more strategic or effortful aspects. Exceptions to this include work by Eccleston and Crombez who have explored the role of pain and pain-related fear in affecting the performance of attentionally demanding tasks. For example, Eccleston (1995) has shown that high levels of pain intensity interfere with complex, attentionally demanding task performance, and Crombez, Eccleston, Baeyens, van Houdenhove and van den Broeck (1999) have shown that high levels of pain intensity combined with high levels of pain-related fear predict interference in performing attentionally demanding task. Such results have been interpreted as demonstrating the

'interruptive' function of chronic pain, i.e. the extent to which it captures attention (Eccleston and Crombez, 1999).

In summary, although schema are thought to be guide the perception, encoding and retrieval of information, the research findings noted above have shown that the preferential processing of pain-related information in chronic pain sufferers only occurs on certain tasks. Generally speaking, chronic pain is associated with information processing biases on effortful explicit memory tasks and not on implicit memory and attentional tasks in the absence of fear or anxiety symptoms. These findings mirror those found in the depression literature, although, compared to the very extensive research on memory and depression, research on pain and memory is in its infancy, and important differences may yet be found between the effects of depression on memory and those of pain. However, theorizing about information processing biases has focused around the findings that relate to anxiety and depression, rather than pain, and given the close parallels between the findings in the field of depression and pain, these theoretical accounts have been adopted to understand information processing biases in chronic pain sufferers (Pincus, 1993).

2.1.1.3 Information processing biases in depression and anxiety

The pattern of information processing biases in depression have been outlined in detail by Williams *et al.* (1997). In brief they show that depressed mood is associated with the enhanced recall of negative material presented as part of explicit memory tasks, such as free recall (Lloyd and Lishman, 1975; DeMonbreun and Craighead, 1977; Bower, Monteiro and Gilligan, 1978). In addition, manipulations both at encoding and retrieval have been shown to influence the demonstration of a negative recall bias. Negative recall biases specific to negative words which have been encoded self-referentially, compared to those encoded with reference to someone else, have been demonstrated (Bradley and Mathews, 1983). Also self-focused attention prior to recall

has been shown to moderate the negative recall bias found in depressed patients (Pyszczynski, Hamilton and Herring, 1989), such that a negative recall bias has been demonstrated in depressed participants but only following the self-focus and not the external-focus manipulation. Pyszczynski *et al.* (1989) argue that this result shows the bias resides somewhere in the retrieval process because it was focus immediately prior to recall that had an effect. However, such an effect can be seen as a result of mood-congruity, as self-focus has been associated with increases in negative mood (Scheier and Carver, 1977).

In contrast, recall biases using implicit memory tasks, e.g. stem-completion, have generally not been demonstrated in depressed participants (Denny and Hunt, 1992). There is also little evidence for a perceptual (e.g. visual attentional) bias towards negative information in depressives, and research that appears to have supported such a conclusion has generally failed to control adequately for the effect of anxiety (Williams *et al.*, 1997).

Anxiety, on the other hand, does not appear to be associated with recall biases toward anxiety-related information in explicit memory tasks (Pickles and van den Broeck, 1988; Mogg, Mathews and Weinman, 1987). Studies which have demonstrated a recall bias towards threat-related words in anxious participants, have been associated with high levels of depression and state anxiety rather than high levels of trait anxiety (Reidy and Richards, 1997). In contrast, implicit memory biases have been linked to anxiety (Mathews, Mogg, May and Eysenck, 1989). Whilst there has been some debate about whether particular tasks can be considered 'implicit' or 'explicit', and suggestions have been made that performance on so called 'implicit tasks' may include contributions from explicit and implicit memory (Jacoby, 1991), these results have generally been taken as supporting the differential role of different mood states on implicit and explicit memory.

Anxiety has also been associated with heightened perceptual screening of threat related information, which, it is argued, is then not properly processed, or processed no further. Such heightened perceptual screening has been demonstrated in lowered identification thresholds for, and increased perceptual orientation towards, concern-related information. For example, Parkinson and Rachman (1981) demonstrated lowered thresholds for identification of concern-related information compared to neutral information in women whose children were about to undergo an operation compared with women whose children were not. The concern-related words were ones relating to operations. In addition, MacLeod, Mathews and Tata (1986) have demonstrated increased perceptual (attentional) orientation towards anxiety-related words in comparison to neutral words, in anxious participants.

2.1.2 Theoretical accounts of mood-related recall biases: from structure to process

There are a number of theories that have been put forward to explain the effect of pain and mood on information processing biases, such as Bower's Network Theory of Affect and the schema theories of Beck (1970) and Leventhal and Everhart (1979). Whilst these theories can be successfully applied to interpret a number of the research findings, there are several major problems with them which have been discussed in detail by both Williams *et al.* (1997) and Teasdale and Barnard (1993). In brief, the most important of these is that anxiety and depression do not appear to have comparable effects on perception and memory, and neither Bower's Network Theory of Affect nor schema theories predict such asymmetrical effects. In order to account for these differential effects, Williams *et al.* put forward their Integrated model (discussed in section 1.4.2) which distinguishes between the processes of priming and elaboration. Whilst they adopted this distinction from Graf and Mandler (1984), in contrast to the latter, Williams *et al.* argue that the processes of priming and elaboration are

independent of one another. As a result they argue that these processes are differentially affected by different mood states, meaning that explicit memory biases can exist without implicit ones.

In their model Williams *et al.* argue that depression and anxiety do not affect memory and attention *per se* but affect automatic processing and strategic/ controlled processing. They propose that different mood states exert their effects on either or both of these types of processes, but that crucially, because the two types of processes are relatively independent of one another, different mood states can affect one or the other.

Automatic processes (e.g. implicit memory), are thought to be affected in anxiety and controlled ones (e.g. free recall), affected in depression. Williams *et al.* suggest that resources are deployed at different stages of information processing according to different mood states, and that, as a result, the recall bias towards negative information in depressed participants results from "the facilitated search for associated mnemonics at the elaboration phase" (Williams, Watts, MacLeod and Mathews, 1988; p. 175) whereas inhibition of such mnemonic search will result in reduced recall or 'cognitive avoidance'. Williams *et al.* suggest that the intentional recall of items involves the availability of mnemonic cues to help access the target information. These cues may be 'generated' at encoding or retrieval and it may be the case that different emotions vary in the extent to which the utilization or generation of such cues is facilitated or inhibited.

Whilst this model can explain the differential effect of anxiety and depression on information processing biases, it does not appear to offer an account of the flexible nature of such biases. Inflexibility is considered to be a problem with theories that invoke the concept of static structures such as schema, as Williams *et al.*'s model does. For example, once a pain or depressive schema has built up through experience there should be evidence that it biases information processing towards thematically-related

concerns on a permanent basis. However there is evidence that these effects disappear once the chronic pain or mood state has resolved (e.g. Edwards *et al.*, 1995). As noted in section 1.4.3, concerns about conceptual inflexibility inherent in accounts based on the notion of schema have been sufficient to prompt the development of a new framework: Interacting Cognitive Subsystems (ICS).

Teasdale and Barnard's framework (discussed in section 1.4.3) assumes it is the dynamic cycle between the Propositional-Implicational levels of information representation which generates the recall biases demonstrated in depression rather than the existence of a schema itself. Hence by emphasizing the dynamic nature of a system, this framework can account for the findings that there do not appear to be any fixed or 'trait' differences in dysfunctional attitudes between recovered depressives and non-depressed people (Teasdale, 1988). In addition, there is evidence that differences in dysfunctional attitudes only become apparent in mild mood states. For example, Teasdale and Dent (1987) reported that in mild mood states, recovered depressives differed from controls in measures of accessibility (recall) for trait adjectives encoded self-referentially. Also, Williams *et al.* (1997) reported it was not the measure of negative self-view taken in a normal mood that predicted later depression but the change that occurred in this measure from normal to mild mood state. This suggests that the *state* of emotion interacts with and generates *trait* factors (e.g. dysfunctional attitudes) to produce a situation whereby the individual is vulnerable to the development of a vicious cycle with mood and negative thoughts interacting and hence maintaining the emotional disorder.

The mood generating system, (the Implicational-Propositional loop), becomes interlocked in the generation of meanings, both implicit (Implicational) and explicit (Propositional), which relate to depressive themes. This loop also generates descriptors which serve as cues to accessing memories and which clearly favour the retrieval of

depressive memories. Hence in their framework, Teasdale and Barnard state that the recall bias is a by-product of the mood generating system.

Using a more dynamic model may also incorporate the role of cognitive resource deficits in information processing biases (discussed in more detail in sections 2.2.1.4 and 2.2.3.4). For example, in the ICS framework it is assumed that the mood generating system occupies the 'central engine' of cognition. Although Teasdale and Barnard explicitly state that they do not postulate a separate attentional system (e.g. Central Executive or Supervisory Attentional System), the Implicational-Propositional loop is seen as having a similar role to such a system. If it is occupied in the generation of emotion, and involved in processing material with a particular thematic content, it may be less able to deal with alternative material. However, explicit hypotheses cannot easily be generated from the ICS framework. Nevertheless, it raises important points about considering not just whether there is evidence for trait schematic factors in information processing biases but potential processes which may lead to schema generation or selection. Hence, recent theorizing in recall biases in depression seems to have moved away from according primary status to *structures* (e.g. semantic networks and schema) towards placing primary emphasis on *processes* such as a mood-generating system, a shift which is also echoed in the literature on concepts and concept formation (Smith and Jones, 1993).

Little theorizing has been conducted about information processing biases in chronic pain patients. However drawing from the theoretical accounts in the emotional disorders literature suggests that controlled processes are affected by pain and that theoretical accounts need to centre not simply on invariant structures such as pain schema, but on dynamic cognitive processes in order to understanding patterns of information processing biases. Whilst information processing biases in chronic pain patients provide evidence of the presence of pain schema, little is known about the

processes involved in their continuing to dominant information processing. The first study in this thesis therefore focuses on examining a potential cause of the sensory-pain recall bias, by studying a process which might be involved in the process of preferential schema selection: retrieval inhibition.

2.2 INHIBITORY PROCESSES

Inhibitory processes are considered crucial to the efficient performance of a variety of cognitive functions. Evidence consistent with inhibitory action has been demonstrated in studies on selective attention (Tipper, 1985), language and number processing (Gernsbacher and Faust, 1991; Campbell and Clark, 1989), and motor skills (Grossberg and Kuperstein, 1989). In her review of this area, Arbuthnott (1995) states that neuropsychological theories, in particular, place primary emphasis on inhibition as a control mechanism saying that:

> "Activation of environmentally-present stimuli and their associates is generally observed to be rather unconstrained ... suggesting that some means of selection among encoded or activated alternatives is necessary" (p. 4).

She goes on to say:

> "If inhibition is the means by which activated representations are selected for further processing or action, behavioural goals must thus influence inhibitory processes" (p. 5).

These behavioural goals, she states, are usually intentional (consciously aware goals) which are therefore sensitive to the contextual demands of the particular task being performed.

As inhibitory function has been linked to efficient performance on a number of tasks, it seems plausible to speculate that a change in inhibition may relate to forms of potentially maladaptive information processing styles such as those seen in patients with chronic pain conditions and/or emotional disorders. The exploration of inhibitory processes within the context of cognition and emotion has been a relatively recent

development (Fox, 1994; Myers, Brewin and Power, 1998). This work has attempted to explore inhibitory processes in attention to and memory for mood-congruent information.

2.2.1 Emotion, information processing biases and inhibitory function

2.2.1.1 Anxiety

In her study on attention and anxiety, Fox (1994) argued that those tasks most likely to demonstrate an anxiety-related attentional bias towards threat material were also those most demanding of selective attention, i.e. those which required effective inhibition of distracting information. Fox presented evidence consistent with the view that anxiety sufferers are generally more distractible, and she relates the attentional bias towards threat to reduced inhibitory function. She writes:

> "It is suggested ... that a deficit in the effective inhibition of distracting information may be the causal mechanism which produces this preferential allocation of resources to threat-related information in anxious individuals" (p. 191).

And goes on to say:

> "... a defective inhibitory system in anxious individuals would explain why attentional biases are only apparent when there is competition for processing resources" (p. 192).

However, whilst this 'defective inhibition hypothesis' describes why the locus of mood-related processing deficits related to anxiety is attentional, the specificity of this deficit (i.e. that resources are preferentially allocated to threat-related items) is not a natural consequence of this hypothesis and must be presumed to be a function of present personal concerns in these patients.

2.2.1.2 Repressive coping and depression

Myers *et al.* (1998) explored inhibition within the context of suppressed recall, or cognitive avoidance, of negative information in so called 'repressive copers'. People

possessing this cognitive style are identified as being those typically reporting low levels of distress on self-report measures but showing high levels of distress (autonomic arousal) on physiological measures. Such cohorts have also shown impoverished recall of negative autobiographical and negative experimental material (Myers and Brewin, 1994; Myers and Brewin, 1995). In their study, Myers *et al.* (1998) demonstrated that repressive copers were more effective than normal controls at inhibiting the retrieval of negative information, compared to positive information, when instructed to do so. They interpret these results as providing evidence for a repressive coping style which results in the inhibited retrieval of negative information, particularly that relating to the self. More recently, Power, Dalgleish, Claudio, Tata and Kentish (2000) demonstrated retrieval facilitation for to-be-forgotten negative words in clinically depressed subjects.

2.2.1.3 The role of inhibitory processes in information processing biases

It is unclear whether the role of inhibitory processes in information processing biases, as conceptualized by the above researchers, is a consequence of the mood disorder or plays a causal role in its development, and/or subsequent maintenance. Myers *et al.* are clearly of the opinion that the heightened retrieval inhibition for negative self-related words in repressive copers reflects the functioning of an intentional coping style which has become automatized to some extent. Similarly, it might be the case that in the chronically anxious individual, the heightened levels of distractibility Fox demonstrated, might reflect the operation of something that started off as an intentional scanning of the environment for threat-related information (i.e. a deliberate distractibility), but which has become a well-learned strategy which is now automatic.

However the work by Power *et al.* suggests the role of inhibited retrieval in depression is less clear than for those involved in anxiety and repressive coping: sometimes cognitive avoidance and poor recall of negative material is demonstrated in depressed participants but often enhanced recall for such items is also shown. Whether cognitive avoidance/enhanced inhibitory function towards negative material reflects an

individual difference (trait) variable or a more temporary shift in strategy by individual participants (state variable) is currently unclear.

In addition to empirical demonstrations of the potentially important role of inhibition in chronic mood states noted above, inhibition has been invoked, at least implicitly, in theories of cognition and emotion. The hypothesis that inhibition might play a crucial role in the continuation of emotional disorders is arguably hinted at by Teasdale and Barnard (1993) in their discussion of mood maintenance (see section 1.4.3), and it seems plausible that a failure to inhibit information processing may contribute to mood maintenance once a mild mood state has been established. In addition, Williams *et al.* (1997) argue that the recall bias towards negative information in depressives results from "the facilitated search for associated mnemonics at the elaboration phase" (Williams *et al.*, 1988; p. 175) whereas inhibition of such mnemonic search will result in reduced recall or 'cognitive avoidance'. It seems plausible to suggest that if enhanced specific inhibitory function relates to impoverished recall (as shown in 'repressive copers'), decreased specific inhibitory function may relate to enhanced recall, such as that shown in chronic pain sufferers for pain-related words. In addition, the study of inhibitory processes offers two further possibilities:

i) the potential to draw together work on poor overall task performance in chronic pain groups with the demonstration of a pain-related recall bias, and,

ii) the possibility of exploring whether retrieval or encoding processes seem principally responsible for the recall bias by exploring retrieval inhibition.

2.2.1.4 Inhibitory processes and pain

Gating, or inhibitory mechanisms, play a central role in the Gate Control Theory of Pain. These are conceived as operating throughout the central nervous system, including the brain. For example, in their discussion of feelings of tenderness which accompany injury, Melzack and Wall (1996) state:

> "Early evidence suggests that it (the feeling of tenderness) does not simply fade away but is positively turned off by restorative control mechanisms" (p. 107).

Whilst physiological models are not necessarily relevant to cognitive models of pain, the role of inhibition in cognitive processing in chronic pain patients has received scant attention. As noted earlier, inhibitory processes are considered crucial to efficient performance on a number of different tasks and there is some evidence that performance on cognitive tasks is impaired in chronic pain sufferers. For example, chronic pain sufferers typically recall fewer words than control participants (e.g. Edwards *et al.*, 1992), have demonstrated slower reaction times in Stroop tasks (Pincus *et al.*, 1998), and taken longer to perform complex tasks when pain levels are high (Eccleston, 1995) than pain-free controls. Impaired task performance has been linked to reduced cognitive 'resources', although the exact reasons for reduced resources could be numerous and include the presence of pain, reduced motivation and the result of medication.

Inhibitory processes are linked by some researchers, although not all to the concept of depleted cognitive 'resources'. The term 'resource' is itself vague and has been used by different researchers to refer to different things. However, the aim of the term is essentially the same as that of 'attention': i.e. to account for the limitation on the ability to do more than one thing/task at the same time. This limitation can arise because two tasks require the same structure, or because there is competition for a 'central pool' of cognitive resource or attention, *unconstrained* by specific structures. An example of the latter would be the Supervisory Attention System, proposed in the attentional model of Norman and Shallice (1986). There has been a great deal of criticism about the difficulties operationalizing (i.e. measuring) cognitive resources (e.g. Navon, 1984), a central problem being how to determine whether task performance is deficient because too few resources are being deployed in the task (i.e. a motivational deficit exists) or whether cognitive resources are being used on task irrelevant processing (such as intrusive depressive thoughts, pain intensity) at the time of task performance.

Nevertheless, the issue does potentially have bearing on information processing biases in mood disorders (see section 2.2.3.3 and 2.2.3.4).

As noted earlier, the information processing biases in chronic pain sufferers demonstrated to date seem to be specific to explicit, effortful, recall tasks, notably free recall. Free recall is regarded as more resource demanding than recognition, cued recall and implicit retrieval and a link between information processing biases and reduced cognitive resources or cognitive efficiency is possible. In line with Williams *et al.*'s (1997) conclusions about recall biases in depression, the pattern of recall biases in chronic pain sufferers suggests that these biases are specific to controlled processes. Inhibitory processes have been discussed with reference to efficient performance and, in particular, have been linked to performance on controlled tasks.

The present study therefore aimed to explore the role of intentionally directed (retrieval) inhibition in recall biases of pain sufferers by use of the directed forgetting (DF) paradigm.

2.2.2 Directed forgetting and retrieval inhibition

Bjork (1989) has described the intentional instruction 'to forget', which forms the key to the DF paradigm, as initiating retrieval inhibition "to achieve some goal, such as ..... the avoidance of painful recollection" (p. 325) and as such, explicitly examines the way behavioural goals influence inhibitory function.

The directed forgetting paradigm involves the presentation of material which is labelled 'to-be-remembered' (TBR) or 'to-be-forgotten' (TBF), all of which (regardless of its label) is to be recalled at the end of presentation. The method of labelling words as TBR or TBF usually takes one of two forms: either the label is given immediately after presentation of the individual word (the word method) or following the presentation of the first half of the material (the list method). The list method is generally thought to reflect the action of retrieval inhibition, and the word method as reflecting clear

encoding differences between the TBR and TBF information, as in the word method once a word is labelled TBF, processing or encoding of that word ceases (in contrast to words labelled TBR).

The list method of directed forgetting typically takes the form of giving participants the expectation that they will be presented with a number of words, all of which they will be asked to recall following completion of presentation. However, half way through presentation, participants are given one of two instructions:

1) they are told to keep remembering the words they have seen (List 1) as well as the words which they are about to see (List 2) (the 'remember' condition), or

2) they are told that the words they have seen (List 1) were just 'for practice' and are to be forgotten, whilst the words about to be shown (List 2) will be the ones they will be tested on (the 'forget' condition).

At the end of the presentation all participants are then asked to recall as many of the words they have seen as possible. For the participants in the forget condition it is stressed that this includes words shown as part of the practice session.

Typical findings in the 'forget' group are of impoverished recall of List 1 material followed by enhanced recall of List 2 material (e.g. Bjork, 1970). Explanations of this effect initially focused on encoding differences of TBF and the TBR information. For example, Bjork (1970, 1972) hypothesized that encoding processes such as enhanced rehearsal of the TBR information and the functionally distinct encoding of the TBF and TBR information accounted for the directed forgetting (DF) effect. However there has been an accumulating body of evidence which suggests that the DF effect is not due to encoding differences between TBR and TBF information but to retrieval inhibition of the TBF words. This conclusion stems principally from three findings:

1) Words not expected to be recalled but ones which have just been judged according to pleasantness show a DF effect (Geiselman, Bjork and Fisherman, 1983). In their study, Geiselman *et al.* presented participants with a mixture of both words which

participants would be tested on at the end of presentation, and words which participants were just asked to rate in terms of how pleasant they thought they were, as part of the same task. A subsequent memory test was given for both items: those which were explicitly 'recall' items and those which were 'judge only' items. They found a directed forgetting effect for both items, with fewer words being recalled from the first list seen following a forget instruction, regardless of whether they were 'recall' items or 'judge only' items (compared to those recalled by participants given a remember instruction). This provides evidence that the DF effect cannot be attributed wholly to differences in the encoding of TBR and TBF items.

2) 'Inhibition' can be released and recall restored to control group levels by re-presentation of some of the inhibited information (Basden, Basden and Gargano, 1993). For example, presenting a recognition task prior to a free recall task restores recall levels of the TBF items to control group levels (Whetstone, Cross and Whetstone, 1996).

3) The DF effect only occurs on explicit memory tests and not implicit ones (Basden *et al.*, 1993). Basden *et al.* (1993) demonstrated that implicit memory tests resulted in comparable performance levels across lists for both 'remember' and 'forget' instructed participants, whilst performance differences between the two groups emerged when explicit memory tests were used (e.g. free recall). All these studies strongly suggest that the TBF items are *available* in memory but temporarily *inaccessible.*

2.2.3 Cognitive theories of emotion and the role of inhibitory function

As noted by Fox, the concept of inhibition may help explain why recall biases are typically only demonstrated when a mixed list format is used, i.e. when there is competition between items (McDowell, 1984). However, if it is accepted that the list method DF paradigm assesses retrieval inhibition how might this relate to theories of mood congruent retrieval?

2.2.3.1 Interacting Cognitive Subsystems

The role of intentional action and conscious experience is only touched upon briefly in the ICS framework. Teasdale and Barnard state that an intentional goal (such as to forget certain material) would be represented in the Propositional system. This would then serve as input to further processing systems, such as the Implicational system, which together with the Propositional system, is crucially involved in mood maintenance. When this system becomes 'interlocked' it processes material that relates to one theme, (e.g. depressive), and in so doing generates descriptors that favour the access of mood congruent material. Within this framework, the success of an instruction to forget could potentially be interpreted as a reflection of the ability to intentionally prevent certain processing cycles of fixed thematic content from dominating the system and leading to a recall bias. Hence, the success of a forget instruction may demonstrate that the mood-generating loop can be interrupted and the demonstration of a recall bias disrupted in addition. However, the success of a Propositional statement in altering the generation of models depends on the type of models that have typically been generated in the past. As a result, attempts to forget material which is usually remembered would be expected to fail.

2.2.3.2 Integrated Model

In their Integrated Model, Williams *et al.* (1997) suggest that the apparent 'double dissociation' between information processing biases observed in depressed and anxious individuals reflects the fact that different processes are affected by different mood states. They have suggested that the distinction lies not between attention and memory but between automatic processing and strategic/controlled processing, with different mood states exerting their effects at either or both of these levels. They argue that the pattern of information processing biases in depression suggests that depression

affects controlled processes. However they explicitly state that controlled processes are not necessarily ones that can be brought under voluntary control:

> "Although in principle these processes may be amenable to strategic control (as in depth-of-processing), we assume that people do not, in general, know how such processes could be brought under voluntary control." (Williams *et al.,* 1988; p. 172)

In addition, they suggest that resources are deployed at different stages in information processing according to mood state, and that in depressives, the recall bias towards negative information results from "the facilitated search for associated mnemonics at the elaboration phase" (Williams *et al.* 1988; p. 175) whereas inhibition of such mnemonic search will result in reduced recall or 'cognitive avoidance'. Hence they appear to make some appeal towards inhibitory and facilitatory processes.

They further propose that recall biases are the result of processes of elaboration, i.e. the forging and re-establishing of links among words which then aid their subsequent retrieval. Hence, if a failure of retrieval inhibition was demonstrated that was specific to pain words in chronic pain sufferers, this would mean that the 'forget' instruction does not work for chronic pain sufferers, i.e. that the strategic facilitation relating to the encoding and retrieval of pain-words cannot be brought under conscious control, and operates regardless of an instruction to forget.

However, the concept of 'schema' is often used by other researchers to mean something different to that meant by Williams *et al.* than that used by Williams *et al.* (e.g. Neisser, 1966; Leventhal and Everhart, 1979). The traditional view of schema is one of a holistic representation that encompasses all experiences of a certain type, for example, all pain experiences would be considered to be embodied in a pain schema, all depressive experiences as embodied in a depressive schema. Hence elaboration within a more holistic schema would involve pain words, for example, being preferentially recalled because they are incorporated into a pre-existing pain schema. It is this incorporation into a larger pre-existing context which would constitute elaboration, i.e.

connections between the target word and other pain concepts, pain words etc., thereby facilitating the encoding, search for and retrieval of the target word through the operation of these schema.

However, Williams *et al.*'s use of the term schema refers to something less generic and holistic. They state that their use of the term schema derives from that of Graf and Mandler (1984). Graf and Mandler (1984), though, explicitly use the term 'schema' to describe the representation *of a word*, rather than a set of similar experiences. Elaboration in their terms therefore means developing links between the representations of particular words, seeming somewhat divorced from a wider context. The significance of this point will be returned to in Chapter 4.

The more traditional, holistic, use of the term schema however points to another possible theoretical conceptualization.

2.2.3.3 Norman and Shallice's model of attentional control

The model of attentional control put forward by Norman and Shallice (1986) combines the more holistic conception of schema with automatic and controlled processing and with the concept of inhibition. However, not only does their concept of schema differ from that of Williams *et al.*, Norman and Shallice's use of the term 'controlled processes' also appears to differ.

In Norman and Shallice's model, schema compete for access to awareness or domination of action. Hence schema are involved in the selection of behaviour and the selection of thoughts from memory into conscious awareness. The competition between schema for domination can be resolved either by: i) levels of schema activation whereby the schema that is most 'active' (i.e. primed) dominates, or, ii) given equal levels of activation, by the intervention of the Supervisory Attentional System (SAS), which inhibits competing schema allowing a particular one to dominate. These different methods of schema selection correspond to the distinction between automatic and controlled processes, with the former method being 'automatic' and the latter

'controlled'. However, the use of the term 'controlled' within this theory suggests that such action selection is under conscious intentional control and therefore contrasts with the understanding of controlled processes offered by Williams *et al.*.

Within Norman and Shallice's model, strategic facilitation of a schema would mean that pain-related schemas were preferentially selected by the SAS in comparison to schema with other thematic content (e.g. negative, neutral) when presented with a mixture of different word types. This may appear in the context of the present study as enhanced inhibitory control over the use of non-pain related schema in the encoding and retrieval of the presented words. Reduced inhibition specific to pain words in pain sufferers could be viewed, therefore, as the result of a strategic selection of a pain-schema for encoding and/or retrieving the words presented, with other competing schema typically being inhibited.

2.2.3.4 Working memory

The concept of inhibitory processes has also been linked to conceptions of working memory, and hence offers a link between inhibitory processes and overall task performance. However there are two conceptualizations of working memory function that should be considered, although they lead to similar conclusions regarding the current study.

The capacity notion of working memory

Ellis and Ashbrook (1988) put forward a resource allocation model to account for deficits in task performance noted in depressed patients. They suggested that mood could act to reduce the amount of available attentional resources that could be dedicated to a particular task and that mood-related deficits in performance would be evident in tasks which were particularly demanding of such resources. Reduced resources may mean that the participant preferentially processes (devotes more resources/attention to) material which is consistent with their current concerns, thereby prioritising the processing of a certain type of information. Hence competition for attentional resources

might play a key role in the demonstration of in recall biases in depression and hence potentially in pain. The type of processing which resources are devoted to may vary according to mood state as noted by Williams *et al.* (1997).

If it is assumed that both pain intensity levels (Eccleston, 1995) and mood states can reduce available working memory/attentional capacity, then the implications of this conceptualization for inhibitory function in the current study would be as follows. Reduced working memory capacity has been linked to a hypothesized reduction in the ability to hold a particular goal in mind. That is, "*off goal-path thoughts*" (Hasher and Zacks, 1988; cited by Hertel and Rude, 1991; p. 308)[1] and prolonged attention to "*goals that are not immediately relevant*" (Hertel and Rude, 1991; p. 308 commenting on Kuhl and Helle, 1986) have been linked with inhibitory disturbances, in this case those associated with elderly adults. Both clinically anxious and depressed people report more task-irrelevant thought intrusions than non clinical subjects. Such an effect could be the result of a failure to inhibit information from entering consciousness such as reported in elderly adults.

Using a working memory capacity conceptualization of the current study, pain and mood may contribute to the reduction of attentional resources which may lead to a generalized reduction in the ability to maintain a goal, such as "forget List 1 items, just concentrate on List 2 items". This would imply that pain sufferers may fail to respond to the forget instruction. This in turn would lead to the hypothesis that pain sufferers will show a *generalized* inability to inhibit the retrieval of words which is *not specific* to any given word type. Alternatively, if reduced attentional resources is also linked to issues of preferential recall for mood-congruent material (perhaps because working memory capacity is being used by a mood-generating system such as that proposed by Teasdale

[1] It should be noted that Hasher and Zacks' concept of working memory and reduction in inhibitory function rejects notions of capacity in the above sense in favour of an inability to inhibit the contents of consciousness such that more, rather than less information enters awareness.

and Barnard) there may be *both* a generalized inability to respond to the forget instruction in chronic pain sufferers, but one which is accentuated in the pain-related words compared with the other words.

The efficiency notion of working memory

Pain status may reduce the efficiency (rather than capacity) of working memory such that inhibitory function is compromised allowing both 'forget' and 'remember' material to enter working memory space. This could lead to the first scenario mentioned above, that of a generalized inhibitory failure. Alternatively, at the point of entering working memory space, preferential processing resources may be allocated to pain material such that it is given preferential output, either to consciousness and/or in terms of order of report. Inhibitory function may be generally compromised but more so in the case of inhibiting retrieval of pain words.

2.3 AIMS

The aim of this study was to explore the role of retrieval inhibition in the recall bias demonstrated in chronic pain sufferers towards pain-related words. It aimed to explore whether encoding or retrieval issues are central in the demonstration of a recall bias in chronic pain sufferers towards sensory pain material, and whether the process of inhibition is important in understanding the domination of pain schema and hence pain meanings in chronic pain sufferers.

Two related, subsidiary aims were:

i) to explore whether the pattern of retrieval inhibition specific to pain-related words in chronic pain sufferers would relate to depressive status, i.e. whether lack of retrieval inhibition would be specific to sensory pain words in non-depressed pain sufferers, and specific to both sensory and affective pain words in depressed pain-sufferers, and

ii) to explore whether a lack of retrieval inhibition would be associated with pain as a persistent negative state or pain as reflecting something of personal concern. A group who had a personal interest in a portion of the words presented (keen amateur gardeners re: gardening words) was therefore also included in the present study. This group was chosen because previous research into recall biases in chronic pain sufferers has used gardening words to control for any effects of categorization of material in the demonstration of a recall bias, by using gardening words to constitute a neutral word category. Previous research has also shown that emotional words are preferentially recalled in comparison with uncategorized neutral words, so a categorized neutral group of words were used to see whether any retrieval inhibition effect was due to the type of word rather than categorization effects.

2.4 METHOD

2.4.1 Participants

95 participants took part in the present study. They comprised four groups: pain patients who were not depressed (N=35), pain patients who were depressed (N=20), pain-free non-depressed participants pursuing gardening as a hobby (N=20), and pain-free non-depressed non-gardening controls (N=20).

Chronic pain was defined as present if it was linked to a benign condition, was ongoing and had persisted for more than 6 months despite medical treatment. The other inclusion criteria, which applied to all the groups, were:

- No visual and /or auditory problems.
- An ability to read and write English.
- Aged over 18 years.

The presence of depression was defined as those participants scoring 21 or more on the Beck Depression Inventory (as recommended by Beck *et al.*, (1979) when using the BDI as a research rather than a clinical tool). The pain sufferers were recruited from

the Inpatient Pain Management Programme (INPUT) at St Thomas' Hospital. The non-pain participants were all recruited from local advertisements or advertisements in garden centres. The study was approved by the Institutional ethical committee and all participants gave written, informed consent (see Appendix A)

2.4.2 Design

A directed forgetting (DF) paradigm was used, using the list method. The current study was a mixed design with 3 between group variables:

group: pain not depressed /pain depressed /amateur gardeners /controls;

instruction: forget/remember;

list order: List 1 first/ List 2 first;

and two within group variables:

recall: List 1 recall/ List 2 recall;

word type: sensory pain, affective pain, gardening and filler items.

2.4.3 Materials

The words used were selected from those used in previous research (Edwards, 1992). They were matched across lists as closely as possible for frequency (Kucera and Francis, 1967) and syllable length (see Table 2.1).

The words were presented in fixed order with three fillers at the beginning and one at the end of each of the respective lists to reduce primacy and recency effects respectively. The order of words within lists was randomized but with one constraint: two words of the same type were not presented consecutively.

2.4.4 Procedure

All participants were instructed that the study was an investigation of memory and pain but they were not aware of the specific hypothesis under test.

Participants were given the following instructions verbally prior to the start of the task:

> "This is a study investigating memory and long term pain. It will involve reading aloud one word at a time. There are 44 words and after you have read all of them, you will be asked to remember as many of them as you can."

Table 2.1: Sensory, affective, gardening and filler words used in the directed forgetting study (with word frequency scores in brackets)

LIST 1			
Sensory	**Affective**	**Gardening**	**Fillers**
Scalding (1)	Punishing (1)	Potting (1)	Windy (2)
Pinching (2)	Excruciating (2)	Sowing (1)	Swaying (3)
Hurting (3)	Tiring (4)	Bedding (3)	Spacing (6)
Splitting (3)	Annoying (6)	Fertilizer (4)	Adjoining (13)
Pounding (6)	Distressing (7)	Sprouting (6)	
Tender (11)	Horrible (15)	Spreading (16)	

LIST 2			
Sensory	**Affective**	**Gardening**	**Fillers**
Stabbing (2)	Sickening (2)	Budding (1)	Resounding (2)
Searing (2)	Gruelling (2)	Leafy (1)	Stony (5)
Throbbing (3)	Exhausting (3)	Watering (4)	Focusing (6)
Gnawing (4)	Suffocating (5)	Planting (5)	Collecting (13)
Aching (6)	Terrifying (7)	Digging (7)	
Sore (10)	Fearful (13)	Spraying (8)	

The words were presented individually on cards that were placed in front of the participant at five second intervals. They were told to continue to look at the word after having read it aloud.

After half of the words were presented (22 of the 44) a card was placed in front of them with either the "forget" or "remember" instruction printed on it, depending on

which condition the participant had been allocated to. For the "forget" manipulation the midpoint instructions were as follows:

> "What you have done so far has been practice. You should therefore forget all the words that you have seen so far. Concentrate on the words which you are about to see. It is the next set of words that you will be asked to remember."

For the "remember" manipulation, the midpoint instructions were as follows:

> "You have now seen half of the list of words. Continue to try to remember those as well as the words which you are about to see."

The remaining 22 words were presented in the same way as the first. The end instruction for the "forget" manipulation was:

> "I would now like you to tell me as many of the words as you can remember. This includes the words you were shown as part of the practice session."

The end instruction for the "remember" manipulation was as follows:

> "I would now like you to tell me as many of the words as you can remember."

Each participant was then given 3-4 minutes to recall these words. These were written down by the experimenter.

Participants were then asked to rate on a scale of 0-10 how hard they tried on the memory task, anchored "I didn't try at all" to "I tried my hardest". They were asked if they noticed anything unusual about the words and whether they had used any particular strategy to try and remember the words. They then completed the following battery of questionnaires in fixed order:

1. National Adult Reading Test

2. 100 mm Visual Analogue Scales anchored "no pain" and "worst imaginable pain" for them to rate:

a) their pain now,

b) their average pain over the last week,

c) their worst pain over the last week, and

d) their least pain over the last week.

3. The Mood Rating Scale (Bond and Lader, 1974)

4. The Spielberger State/Trait Anxiety Inventory (Spielberger, Gorsuch, Lushene, Vagg and Jacobs, 1983)

5. The Beck Depression Inventory (Beck *et al.*, 1979)

They were asked whether they had a current pain problem, and, if so:

- how long they had had pain for
- the location of their pain
- their diagnosis (if known/if they had one)
- their current medication intake for their pain.

They were also asked

- their present occupation (if not working, their previous occupation).

The non-pain participants were asked the following questions in addition to the above:

- whether gardening was a hobby
- to rate how much they enjoyed gardening on a 0-10 scale anchored "not at all" to "very much"
- to rate how often they gardened on a 0-10 scale anchored "never" to "very often"

Following completion of the memory task, participants were also asked:

i) how much effort they put into trying to remember the words on a scale of 1 to 10, ii) whether they used any strategies to help them remember the words, and iii) whether they noticed anything unusual about the words.

(These questionnaires are in Appendix A).

2.5 HYPOTHESES

It was hypothesized that the tendency to recall more pain-related material than pain-free controls might be due to a failure of retrieval inhibition which meant that the operation of pain schema could not be voluntarily suppressed. The method of tapping pain schema was word lists. This first study therefore focused on an aspect of schema activation and used word lists to access the pain schema.

Replication of previous results:

Hypothesis 1 (H1) There will be a main effect of group. The clinical participants (pain not depressed and pain depressed) will remember fewer words overall than the controls.

Hypothesis 2 (H2) There will be a main effect of instruction. Participants receiving the 'forget' instruction will remember fewer words from the first list than those receiving the 'remember' instruction.

Hypothesis 3 (H3) A pain related recall bias will be demonstrated in the 'remember' instructed groups, hence there will be an interaction between Group and Word type such that pain non-depressed participants will remember more sensory words, pain depressed participants will remember more sensory and affective words, participants with gardening as a hobby will remember more gardening words and controls will show no recall bias.

As noted earlier, none of the dominant theories under consideration provide explicit hypotheses as to how a 'forget' instruction may relate to the demonstration of a recall bias. Extrapolating from them results in different hypotheses and there are three possible outcomes which may occur.

Hypothesis 4 (H4) The interaction between the Forget Instruction, Group and Word type may take one of three forms:

Hypothesis 4a (H4a) Pain sufferers will show a reduced ability to inhibit the retrieval of information regardless of its valence.

Alternatively, given reduced working memory/attentional capacity or inefficient working memory function, the 'forget' instruction may not be adequately maintained and in addition, material may be prioritized in line with current concerns (e.g. pain), leading to hypothesis 4b,

Hypothesis 4b (H4b) Pain sufferers will show general reduced retrieval inhibition but this will be more marked with reference to the pain-related words as these are given processing priority regardless of whether they have been given a 'forget' or 'remember' instruction.

Hypothesis 4c (H4c) Pain sufferers will show no general inhibitory failure but a specific inhibitory failure re: pain-related words.

2.6 STATISTICAL ANALYSIS

All statistical analyses were computed using SPSSwin version 6.0.

The main analyses conducted used analysis of variance (ANOVA). ANOVA is an analysis which uses differences in sample means to draw inferences about the presence or absence of differences in population means. It has two major assumptions. These assumptions are normality of distribution of scores within the populations which are being sampled, and homogeneity of variance. If these two assumptions are met, two set of distributions can differ only in terms of their means. Hence in order to be confident about the validity of inferences concerning the difference between sample means, and hence population means, the validity of these assumptions need to be considered for each analysis.

The assumption of normal distribution is more concerned with the sampling distribution of the mean than with the distribution of observations in any one sample. As a result, the distribution of the sample scores can often depart substantial from normality and have little effect on the validity of the F statistic (Howell, 1997). However, the assumption of homogeneity of variance does relate to the samples. It is the sample

variances which are pooled and which, if their variances are homogeneous, can be considered to be an estimate of common population variance. It is the latter which is used to calculate the mean square error and hence is used to test the truth or falsity of the null hypothesis. If this assumption is not met, this could result in a biased estimate of common population variance, lead to a biased error term and, hence, spurious results relating to the F statistic.

For the ANOVAs, variances per cell were therefore examined to check the assumption of homogeneity of variance.

For the complete 5-way ANOVA some of the cell variances were zero, most probably due to the small sample sizes, as some of the cells had only 4 values in them. This is problematic because it suggests that either this is an inadequate sample or, if it is an adequate sample, that the population from which it is drawn is not normally distributed. As no transformation is going to be able to rectify the problem of zero variance, the main ANOVA was simplified. List order was the least important of the independent variables, so the variances were examined across the two cells, representing the two different levels of this variable (List 1 first, List 2 first) to check the assumption of homogeneity of variance. The range in variance was 0.59 - 1.66, and hence within acceptable limits (Howell, 1997) thus allowing for a test of the Main effect of List order to be legitimately made. As this was non-significant (see section 2.7.3), a four-way ANOVA was computed to test the central hypotheses, collapsing across cells by List order.

The cell variances for the four-way ANOVA were further examined. Looking at all four word types, the three main ones plus the fillers revealed that there were still zero variances in some of the cells, but these related to the cells for filler items. Looking just at the main three word types, univariate homogeneity of variance tests on the cell variances for the four-way ANOVA using the three key word types showed there still remained significant heterogeneity of variance. Whilst logarithm transformations

rectified this problem, the results of the main four-way ANOVA on the three main word types (excluding the filler items) on both the log transformed data and the untransformed data showed that log transformations did not significantly alter the pattern of results, i.e. did not affect which variables emerged as significant. The analyses reported here will therefore be those computed on the untransformed scores, for ease of reporting.

On the one-way ANOVAs, where homogeneity tests were significant (indicating departure from homogeneity of variance), analyses computed on the transformed scores which restored homogeneity of variance again did not alter the pattern of results in comparison to those computed on the untransformed scores, either in terms of overall significance of the one-way ANOVA or in terms of the post-hoc comparisons, so again, it is the analyses on, and the means of, the untransformed scores which are reported.

2.7 RESULTS

Table 2.2 presents scores across the different subject groups on variables relating to group membership. One way ANOVAs were computed on the variables in this table.

Present Pain scores differed significantly between the groups $F_{(3,91)}=62.49$; $p<0.0001$. Tukey's Honestly Significant Difference (HSD) tests revealed that these differences lay between the following groups: P *vs.* AG, P *vs.* C, PD *vs.* AG, PD *vs.* C and PD *vs.* P. Hence, the depressed group rated their present pain intensity as higher than all the other groups, and the non-depressed pain group reported significantly higher present pain scores than the non-pain groups. Present pain intensity scores did not differ between the Gardeners and the Controls.

Average Pain scores differed significantly between the groups $F_{(3,91)}=80.96$; $p<0.0001$. Tukey's HSD tests revealed that these differences were between the following groups: non-depressed Pain (P) *vs.* Amateur gardener (AG), P *vs.* Control (C); Depressed Pain (PD) *vs.* AG, PD *vs.* C. Thus the two pain groups rated their average

pain intensity over the previous week as higher than the non-pain groups. There was no significant difference between the two pain groups on this pain measure.

Table 2.2: Means (and standard deviations) of variables relating to group status

	Group P *(Pain, not depressed)* (N=35)	**Group PD** *(Pain, depressed)* (N=20)	**Group AG** *(Amateur gardeners)* (N=20)	**Group C** *(Controls)* (N=20)
Present pain (0-100mm scale)	45.48 (24.48)	66.75 (21.41)	3.50 (6.58)	3.30 (6.33)
Average pain (0-100mm scale)	58.42 (21.69)	70.70 (21.77)	5.65 (8.19)	8.35 (9.08)
Pain Chronicity (years)	9.31 (10.24)	11.42 (11.12)	0.11 (0.47)	0.48 (2.01)
BDI Score	11.25 (5.38)	28.10 (5.73)	5.05 (3.23)	5.40 (3.76)
VAS measure of current sadness (mm) (taken from Mood Rating Scale)	33.5 (18.3)	54.2 (22.2)	24.4 (21.8)	20.3 (14.1)
Enjoyment of gardening (mm)	-	-	83.2 (18.5)	32.0 (26.7)

Pain Chronicity scores differed significantly between the groups $F_{(3,89)}=10.89$; $p<0.0001$, Tukey's HSD tests revealed that these differences were between the following groups: P *vs.* AG; P *vs.* C; PD *vs.* AG; PD *vs.* C. Thus there were significant differences between both pain groups and both non-pain groups but no differences in pain chronicity between the two pain groups and no significant difference between the two non-pain groups.

Beck Depression Inventory scores differed significantly between the groups $F_{(3,91)}=102.57$; $p<0.001$. Tukey's HSD tests revealed these differences were between: P *vs.* PD. These groups were originally defined according to BDI scores so these

differences were orchestrated. Group PD also differed significantly from both of the non-pain groups, as did Group P, so both pain groups were still higher on BDI scores than the pain-free controls.

Present sadness levels as measured by the Visual Analogue Scale on the Mood rating scale anchored 'happy' and 'sad' differed significantly between the groups $F_{(3,89)}=12.32$; $p<0.0001$. Tukey's HSD tests revealed these differences lay between PD *vs.* P; PD *vs.* AG; and PD *vs.* C. This indicates that on this measure the depressed pain group were scoring higher levels of current sadness than the other groups.

Enjoyment of gardening An independent group t-test was computed to compare Groups AG and C, and showed predictably, there was a significant difference between them $t_{(1,38)}=7.05$; $p<0.001$. The means shown in Table 2.2 indicate that the Amateur gardeners were scoring higher on this measure than the controls. This measure was not given to people classified as being in one or other of the two pain groups.

These results confirm the status of the groups in terms of pain levels and depression levels and enjoyment of gardening as a hobby. Table 2.3 shows the group scores on age, sex and NART variables.

Age A one-way ANOVA was performed on group scores for age and revealed significant differences $F_{(3,91)}=2.63$; $p<0.05$. Tukey's HSD test demonstrated that this difference was due to differences between AG and C, with the control group being younger than the gardeners.

Sex The frequencies of men and women did not significantly differ according to Group status. The df=2, and the Chi-square statistic= 4.59; NS.

Table 2.3: Means (and standard deviations) on age and NART scores, and sex distributions across the groups

	Group P *(Pain, not depressed)*	**Group PD** *(Pain, depressed)*	**Group AG** *(Amateur gardeners)*	**Group C** *(Controls)*
Age	42.17 (13.72)	42.55 (7.33)	46.00 (9.50)	36.00 (12.27)
Sex Ratio Male: Female	1:2 (12:23)	1:1 (9:11)	1:4 (4:16)	1:1 (10:10)
NART error score	16.48 (8.29)	19.75 (9.79)	8.95 (5.85)	9.55 (5.67)

NART error scores differed significantly between the groups $F_{(3,91)}=9.96$; $p<0.001$. Tukey's HSD test revealed these differences were between: P *vs.* AG, P *vs.* C, PD *vs.* AG, and PD *vs.* C. Hence, both the non-pain groups made significantly fewer errors on the NART than the chronic pain groups, though there were no significant differences in NART scores between the two pain groups and between the two non-pain groups. Predicted verbal IQ scores for the pain groups based on these NART error scores, average 114 for Group P, 112 for Group PD, 121 for Group AG and 120 for Group C.

Table 2.4 shows group differences on recall scores, both Total and Core recall (the latter of which excludes the filler items) and differences on a self-report measure of effort put into the recall test. One way ANOVAs were computed on the variables listed in Table 2.4.

Total recall scores differed significantly between the groups $F_{(3,91)} = 5.25$ $p<0.005$. Tukey's HSD tests revealed these differences lay between P *vs.* C, and PD *vs.* C. Hence, both the pain groups recalled significantly less than Group C, the control group, though there were no significant differences in Total recall between the two pain groups and the gardeners.

Table 2.4: Means (and standard deviations) of recall performance, NART errors and reported effort exerted on the memory task

	Group P *(Pain, not depressed)*	**Group PD** *(Pain, depressed)*	**Group AG** *(Amateur gardeners)*	**Group C** *(Controls)*
Total recall (List 1 + List 2)	9.94 (3.94)	10.15 (3.34)	11.95 (2.60)	13.50 (3.62)
Core recall (List 1 + List 2, excluding filler items)	8.57 (3.37)	8.75 (2.95)	10.00 (2.07)	10.60 (3.80)
Effort	7.74 (2.16)	8.90 (2.29)	8.05 (1.78)	6.95 (1.85)

Core recall This score comprised recall levels excluding filler items. The difference between the groups did not reach conventional levels of significance $F_{(3,91)} = 2.27$ $p=0.085$.

Effort score Differences between the groups were significant $F_{(3,91)}=3.10$; $p<0.05$. Tukey HSD differences revealed the significant difference was between PD *vs.* C. Means shown in Table 2.4 reveal these differences are a result of the depressed pain group rating effort scores as higher than the controls.

2.7.1 Background variables

As Tables 2.3 and 2.4 show, the groups differed on measures of age and errors made on the NART. As both age and verbal ability (as measured by the NART) have been linked to reduced inhibitory function (Hasher and Zacks, 1988), these were entered as covariates into the main ANOVA.

2.7.2 The use of covariates

Covariate analyses are computed to partial out variance accounted for by a known variable. However, if the groups differ in terms of their mean scores on a covariate, ANCOVA partials out variance attributable to this covariate and, in addition,

adjusts the group means to predicted values, i.e. to values *they would be predicted to have*, had the groups been equal on the covariate. Such an estimate is based on the actual values they have. This latter use of ANCOVA is questionable if differences between groups on the covariates is central to group membership. As a result, it becomes meaningless to ask how the groups *would have performed* had they been equivalent on these variables, because had they been equivalent, they would not be the groups that they are. However, in the current study, the demographic variables on which the groups differ are not thought to be constitutive of group membership, that is age and NART error scores are not considered core features of pain group or non-pain group membership, i.e. it is not a core feature of being a pain sufferer that you are a certain age, and/or make a certain number of errors on the NART.

As a result, these covariates were entered into an ANCOVA as part of the main four-way ANOVA. However, they did not alter the pattern of results, except to change the main effect of Group from approaching significance to not significant.

2.7.3. Results relating to the hypothesis tests

The main effect of List order was not significant $F_{(1,79)}=0.19$ indicating that recall levels were not affected by list presentation order. This variable was therefore collapsed across groups (see also section 2.6).

The main hypotheses were therefore tested using a 4-way split-plot ANOVA.

Hypothesis 1: Effect of Group status on Recall levels.

The main effect of Group was not significant $F_{(3,87)}=2.29$; $p=0.08$ indicating Core recall levels did not significantly differ across the groups. The prediction that pain sufferers (depressed and non-depressed) would recall fewer words overall than the non-pain participants (gardeners and controls) was therefore not supported

This meant that the analyses in the present study could use total number of words rather than proportions. However, it also meant that hypotheses relating poor

overall performance to the recall bias and retrieval inhibition, either through the concept of working memory capacity or working memory efficiency, could not be tested in the present study.

The dependent variable (DV) used was 'Core recall'. This was for two reasons: i) the recall of filler items was not central to the hypotheses under test and ii) some of the cell variances for the fillers words were zero. However, some analyses was computed with Total recall as the DV where this helped to clarify some of the results computed using Core recall as the DV. In these analyses filler items were collapsed across cells and hence no variances remained at zero.

Hypothesis 2: Effect of Forget Instruction on Recall.

The main effect of instruction was not significant, $F_{(1,87)}= .07$; indicating that those participants receiving a forget instruction did not recall fewer words overall than those receiving a remember instruction, using Core recall (i.e. excluding the filler items).

The interaction between Instruction and Core recall across lists did not reach significance $F_{(1,87)}=3.26$; $p=0.07$. The typical finding using the DF list method of impoverished recall from List 1 followed by enhanced recall from List 2 was therefore not obtained in the present study. However, the trend was in the predicted direction (see Table 2.5).

Table 2.5: Means (and standard deviations) of Core recall across lists for 'Forget' and 'Remember' instructed participants.

	Remember	Forget
Core recall List 1	4.55 (2.46)	3.98 (1.87)
Core recall List 2	4.89 (1.83)	5.25 (2.25)

This means that the directed forgetting effect was not demonstrated in the present study.

When Total recall (including the filler items) was entered as the DV, the interaction between Instruction and Recall across the lists did reach significance $F_{(1,87)}=8.26$; $p<0.005$. As the filler items were unrelated items this raises the possibility that the failure to demonstrate a directed forgetting effect using Core recall as the DV may have been due to the high degree of semantic association between the words used in this study, namely the three categories of words, sensory-pain, affective-pain and gardening. This possibility will be discussed further in sections 2.7.4 and 2.8.1. An alternative explanation might be that the directed forgetting effect works by affecting primacy and recency effects and reducing recall from List 1 in this way. However, research into the directed forgetting effect has typically controlled for the contribution of primacy and recency effects (e.g. Myers *et al.,* 1998), so this interpretation seems unlikely.

Hypothesis 3: Demonstration of recall bias.

There was no evidence of a generalized 'recall bias' towards pain-related words in the pain groups compared to the pain-free controls as the interaction between Group x Word type was not significant, either for all the participants overall $F_{(6,174)}< 1$ (see Table 2.6), or for the 'remember' instructed groups alone $F_{(6,88)} <1$.

However, there was an overall tendency for all participants to preferentially recall words of a certain type $F_{(2,174)}=26.05$; $p<0.001$. The means are shown at the bottom of Table 2.6. Related t-tests were used to compare the three main word types. Significant differences were found between recall of sensory words and gardening words ($t_{1,94} = 5.76$; $p<0.001$) and between recall of affective words and gardening words ($t_{1,94}) = 6.6$; $p<0.001$) but not between recall of sensory words and affective words ($t_{1,94} = 1.23$; NS), indicating that all participants tended to recall more gardening words than sensory-pain or affective-pain words.

Hypothesis 4: The relationship between Instruction, Group, Word type and Recall across lists 1 and 2.

Hypothesis 4a stated that pain sufferers may show a reduced ability to inhibit the retrieval of information regardless of its valence (i.e. regardless of word type).

Table 2.6 Recall of Word type across different groups

	Sensory	Affective	Gardening
Group P	2.69 (1.51)	2.37 (1.44)	3.51 (1.87)
Group PD	2.55 (1.10)	2.35 (1.53)	3.85 (1.53)
Group AG	2.85 (1.53)	2.85 (1.39)	4.30 (0.98)
Group C	3.35 (1.50)	2.95 (1.99)	4.35 (1.57)
TOTAL (collapsed across Groups)	2.83 (1.44)	2.59 (1.57)	3.93 (1.60)

There was no significant interaction between Group x Instruction x Core recall across lists $F_{(3,87)}=0.77$ indicating that there was no difference between the groups in their response to the Forget instruction and hence no evidence to support the hypothesis that pain sufferers are less able to inhibit information retrieval than non-pain controls.

As conclusions that might be drawn from this result may obviously be compromised because a directed forgetting effect was not demonstrated, this analysis was repeated using Total recall as the DV, where a directed forgetting effect did occur. The interaction between Group x Instruction x Recall across lists still remained non-significant $F_{(3,87)}<1$. This provides some evidence to support the view that pain sufferers do not show a generalized reduction in inhibitory function.

Evidence cited as consistent with general inhibitory failure includes increased intrusion rates in free recall. In the present study there was no evidence of increased

intrusion rates in the pain groups as compared to the non-pain groups in terms of total intrusion rates $F_{(3,91)}=0.80$ and hence appears to support the above result.

However, the generality of these findings as they relate to intrusion rates is difficult to assess as the level of intrusions was low and the lack of a significant difference in intrusion rates across the groups may merely reflect a floor effect in the present study (see Table 2.7).

Table 2.7: Mean number (and standard deviation) of recall intrusions for each group

	Group P	Group PD	Group AG	Group C
Average total intrusions	1.62 (1.71)	1.20 (1.54)	1.70 (1.62)	1.45 (1.60)

Hypothesis 4b stated that the pain sufferers may show both a general reduced retrieval inhibition but one which was more marked with reference to pain-related words

As noted above, there was no evidence for generally reduced retrieval inhibition in chronic pain sufferers as compared to non-pain controls, as the interaction between Instruction Group and Recall across lists was not significant. This therefore leads directly on to:

Hypothesis 4c: that pain sufferers would show failure of directed forgetting that was specific to pain words.

The interaction between Group x Instruction x Core recall across lists x Word type was not significant $F_{(6,174)}=1.03$ indicating that there was no difference between the groups in their ability to inhibit retrieval that was specific to word types. However this result must be considered inconclusive, as the forget instruction was only having a weak effect (if any) on recall of the three word types (demonstrated by the non-significant interaction between Instruction and Recall across lists when Core recall was entered as the DV).

In the absence of a demonstrated effect of the 'forget' instruction and of a 'recall bias', the failure to find evidence supporting a specific inability to inhibit the retrieval of pain words is unsurprising, as it depends on the demonstration of the former.

Additional results

Additional results from the four-way ANOVA that did not directly relate to the hypotheses are as follows.

There was a main effect of Core recall across the lists $F_{(1,87)}=7.98$; $p<0.01$. The means shown in Table 2.8 show that, overall, participants recalled a greater number of words from the second list seen than from the first list.

Table 2.8: Mean Core recall (and standard deviations) across first and second lists seen, for all participants

	Recall from first list seen	Recall from second list seen
Mean (sd)	4.26 (2.19)	5.07 (2.05)

However, there was also a significant interaction between Recall across the lists and Group $F_{(3,87)}=2.77$; $p<0.05$. As can be seen from Table 2.9, this is due to pain groups performing less well in terms of recall from the first list seen compared to controls.

Table 2.9: Mean Total recall (and standard deviations) across lists for each group

	Group P	Group PD	Group AG	Group C
Recall from first list seen	3.86 (2.28)	3.30 (1.87)	4.95 (1.57)	5.15 (2.18)
Recall from second list seen	4.71 (1.86)	5.45 (1.76)	5.05 (1.85)	5.45 (2.91)

None of the other interactions were significant.

2.7.4. Semantic association and the forget instruction

A directed forgetting effect was not demonstrated when looking at Core recall, i.e. the three main word types under study. However, it was demonstrated when looking at Total recall which included the three main word types plus the filler items. This raises the possibility that high levels of semantic association across List 1 and 2 might weaken any directed forgetting effect. If this were so it might be expected that a relationship would exist between the type of strategy people used in attempting to remember the words and the success of the forget instruction i.e. those people using a strategy which exploited semantic relatedness might show a weaker directed forgetting effect than those who did not.

To further explore this possibility, the use of strategies to aid recall was examined to see whether strategies which exploited this semantic association were more likely to be associated with a failure to respond to the forget instruction in the predicted manner. The strategies participants reported were partitioned, post-hoc, into six groups (see Table 2.10).

Linking to the self refers to participants who mentioned 'identifying with the words', finding the words 'described them' or 'described their condition'.

Table 2.10: Frequency of strategies used to aid recall across groups

	Group P	Group PD	Group AG	Group C	Total
Linking to self	34%	45%	20%	8%	28%
Visualization	33%	25%	40%	22%	30%
Categorization	40%	35%	47%	58%	44%
Alphabet	6%	10%	0%	10%	6%
Repetition	13%	5%	5%	23%	12%
None	20%	20%	15%	23%	20%

Visualization refers to participants reporting attempting to visualize a scene to which the words related. If this scene involved themselves explicitly e.g. imagining themselves walking around their garden, this would count as use of both visualization and linking to the self.

Categorization refers to participants mentally grouping the words into categories and using this information to aid recall.

Alphabet refers to participants going through the alphabet during the recall phase to try and prompt their memory as to whether they had seen a word beginning with that letter, or by generating a word beginning with that letter and attempting to try and recognize whether or not it had been amongst those presented.

Repetition refers to participants reporting mentally repeating/rehearsing some of the words they had seen during presentation.

The number of participants falling into the different strategy categories in each group are too small to permit a Chi-squared analyses (the number of Ss per cell should be at least 5 and drops as low as 2 in this case) so the pattern of strategy use across the groups must be considered as merely suggestive of possible differences that might exist on a broader scale. Overall the most popular strategy was that of categorization, although the preference for this strategy was most marked in Group C, the control group, with 60% reporting using this to aid recall. The frequencies shown in Table 2.10 show that the majority of participants did make use of the fact that the words were semantically associated as an aid to recall.

However, speculation about which strategies may involve making use of semantic associations is less than straightforward. For example, whether the strategies of linking to oneself or visualization would promote semantic linkage is unclear. However, it seems plausible to suggest that the strategies of using the alphabet to promote recall, repetition or using no strategy can safely be assumed to involve no semantic linkages among words.

Strategy use was therefore divided into two types: semantic strategy (linking to the self, visualization and categorization) and non-semantic strategy (alphabet, repetition and none). The directed forgetting effect is evident in reduced recall from List 1 in participants given the forget instruction, compared to participants given the remember instruction. Type of strategy was therefore correlated with Core recall from List 1 and 2 and broken down across type of instruction received (Table 2.11). Developing semantic associations among the words would be expected to result in links being made across Lists 1 and 2, thereby weakening any instruction to forget. It was therefore predicted that semantic strategies would correlate with enhanced recall from List 1 in the 'forget' instructed group. As shown in Table 2.11, there is a significant correlation between the type of strategy participants used and the number of words they recalled from List 1 in the forget instructed group $r=0.22$; $p<0.05$. This relationship approaches significance in the remember instructed group. This provides some supportive evidence for the view that semantically related words and the use of strategies which may exploit this fact to aid recall, may weaken a directed forgetting effect.

Table 2.11: Correlation between the type of strategy used and the number of words recalled from List 1 in the 'Forget' and 'Remember' instructed groups

	Strategy encouraging semantic linkage (Yes/No)	
	Remember instructed	**Forget instructed**
List 1 Core recall	0.19 p=0.06	0.22 p<0.05
List 2 Core recall	0.08 NS	0.14 NS

2.8 DISCUSSION

The main hypothesis under test, that a pain-related recall bias in chronic pain sufferers might be associated with a failure of retrieval inhibition specific to these word types, was not supported, as there was no significant interaction between Group x

Instruction x Core recall across lists x Word type. However, a recall bias was not demonstrated in this study and only an arguably weak DF effect, so the data must be considered inconclusive.

There was limited evidence to support the view that pain sufferers do not demonstrate a general reduction in inhibition as there was no significant interaction between Group x Instruction x Recall across lists even when using Total recall levels where a significant DF effect was demonstrated. This result is consistent with other findings in the area of pain research. The notion of inhibitory failure as reformulated by Hasher and Zacks predicts that reduced inhibitory function will be associated with things such as:

i) increased intrusion rates during recall, and

ii) increased interference on the classical Stroop interference task

The present study has found no evidence to support the first of these although the overall intrusion rates across the groups in the present study were low and may reflect floor effects. However, in her report of the results of an emotional Stroop paradigm comparing pain sufferers with pain free controls, Pincus (1993) found no significant group differences in response to the classical Stroop with an average response time for the pain sufferers of 1049 m/secs (SD=480) and an average response time of 999 m/secs (241).

The hypothesis relating failed retrieval inhibition to the pain-related recall bias however was not adequately tested as the DF effect and the pain-related recall bias were not demonstrated in this study.

2.8.1. The 'forget' instruction

The present study has been one of the first to explore the role of retrieval inhibition in mood-congruent recall. A feature of research into mood-congruent recall is the use of thematically linked words, some of which may have very close semantic

associations. Work on DF typically uses unrelated words in the demonstration of a DF effect. However, Golding, Long and MacLeod (1994) found that semantic association reduced the DF effect when the word-method of forgetting was used. To date there is no record of semantic relatedness being explicitly studied using the list method.

Golding *et al.* (1994) found a failure of intentional forgetting when the word labelled as to-be-forgotten (TBF) was closely semantically linked to a preceding word which was labelled to-be-remembered (TBR). For example, recall levels of the word 'belt' were high even if it was labelled TBF if it followed the word 'seat' which was labelled TBR. Previous studies using the list method with related words used an incidental recall test (Myers *et al.* 1998; Power *et al.*, 2000). This may have minimized the effect high levels of semantic association might have had in interfering with retrieval inhibition. However, an additional feature of these two studies was that although words fell into two categories (positive and negative) these were arguably less closely semantically linked than the words used in the present study. For example the negative category in the Myers *et al.* study included words such as 'risky', 'selfish', 'outraged', and the positive category words such as 'jolly', 'purposeful', and 'respectful'.

A large proportion of participants in the present study used categorization as an aid to recall. In addition, the use of strategies that potentially made use of semantic relatedness (i.e. linking the words to oneself, visualization and categorization strategies), was positively correlated with higher recall from the first list seen in 'forget' instructed participants compared with using a strategy that did not capitalise on the meaning of the words (i.e. repetition, using the alphabet to aid retrieval or using no strategy at all). This result therefore provides some support for the view that the semantic relatedness of the words may have weakened the directed forgetting effect in the present study. This weakened DF effect may in turn have meant that a significant DF effect was not demonstrated in the present study due to insufficient power in the analysis, that is, the failure to find a DF effect when looking at Core recall may have been a Type II error.

In the test of the directed forgetting effect there was an N of 48 in the 'forget' condition and an N of 47 in the 'remember' condition and these compare favourably with Ns used in other work using this paradigm on both 'normal' participants and those with emotional disorders (e.g. Geiselman and Bagheri, 1985; Power *et al.*, 2000 respectively). Furthermore, Power *et al.* (2000) conducted a power analysis and demonstrated that a directed forgetting effect specific to negative adjectives in clinically anxious participants required an N of 25, and successfully demonstrated facilitated retrieval of forget instructed negative words specific to clinical depressives with an N of 14. This means 13 anxious participants were required in each of the 'forget' and 'remember' instructed groups and 7 depressed participants. In the present study there were 10 in the forget and remember instructed groups. Collapsing the participant groups such that there were two participant groups (pain *vs.* non-pain) rather than four, meant that there were 20 in the forget and remember instructed and this did not alter the pattern of results. The fact that a directed forgetting effect was demonstrated in the present study when all the words presented to participants were included in the analysis suggests that any lack of power in the failure to find a directed forgetting effect is arguably due to the high levels of semantic relatedness of the items used. The directed forgetting effect may be smaller when semantically related words are used, requiring a greater N to detect a significant DF effect when semantically related words are used.

2.8.2 What can be inferred from the DF paradigm?

The issue of semantic relatedness weakening the directed forgetting effect leads to the question of whether the directed forgetting paradigm can be seen as demonstrating processes that really are specific to retrieval or whether encoding strategies still play an important role. Whilst the studies examining the DF effect discussed in the introduction suggest retrieval rather than encoding processes are the cause of the effect, the research

cited did not use interrelated words. In the field of mood-congruent recall interrelated words are used as of necessity.

However, the role of encoding differences within traditional DF studies has not been ruled out. As Whetstone *et al.* (1996) have pointed out, there still remain potential differences in encoding between TBF and TBR information in terms of:

i) remember instructed participants continuing to rehearse List 1 words throughout the presentation of List 2 words, and

ii) the differential contextual segregation of words in List 1 compared to words in List 2 brought about by an instruction to forget. That is, participants told to keep remembering material may view the words as occurring in the same context, whereas participants told to forget half way through word presentation may view the two lists as separate, with different contextual cues attached to the two lists.

In their test of this, Whetstone *et al.* added an extra group in addition to the usual 'forget' and 'remember' instructed groups. This additional group were told that they would be asked to remember all words presented in addition to remembering which list (first or second) the word came from. They called this the 'segregate' group. However, they found that the segregate group performed similarly to the remember group. The purpose of the segregate group was to try and minimize rehearsal of List 1 words during List 2 presentation, attempting to mirror conditions of the 'forget' instructed group. However, a post-test question which asked participants "Did you try to think about the first list while you were studying the second list?" revealed similar answers in both the remember and segregate groups with 50% of people in the remember group answering 'no' to this question and 55% answering 'no' in the segregate group. Given that 76% of participants in the forget condition answered no to this question it seems the study failed in its aim to provide an adequate control for List 1 rehearsal during List 2 presentation. In addition, those forget instructed participants who *did* report thinking about List 1 items during List 2 presentation exhibited a greatly reduced DF effect of 0.8 words

difference in recall between List 1 and List 2 compared to a difference of 2.5 words in those participants who did *not* report thinking about List 1 during List 2 presentation.

It seems plausible therefore that having words from the same categories in both lists may reduce the DF effect either through semantic linkage such as that reported by Goldstone *et al.* and/or through the content of the second list reminding participants of words already seen in List 1 which may enforce a kind of involuntary rehearsal.

2.8.3 The pain related recall bias

A significant main effect of Word type was found across all groups whereby they all tended to recall more gardening words than either of the other two word types, so the failure to find a sensory recall bias in chronic pain sufferers does not appear to be due to a Type II error, as there was no evidence of a non-significant tendency for chronic pain patients to recall more sensory pain words which might have emerged as significant had there been greater power in the analysis. However, there are methodological differences between the current study and those of previous research demonstrating recall biases in chronic pain groups which might account for why a pain-related recall bias was not demonstrated in the current study. In particular, these include whether a self-referential encoding instruction is used, the inter-stimulus presentation time, and the type of neutral words used.

2.8.3.1 Self-referential encoding

It has been suggested that the probability of demonstrating a recall bias is increased using a self-referential encoding manipulation (Williams *et al.*, 1997), and the lack of such an encoding strategy in the present study may account for the lack of recall bias. As noted in the introduction, pain-related recall biases have been demonstrated both with a self-referential encoding strategy (Pincus *et al.*, 1993) and without (Edwards *et al.*, 1992). It has been argued, though, that in the absence of a self-referential encoding strategy participants preferentially recall material of a certain type because

they find it personally relevant. Hence self-reference operates as an implicit coding strategy. An explicit self-referent encoding strategy was not used in the present study

i) because it might have compromised the demonstration of a retrieval inhibition effect (Geiselman, Rabow, Wachtel and MacKinnon, 1985),

ii) because it is not a necessary condition for demonstrating a recall bias (Edwards *et al.*, 1992, Pearce, Isherwood, Hrouda, Richardson, Erskine and Skinner, 1990), and

iii) because that would have added an extra independent variable (self *vs.* other encoding) to an already complicated design.

2.8.3.2 Inter-stimulus interval

The word list stimuli was presented at a rate of one word every five seconds. The one used in the present study was chosen to mirror the interval used in previous directed forgetting work of 5 seconds (Myers *et al.*, 1998). In previous work on pain-related recall biases there has been variation in the inter-stimulus interval used. In the study by Calfas *et al.* (1997) a 5-second inter-stimulus interval was used. Some have used smaller and some have used larger inter-stimulus-intervals, for example, Edwards *et al.* (1992) used 2 seconds and Pincus *et al.* (1993) used unlimited exposure time. Whilst the inter-stimulus interval used in the present study might explain the failure to find a pain-related recall bias, studies varying the presentation rate of word stimuli using the directed forgetting paradigm in chronic pain sufferers would obviously have to be conducted to see whether this affected the pattern of results. However, given that recall biases have been demonstrated with varying inter-stimulus intervals it seems an unlikely account of the lack of a pain-related recall bias in the present study.

2.8.3.3 Structure of the material used /Type of neutral words used

The failure to find a pain-related recall bias in chronic pain sufferers can also be seen as potentially related to the structure of the material and there are two plausible explanations for why this might be an important feature.

i) Internally vs. externally generated strategies

State dependent mood effects have been speculated as occurring only when the dependent variable is an internally generated event (Williams *et al.*, 1988). When words are clearly categorized, as in present study, the material may contain an 'implicit' encoding strategy i.e. to put the words into categories, and hence represent an externally generated strategy. The fact that the words were so clearly categorized, confirmed by the finding that categorizing the words was the strategy most frequently employed by participants in the present study, may have rendered generation of individual encoding strategies largely redundant.

ii) Categorization

It may be that in previous research which used an uncategorized neutral word group the pain words stand out more obviously as a category to pain sufferers than to pain-free controls. Hence it may be pain sufferers tendency to notice and categorize pain words that leads to their enhanced recall. In the present study, a categorized neutral group of words was used in place of the uncategorized neutral group so that an 'interested control' group could be used. The failure to replicate the finding of a pain-related recall bias in pain sufferers may therefore relate to the fact that there was another clear-cut category, that of gardening, which may have been an equally effective aid to recall. Indeed, in the present study all participants regardless of group status demonstrated a recall advantage for the gardening words.

It is well demonstrated that presenting words which are interrelated (e.g. come from the same category or categories) leads to higher recall levels than presenting

unrelated words (e.g. Puff, 1979). However, a further point emerged in the present study.

Poor task performance in depressives has been eliminated when structured materials have been presented (Ellis and Ashbrook, 1988). The use of categorized material alone constitutes more structured material than previously used in studies demonstrating pain-related recall biases. Hence the failure to find overall differences in recall levels between the groups in the present study may be due to this fact. In addition, the finding that there were group differences in recall when Total recall was used as the DV which included the unrelated filler items, could be interpreted as supporting this interpretation, although clearly this would need more careful examination as the filler items are not only unrelated but occupy primacy and recency positions, hence the precise cause of this result is unclear.

Participants were asked to briefly describe their use of strategies and whether they noticed anything unusual about the words they had seen. These questions raised the possibility that different people viewed the meanings of the words shown in different ways. Although much of the previous research exploring memory for pain-related words has attempted to control for this fact by using a group of categorized neutral words as a comparison to the categorized pain words, the words used are typically categorized by the researcher (as was the case in the current study). As such, the words are therefore assumed to have fixed meaning according to their category label and hence do not vary in terms of their category membership across individuals or across different participant groups. However, in the present study, people reported viewing the same words as having different meanings. For example, some people for whom gardening was a hobby reported viewing the words spreading, digging and splitting as gardening related words, whilst some people with chronic pain reported viewing them as pain related words. Other research has also shown that under conditions of ambiguity of meaning, pain

sufferers are more likely to interpret ambiguous cues as pain related rather than related to some other theme in comparison to pain-free controls (Pincus *et al.*, 1996).

The implications of such findings in terms of research into recall biases are clear: if more words are viewed as pain-related by pain-sufferers than anticipated by the researcher, this effectively means that more pain words are being presented to pain sufferers than to controls. If there are more words in a category, they are more likely to be categorized together and there is also a greater probability that a given item under that category will be recalled. As a result, the findings that pain sufferers report more pain-related words than pain-free controls seem unsurprising. Such results may still reflect differences in the encoding and retrieval of pain words between pain sufferers and pain-free controls, but the results are confounded with differences between the groups in word interpretation: people suffering pain are viewing more of the words as pain related than the pain-free controls.

It seems plausible to suggest that the recall bias may typically be demonstrated when there are words which are ambiguous and could be subsumed under the category 'pain'.

2.8.4 Conclusions

Reconsidering the question of retrieval inhibition in the context of recall biases presents the following problems. Retrieval inhibition is only put forward as a hypothesis to explain certain effects when accounts which involve differential encoding strategies can be ruled out (e.g. Geiselman *et al.*, 1983). However, such encoding strategies involve questions of differential rehearsal and separation of TBR and TBF information. In the present study the issues relating to differential encoding related to word type and hence cut across the boundary between TBR and TBF information, applying to both remember and forget instructed material, but potentially differed for word type.

Whilst debates in the literature about the processes involved in recall biases have usually stated that such biases could be due to biased encoding, search and/or retrieval strategies, the current study initially set out to explore whether reduced inhibition towards particular words might 'account for' the recall bias, i.e. demonstrate whether the recall bias was specifically linked to processes of retrieval. On reflection, it seems that if the hypothesis of inhibitory failure specific to pain-related words in chronic pain sufferers were supported, this may still reflect an encoding difference between pain words and other word types. That is, as Geilselman *et al.* (1985) have previously demonstrated, if depth of processing manipulations are used and this leads to a weakening of the DF effect, a failure of retrieval inhibition specific to pain words may just reflect the fact that a form of deeper encoding has occurred for this material. Teasdale and Barnard (1993) have suggested the recall bias is the result of participants identifying with the words at a higher level of meaning (the Implicational level), and cite the use of self-referential encoding strategies and trait adjectives as being particularly likely to result in the demonstration of recall biases as evidence for this. Implied or emotive meaning could readily translate into a 'depth-of-processing' argument whereby such material is automatically encoded more deeply by virtue of its personal relevance. This means that the finding of a specific lack of retrieval inhibition with reference to pain words in pain sufferers would arguably show us another side of the same coin: that such words are being encoded in a deeper manner.

However, an additional problem arises from the possibility that word meaning may differ across participant group, raising further questions about what a positive result might mean. Specifically, it is assumed that the remember group constitute an adequate control group for the forget group. Yet the former are essentially shown one list of words whilst the latter is essentially shown two. The category size of the words may therefore differ for the remember and forget instructed groups as well as differing across participant groups.

The next study therefore aimed to explore the extent to which the words used in the current study are collectively agreed upon as pain-related, regardless of pain status, as this has important implications not only for the adequacy of the control group used in the DF paradigm, but more generally for studies which attempt to examine factors accounting for the recall bias in clinical groups.

2.9 SUMMARY

The role of inhibitory processes in the enhanced recall of pain-related words in chronic pain sufferers was explored using a list method directed forgetting paradigm. Two groups of chronic pain sufferers were studied, depressed and not depressed, and two control groups, keen gardeners and non-gardening pain-free controls. Three word types: sensory pain, affective pain and gardening words plus filler items were presented in a mixed list format. Participants were randomly assigned to a 'forget' or 'remember' instruction condition. The 'forget' group were presented with the first list then asked to forget it and concentrate just on the second list. The 'remember' group were asked to keep remembering both lists. Both groups were then given a recall test for all words that they had been presented with.

There was no evidence for either general reduced inhibitory function in pain sufferers, or specific reduced inhibitory function towards pain words in pain sufferers and possible reasons for this were discussed. The possibility emerged that there might be differences between participants groups in their perception of the meaning of the words presented to them.

Chapter 3

How does pain and personal interest affect perceived word meaning? An unconstrained card sort of pain and gardening words in chronic pain sufferers, amateur gardeners and controls.

> "..a word hasn't got a meaning given to it, as it were, by a power independent of us, so that there could be a kind of scientific investigation into what the word really means. A word has the meaning someone has given to it." (Wittgenstein, 1969; p. 28)

3.1 INTRODUCTION

The second study in the thesis aimed to explore the role of schema in the perception of pain-related meanings in pain and non-pain participant groups, in order to test one of the assumptions of Study 1.

The role of cognitive mediators or 'schema' in the maintenance of depression, anxiety and pain has been a central topic of recent research (Williams *et al.*, 1997; Edwards *et al.*, 1992). However, despite the range of potential methods which can be employed to study schema (Beck, 1970), word lists are frequently used, principally because of the belief that this method offers greater experimental control. For example, in their book on Cognitive Psychology and Emotional Disorders, Williams *et al.* state:

> "The use of word lists allows one to control the affective tone of the encoding material as well as the type of mood prevailing during encoding and retrieval." (p. 141)

This belief that word lists offer experimental control clearly rests on the assumption that the same words are effectively being presented to both control and experimental subjects, particularly as regards emotional valence. However, such an assumption seems questionable on both theoretical and empirical grounds, and potentially has important implications for the inferences that can be drawn from

previous research which has used word list stimuli, in particular, studies that aim to investigate the potential causes of the recall biases previously demonstrated, such as self/other encoding manipulations and retrieval inhibition.

3.1.1 Theoretical and empirical challenges

Schema are widely considered to be structures which help guide what we attend to, what we perceive, what we remember and what we infer (Beck, 1970; Neisser, 1966; Augoustinos and Walker, 1995). Neisser cites Bartlett (1932) as having shown that:

> "Verbatim recall of a story occurs very rarely, while reorganization in line with the interests and values of the subject must be expected" (Neisser, 1966; p. 282).

Hence, according to schema theory, personal interest is expected to play a role in the perception, organization (or understanding) of material and its subsequent recall. However, despite appeals to schema theory in the explication of their results, researchers using word lists frequently assume that any emotional state or hypothetical emotional schema will not affect perceived word meaning. As a result, word lists are typically constructed by the researcher and emotional valence ratings of the words used performed by 'control' subjects (e.g. Bradley and Mathews, 1983; Edwards *et al.*, 1992). The only difference in perceived word meaning that is apparently expected is either under conditions of ambiguity or in the connotation of words, rather than their denotation (e.g. Teasdale and Barnard, 1993). For example, previous research has shown that when ambiguous stimuli are presented, interpretation is biased towards thematically-related concerns. Interpretative biases of this kind have been demonstrated towards anxiety- and pain-related material, in chronically anxious individuals and chronic pain sufferers respectively (Eysenck, Mogg, May, Richards and Mathews, 1991; Pincus *et al.*, 1996). However, these biases are not just confined to conditions of ambiguity. For example, Skelton (1980) (cited in Pennebaker, 1982) has demonstrated that high symptom reporters rated all three word types (health-related, ambiguous and

neutral words) as more health related than low symptom reporters. Thus, in summary, differences in the understanding of words could be expected to vary along with personal interest.

This issue has important implications for the inferences that can be drawn from previous research, particularly those concerning recall biases in chronic pain and depression. If participants are viewing words differently, and in line with personal interests and concerns, they will be categorizing them differently, and hence effectively perceiving different word lists. Pain sufferers, for example, may be perceiving more of the words as pain-related than non-pain sufferers. As a result they are effectively being shown a larger category of 'pain words'. It has been demonstrated that presenting words that are interrelated (e.g. come from the same category or categories) leads to higher recall levels than presenting unrelated words (e.g. Puff, 1979). In addition, category size affects recall performance (e.g. Hunt and Seta, 1984), with larger categories often being linked to superior recall. If pain status is affecting perceived category size, category size is no longer a factor which can be 'controlled for' by having equal numbers of the different word types, but instead, becomes part of the effect being studied.

Although some of the previous research exploring memory for pain-related words has attempted to control for categorization effects on recall performance by using a group of categorized neutral words as a comparison to the categorized pain words (e.g. Edwards, 1992; Pincus *et al.*, 1998), again, the words used were categorized by the researcher. As such, the words are assumed to have fixed meaning according to their category label and be viewed as meaning the same thing across individuals and across different participant groups. However, in Study 1 participants' comments suggested that people did not view the same words as having the same broad meaning, implying that the assumption of stability of category membership was possibly ill-founded: for example, some people reported viewing the words spreading, digging and splitting as

gardening related words, whilst some people reported viewing them as pain related words. In addition, participants mentioned other categories as being present in the list of words they had been shown: for example, as relating to the weather, to stress, to being horrible to people, to doing things, to movement, and to illness, to mention some of the more common categories.

3.1.2 Previous research into the meaning of pain words

Previous research has examined the meaning of pain words taken from pain questionnaires such as the McGill Pain Questionnaire and Tursky's Pain Perception Profile, in both chronic pain patients and pain-free controls. The focus of this research has been on issues surrounding the measurement, and hence the diagnosis and treatment of pain, and therefore differs from the aim of the research presented here (e.g. Clark, 1984; Janal, Clark and Carroll, 1993; Clark, Fletcher, Janal and Carroll, 1995). For example, Clark has argued that understanding the dimensions underlying both similarity judgements of physical sensations varying in intensity and frequency (Clark, 1984, Janal *et al.*, 1993), and pain descriptors used by cancer pain and pain-free controls (Clark, 1984; Clark, Ferrer-Brechner, Janal, Carroll and Yang, 1989), can help provide a test of the different theories of pain and the number of dimensions different pain theories propose. In a study looking at the similarity ratings of brief, radiant heat stimuli by 20 volunteers, Clark found two primary dimensions, the first related to the strength of the sensation, and the second related to the perceptual qualities of the sensation, i.e. heat or pain. In a study looking at the similarity ratings of nine pain descriptors given by 24 cancer-pain and 24 pain-free controls, the dimensional nature of pain received further support (Clark *et al.*, 1989). Clark *et al.* (1989) found that 3-dimensions emerged for both groups of subjects. Clark has argued that the results of studies such as these provide support for multidimensional rather than unidimensional models of pain. For example, in the former study, Clark (1984) argued that the resulting two-dimensional

solution supports multidimensional models of pain, as opposed to unidimensional models, such as pattern theories. As noted in Chapter 1, the latter type of theory proposes that pain is an intense form of simulation of any sort, and hence to support pattern theories, sensation strength and sensation quality (pain vs. non-pain) ought to form part of the same dimension, such that a sensation of a certain strength should also be seen as a sensation of a certain quality. In the latter study, Clark *et al.* (1989) argued that the three dimensions which emerged roughly corresponded to the three dimensions of pain proposed by Melzack and Wall, and embodied in the McGill Pain Questionnaire, of sensory, affective and evaluative.

Whilst this work has different aims from that of the present study, (namely to contribute to understandings of pain measurement rather than to explore group differences in perceived word meaning), it also provides evidence of the variability of perceived meanings, both within pain groups and between pain and non-pain groups. Of particular relevance here is the apparent lack of consistency in the way people judge affective pain words, and differences between pain and non-pain groups in terms of the salience of different pain meanings. For example, Clark *et al.* (1989) examined the group scaling space of cancer-pain and pain-free volunteers separately. Whilst three dimensions emerged in both group scaling spaces, there were differences between the groups in the apparent salience of the different dimensions. Salience was evaluated by looking at the percent variance of the similiarity ratings which was accounted for by the different dimensions. The groups differed in the amount of variance accounted for by the pain intensity dimension of pain: it accounted for more variance in the pain than the non-pain group. The two participant groups were equivalent in terms of the amount of variance accounted for by the emotional (affective) quality dimension. Clark *et al.* interpret this as showing that the pain intensity dimension was less relevant to the pain-free volunteers whilst for people with persistent pain, pain sensation and emotion were

equally 'pervasive' (Clark *et al.*, 1989: p. 29). This suggests pain meanings or at least more subtle differentiations in pain meanings may be less salient to non-pain participants.

There is also evidence that pain words may have a number of dimensions. In a study examining possible reasons for people's unreliability in scaling affective words, people were asked to scale intensity and affective items from Tursky's pain perception profile (Morley, 1989). It was found that the intensity words had effectively one dimension whilst the affective words were found to have three, thought to refer to pain bearability, intensity of emotional reaction to the pain and the apparent extent to which were able to focus attention away from the pain. Whilst this analysis of the dimensionality of different pain words was used to test one of the assumptions of the pain perception profile, it is of relevance here in arguably providing evidence consistent with the view that the salient meanings of pain words may vary both over time and across individuals. The dimensional nature of affective pain words was interpreted by Morley as suggesting that people's unreliability in scaling affective words could arise from the fact that the affective words have more than one dimension, and that the dimension people use to scale the items could change over time, resulting in inconsistent scaling behaviour.

More direct evidence that pain words may have variable or ambiguous meanings arguably comes from a study conducted by Clark *et al.* (1995). In a study which aimed at examining the validity of the structure of the McGill Pain Questionnaire, Clark *et al.* (1995) examined the similarity ratings of 270 pain/suffering and health/happiness words. These words were taken from a variety of sources including the McGill pain Questionnaire and the Zuckerman Multiple Affect Adjective Check list. They used words not included in the MPQ because they argued that the latter does not contain enough words which describe the emotional/motivational component of pain, and

wished to include pleasant as well as unpleasant words to ensure broad, well defined clusters. The similiarity ratings were given by 'experienced pain researchers' rather than pain sufferers, and were analysed using a hierarchical clustering model. In this analysis the three major word groupings in the McGill Pain Questionnaire (sensory, affective, evaluative) were not recovered. For example, each word within the evaluative group was found in a different cluster. Of particular interest here is their finding that the inclusion of other positive words meant some words were apparently no longer seen as referring to pain. For example, the word 'intense' appeared in the 'healthy' subcluster under primary cluster 'health behaviours'. This suggests that the perceived meanings of pain descriptors may vary depending on the other words they are presented with. Indeed in summary, Clark *et al.* (1995) state:

> "It may be concluded that a number of words in the MPQ and other questionnaires are extremely are extremely ambiguous, and that there is no way the investigator can know how a patient interprets them." (Clark *et al.*, p. 328)

As noted earlier, the aim of the present study differs from the aforementioned work in that it aimed at assessing the degree to which the words used in Study 1 were perceived as pain-related regardless of pain status, rather than as exploring some of the assumptions underlying measurement tools such as the McGill Pain Questionnaire and Turskey's Pain Perception Profile. As well as exploring perceived meanings, the present study aimed to examine a further finding from Study 1: namely, the tendency for all participants, regardless of group membership, to recall greater numbers of gardening words than either of the other two types of words (sensory pain or affective pain). As mentioned above, superior item recall frequently results from presenting related words. It seems plausible that the category of gardening words may have been perceived as a more cohesive or more salient category than either of the other two categories, as participants in Study 1 frequently referred to noticing two main categories one relating

to pain, the other to gardening, and some mentioned the gardening words as standing out. An additional factor might be that gardening words are more imageable/concrete than pain words, a factor which also aids recall.

3.2 AIMS AND HYPOTHESES

The hypothesis under test was that pain sufferers would view more of the words as pain-related than pain-free controls. Of further concern was whether such a bias would be associated with pain as a persistent negative state or pain as reflecting something of personal concern. Two control groups were therefore used: one was a group with a specific interest in gardening. The second control group comprised non-pain, non-gardening participants. As differences in understanding would be expected to vary along with personal interest, it was also predicted that gardeners would demonstrate a tendency to categorize more words as related to gardening than to any other theme. It was expected that a control group would show no bias towards categorizing words according to one theme in preference to any other.

In addition the study aimed to explore the difference between the three word types in degree of category cohesiveness. The study directly addressed these two issues using an unconstrained card sorting task.

3.3 METHOD

3.3.1 Participants

51 participants took part in the present study. They comprised three groups: chronic pain sufferers (N=17), amateur gardeners (N=17) and non-pain, non-gardening controls (N=17).

Chronic pain was defined as present if it was linked to a benign condition, was ongoing and had persisted for more than 6 months despite medical treatment. The other inclusion criteria, which applied to all the groups, were:

- No visual and /or auditory problems
- An ability to read and write English
- Aged over 18 years.

The incidence of pain sufferers scoring above the cut-off of 20 on the BDI was too low to be able to recruit for an additional pain, depressed group. Also the key recall bias under study is the one in non-depressed pain sufferers towards sensory-pain words, and hence it is factors related to pain rather than depression and pain which are of interest here. The pain sufferers were recruited from pain clinics at the Middlesex and Northwick Park Hospitals where they were attending appointments for cognitive-therapy and routine medical management respectively. The non-pain participants were all recruited from local advertisements. The study was approved by the Institutional ethical committee and all participants gave written, informed consent (see Appendix B)

3.3.2 Design

A mixed factorial (3 x 3) design was used. The between-subjects factor was *Group* of subjects (chronic pain, gardener, control), the within-subjects factor was *Word type* (sensory pain, affective pain and gardening). The dependent variable in the ANOVA analyses was number of words categorized by the participants as being in one or other of three word groups mentioned above.

3.3.3 Materials

Questionnaires.

Pain measures:

i) Four 101 point Visual Analogue Scales of pain intensity: present pain, average pain over the last week, worse pain over the last week and least pain over the last week. They were anchored 'No pain'/'Worst pain imaginable'

ii) People were also asked whether they currently had a pain complaint, and, if so, how long this pain had lasted. Those with persistent pain continuing for more than six months, despite medical treatment were classified as chronic pain sufferers. (See Appendix A.)

Depression measure: the Beck Depression Inventory (BDI; Beck *et al.*, 1979). (See Appendix A.)

Gardening measures to assess whether gardening was a hobby consisted of

i) the direct question: 'Is gardening a hobby of yours?' (Yes/No), and

ii) 'How much do you enjoy gardening?' (11 point scale, anchored Not at all / Very much). Those who considered it a hobby were classified as gardeners. (See Appendix A.)

Word Stimuli: These were the same words used in Chapter 2 (see section 2.4.3).

3.3.4 Procedure

Participants were asked to carry out an unrestrained card sorting task. They were presented with 44 words, 12 sensory pain, 12 affective pain, 12 gardening words and 8 filler items. As the majority of pain sufferers were going to be completing the study in a pain setting and their expectation that the study would relate to pain was likely to be high, all participants in the study were informed that the card sorting task was about long-term pain and word meaning. Participants were asked to sort the 44 words into as many categories as they felt appropriate, according to word meaning. The verbatim instructions were as follows:

> "This is a study about long-term pain and word meaning. The aim of the study is to find out which words people think are similar to each other in meaning and which words people think are different and therefore belong in different categories. There are 44 words in total which have been pasted onto pieces of card. I would like you to sort these words into categories representing your best judgements about which words are similar to each other in meaning, and which are different from each other. There is no one correct way to sort the cards. Make as few or as many categories as you wish

and put as few or as many cards in each category as you see fit. Spread the cards out on the table and keep moving them around until the categories make sense to you. Before you stop, be sure you are satisfied that each word fits best in the category where you have placed it."

They were then asked to label each of these categories in terms of what the category was 'about'. This could either take the form of a word or a sentence. After completing the card sorting task participants completed the questionnaires mentioned above in fixed order.

3.4 RESULTS

3.4.1 Demographics, and pain and mood measures

The assumption of homogeneity of variance was examined for all measures tested using ANOVA. The range in variances were acceptable (i.e. the largest variance was no more than five times greater than the lowest (Howell, 1997)) in all cases except present pain intensity. For this variable a logarithm transformation was used as this altered the variances to within acceptable limits.

Table 3.1 shows the sex distribution and average ages of the three participant groups. There was no significant difference between the three groups in age ($F_{2, 48}$=1.09). There was no significant difference in the frequencies of men and women in the three groups (df=2; Chi-square =1.45).

Table 3.1: Means (and standard deviations) of age, pain intensity, BDI, gardening enjoyment scores and sex distributions across the groups

	Pain sufferers	Amateur Gardeners	Controls
Age	44.59 (16.67)	40.76 (11.23)	37.53 (13.35)
Sex (% female)	70%	53%	53%
Present pain intensity	43.59 (24.80)	6.00 (11.32)	4.76 (7.34)
BDI scores	14.35 (7.21)	6.35 (3.95)	9.06 (8.55)
Enjoyment of gardening	5.44 (2.82)	7.00 (2.15)	3.24 (2.97)

Table 3.1 also shows measures relating to group status. A one-way ANOVA on logarithm transformed scores showed that there was a significant difference between the groups on present pain intensity levels ($F_{2,48}$=3.32; $p<0.05$). Tukey's honestly significant difference (HSD) tests showed this difference was the result of the Pain sufferers having higher present pain scores than either of the other two groups. There was no difference in pain intensity scores between the Amateur gardeners and the Controls.

A one-way ANOVA on BDI scores showed an overall difference between the groups ($F_{2,48}$= 5.99; $p<0.01$). However, Tukey's HSD test showed that this difference was only significant between the Pain sufferers and the Amateur gardeners, and not between the Pain sufferers and the Controls, nor between the Controls and the Amateur gardeners.

A one-way ANOVA on enjoyment of gardening showed a significant difference between the groups ($F_{2,48}$ = 8.52 $p<0.001$). Tukey's HSD test demonstrated that this difference was between the Amateur gardeners and the Controls. There was no significant difference between the Control group and the Pain sufferers, and between the Pain sufferers and the Amateur gardeners.

Thus these results broadly confirm the different group statuses as they relate to pain and interest in gardening.

3.4.2 Card sort results

The number of categories produced by individual participants varied from 2 to 15 categories. The average number of categories produced was 6.51 (SD=2.30). There was no significant relationship between number of categories produced and group membership ($F_{2,48}$ <1). Thirty-seven of the 51 (73%) participants produced a miscellaneous (i.e. un-named) category. Excluding miscellaneous categories, the average number of named categories was 5.78 (SD=2.31) and again this ranged from 2 categories to 15. The range of named categories was the same as the number of total

categories (which included named and miscellaneous categories) because the people who produced both the largest and the smallest number of categories coincidentally did not produce a miscellaneous category. Again, the number of named categories did not differ significantly between the participant groups: ($F_{2,48}$ <1).

The average category size was much lower than the anticipated 12 per category, the number assumed by a typical research design of this kind. Instead the average number of words per named category (excluding any categories labelled miscellaneous and hence not forming a category as such) across participant groups was 7.90 (SD=3.18) and ranged from 2.93-22.0. This value was computed by deducting the number of words put in a miscellaneous category from the word total of 44 and dividing it by the number of named categories. There was no significant difference between participant groups on average category size (to be expected given the lack of difference in category number) ($F_{2,48}$<1).

Average category size including the miscellaneous words as one category gave an average category size of 7.61 words (SD=2.99) with a range the same as above from 2.93-22.0. The range is the same because as above because whilst people gave only one miscellaneous category, coincidentally neither the person who produce the smallest number of categories (2) giving an average of 22 words per category, nor the person who produced the largest number of categories (15) produced a miscellaneous category, giving an average of 2.93 words per category.

3.4.3 Multidimensional scaling analysis.

Both multidimensional scaling and hierarchical cluster analysis could be used to explore the similarity data generated by the card sort and both techniques have been used in previous research on pain words (Clark, 1984; Clark *et al.*, 1995). Hierarchical cluster analysis proceeds by a progressive subdivision (or synthesis) of the data and uses a two-dimensional diagram called a dendrogram to illustrate the fusions or divisions

which have been made at each stage of the analysis (Everitt, 1993). It offers a discrete (as opposed to continuous) spatial structure, illustrating whether words are grouped together at successive stages of the analysis. Multidimensional scaling is a data reduction technique and attempts to find the structure in a set of distance measures between objects or cases. Similarity or proximity measures are used to generate a map which translates these similarities scores into measures of distance which are then plotted, usually in two- or three-dimensional space. This method produces a continuous spatial structure, illustrating relative similarities among the different stimuli, based on the similarity judgements of the participants. The spatial configuration also reveals the dimensions which are relevant to the participants, which may reflect dimensions that the participants themselves are not explicitly aware of. Interpretable features of MDS can therefore be either dimensions and/or distinct clusters that are visible in the spatial representation.

Multidimensional scaling was used to analyze the present data because: i) it offers a clear representation of the structure in the data (perceived similarity of word meaning) (Shepard, Romney and Nerlove, 1972). In particular, through the provision of a continuous spatial structure rather than a discrete one, it is useful for understanding the relative similarity between the words in the three different groupings, notably the relative closeness of the words in the gardening category compared with those in the other two principal categories, and ii) it provides dimensions which can be used to help describe the stimulus space. However, it should be noted that, in contrast to previous work using MDS and pain words discussed in section 3.1.2, the use of MDS in the present study did not form the main analysis of the card sort data. MDS was used here to illustrate two findings: i) that at a superordinate level, the similarity ratings of the participants produce three groups of words, and ii) that the gardening words form a tighter category than the other two types of words. It was not used to determine the

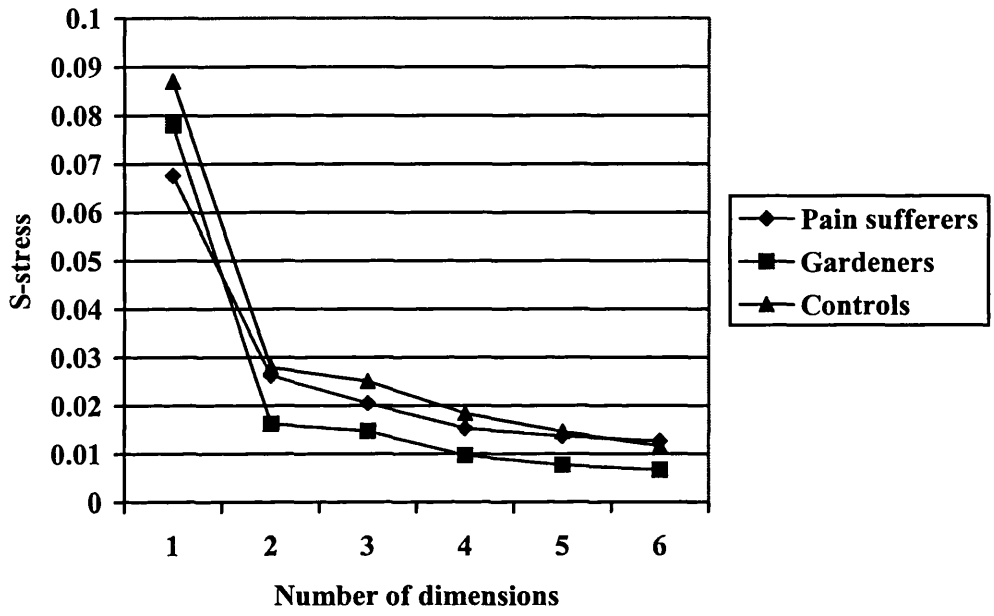
number of dimensions underlying particular words such as affective pain words (cf. Morley, 1989).

MDS is an exploratory technique and the number of clusters is unknown prior to analysis. The data from the card sort was entered in the form of a similarity (distance) matrix. The matrices were square symmetric, with both the rows and columns representing the same thing. Words that were put into the same group were represented by a '0' (i.e. they were as close as they could be), words that were not put in the same group were given a '1' (i.e. they were as distant as they could be). The matrices from each participant within a group (Pain, Gardener, Control) were summed, each group matrix therefore contained figures ranging from 0-17 which indicated the frequency with which two words had been placed in the same category however, as a value of 0 indicated the words were in the same category, a value of 0 in the group matrix meant 17 people had put those two words in the same category, and a score of 17 meant no-one had put the two words in the same category. The similarity matrix was subjected to multidimensional scaling (MDS) using the Phi frequency count measure within SPSS version 9.0. The latter measure is non-metric (nominal) as participants made simple judgements about whether two words should appear in the same category, and the matrix denotes the frequency with which two words were sorted into the same category within each participant group (Schiffman, Reynolds and Young, 1981).

Figure 3.1 shows the S-stress plotted against number of dimensions for each group and illustrates that the best solution for all three groups was a 2-dimensional one. This is demonstrated by the fact that there is a clear change of direction in the slope at 2 dimensions (Everitt and Dunn, 1991). This change indicates that adding further dimensions does not substantially reduce the stress, or lack of 'fit' between the idealized configuration of the points in space compared to the best possible configuration. The

levels of S-stress at 2-dimensions showed that the fit was excellent for the gardeners group and excellent to good for the pain and control groups (Everitt and Dunn, 1991).

Figure 3.1: S-stress against number of dimensions for card sort data for each group



The RSQ value (where RSQ refers to mean squared correlations) indicates the proportion of variance accounted for by the model and therefore gives a measure of the fit of the model to the data. The values for the models for each of the three groups were as follows: for the pain matrix, RSQ = 0.991; for the gardeners matrix, RSQ = 0.994; and for the controls matrix, RSQ=0.989. These values show that in all three cases the MDS model accounted for over 98% of the variance in the data.

The resulting 2-dimensional stimulus configuration for each group is shown in Figures 3.2 – 3.4. These figures illustrate that the grouping of the words is very similar across the three groups and that the two dimensions can be interpreted as corresponding roughly to gardening/not gardening (x axis) and pain/emotion (y-axis). Hence the gardening words vary little around the x-axis (i.e. they are one-dimensional) whilst the pain and emotive words do vary about this axis, but vary little about the x-axis. The

multidimensional scaling (MDS) analysis therefore broadly reproduces the three main word types used in the study. Figures 3.2 to 3.4 also demonstrate that there was greater agreement about the gardening words than about the pain words, shown by the fact that the gardening words are plotted almost on top of one another. Hence the gardening words appear to form a tighter category than either of the other two types of words.

3.4.3.1 Algorithm to adjust for differences in category size

In an unconstrained card sorting task, such as the one used in the present study, people produce different numbers of categories and hence the categories produced vary in size. Burton (1975) has argued that, following principles derived from information theory, measures of similarity can be developed to take account of such individual differences in the number of categories produced. One such measure is based on the argument that if two items (x and y) are put together in one category which contains few other items, i.e. items x and y form part of a small category, then the average similarity between these items is greater than when they are placed together as part of a larger category. The argument is based on the proposition that people who form more categories (and hence form categories of a smaller size) are more discriminating and hence that if they put two words together they should be weighted as more similar than when put together within a larger category (arguably by a participant who is less likely to discriminate).

Figure 3.2: Position of word types for the Pain Group in 2-dimensional space

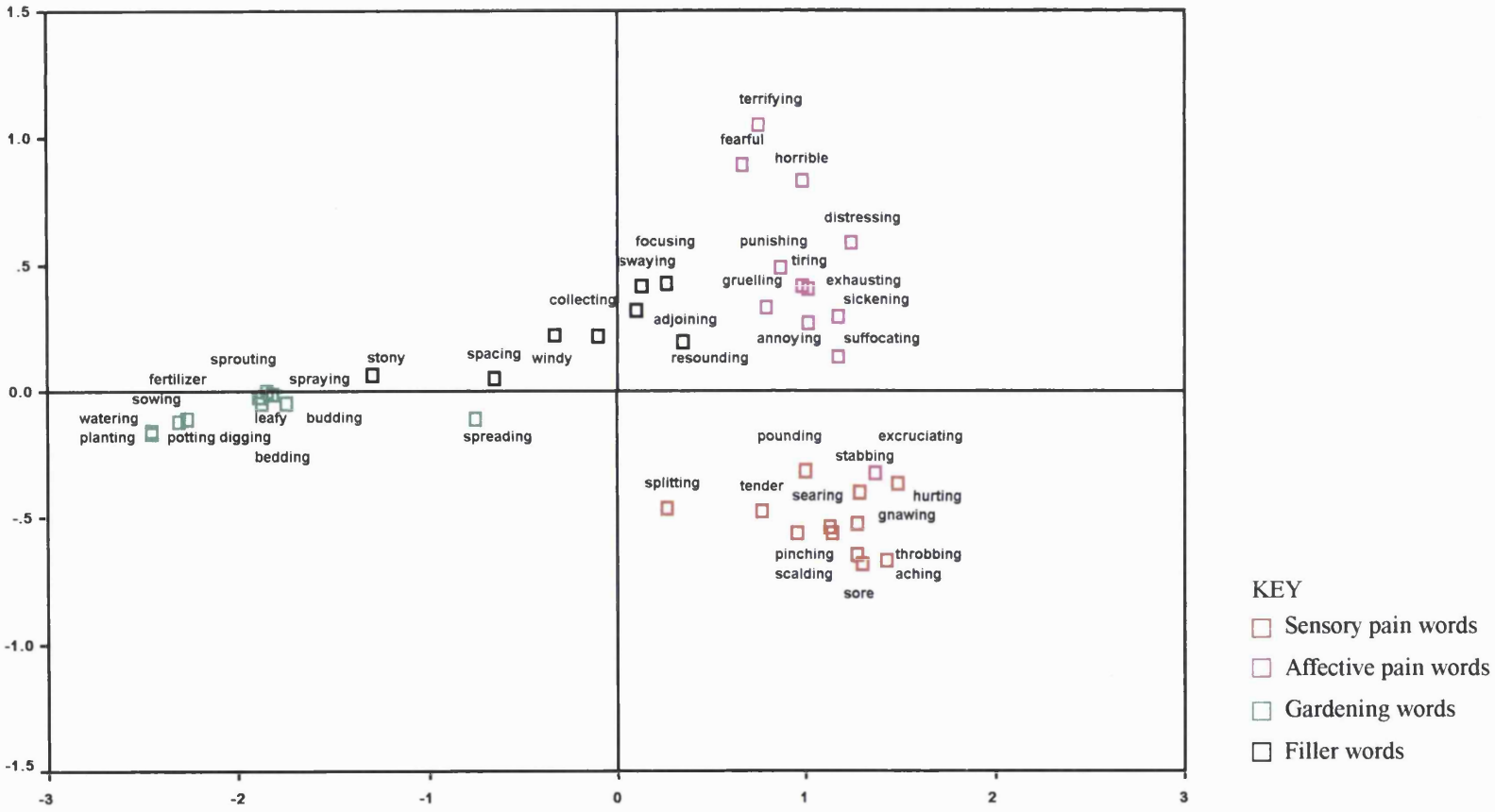


Figure 3.3: Position of word types for the Amateur gardener group in 2-dimensional space

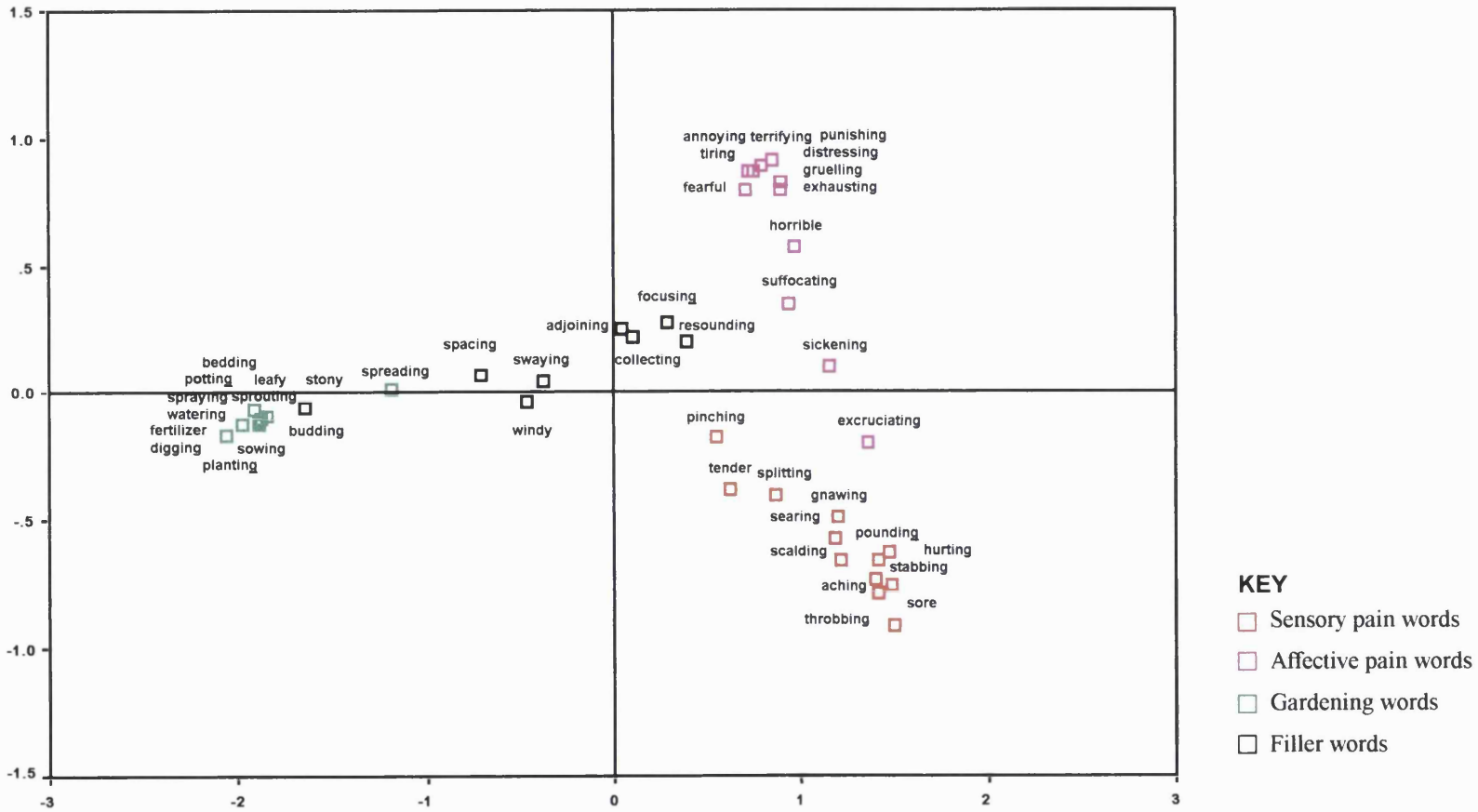
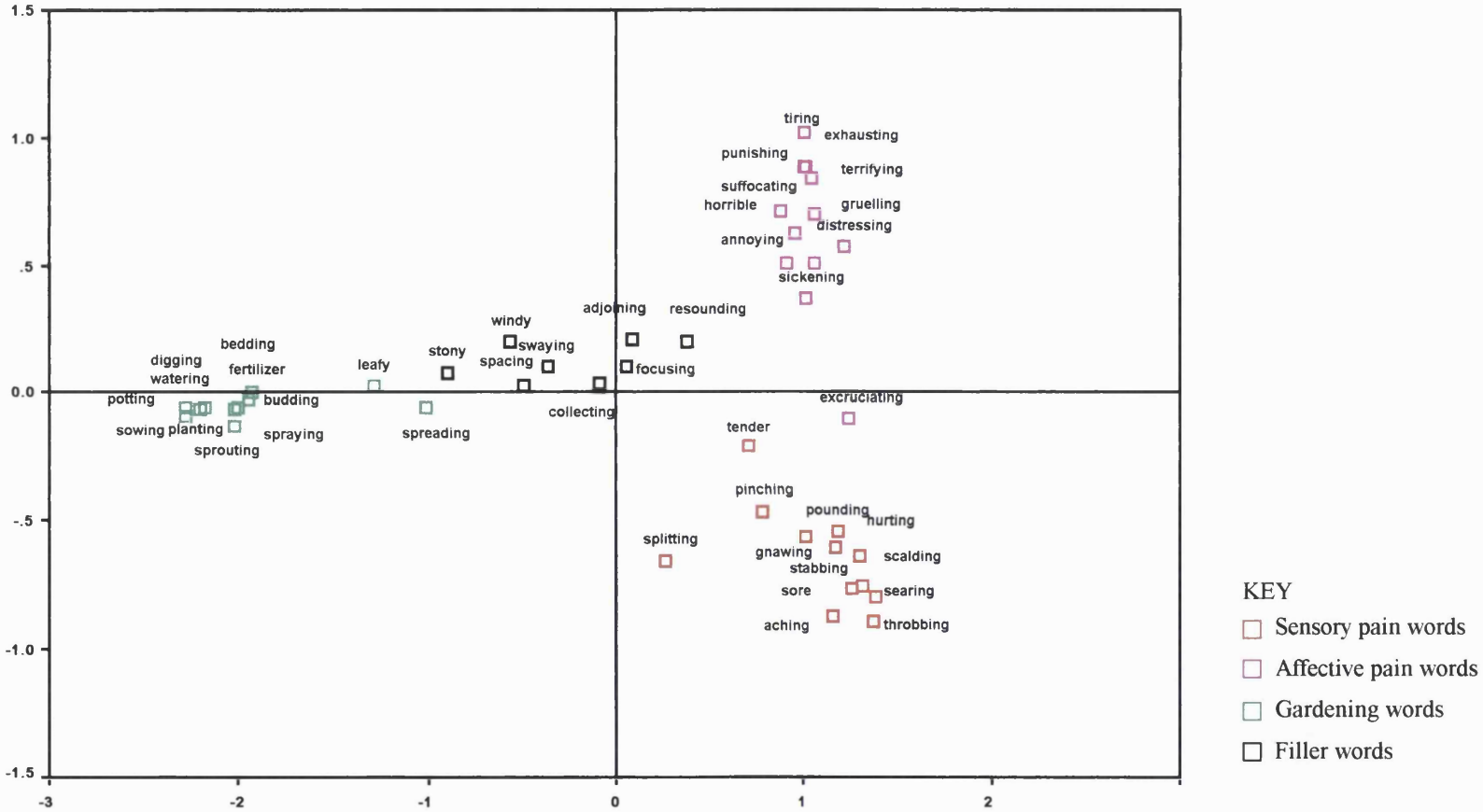


Figure 3.4: Position of word types for the Control Group in 2-dimensional space

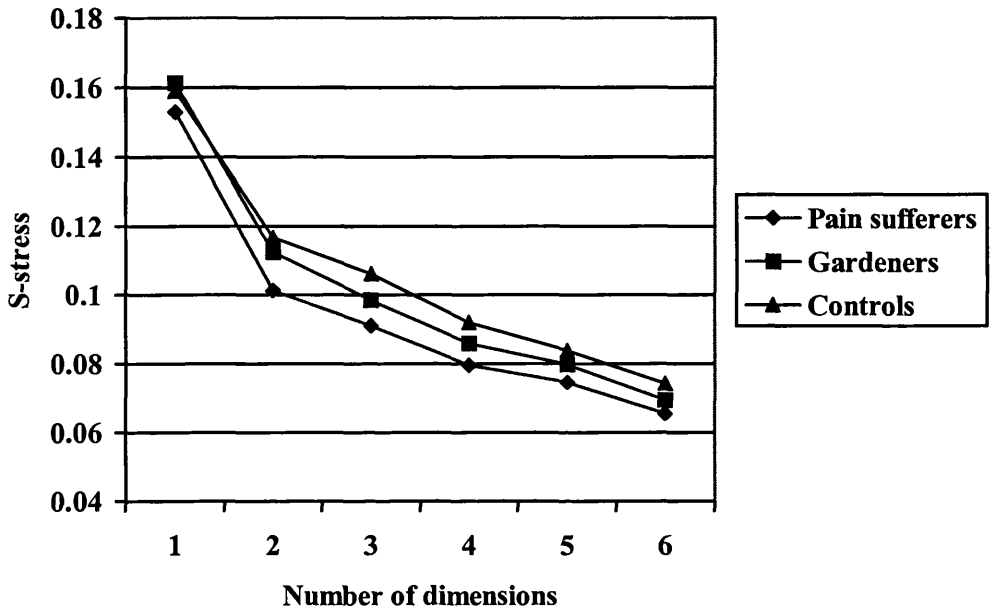


Details of an algorithm which weights the similarity of items put together as being more similar if they co-occur in a small category than if they co-occur in a larger category has been described by Reading, Everitt and Sledmere (1982). This algorithm, which, as noted above, takes into account individual differences in the size of categories which are produced, was used on the present data to see whether a similar higher order pattern emerged when variation in the number of categories people produced was taken into consideration.

The matrices were again square symmetric, with both the rows and columns representing the same thing. The matrices were transformed according to the algorithm outlined by Reading *et al.* (1982). These matrices were then subjected to multidimensional scaling (MDS) using the squared Euclidean distance option within SPSS version 9.0. This method was chosen because it is the most commonly used option for transforming dissimilarity measures into measures of distance (Everitt and Dunn, 1991).

Consideration of the relationship between S-stress and the number of dimensions suggests that a two or three-dimensional solution offered the best fit (see Figure 3.5). A two-dimensional solution was chosen because the additional variance accounted for by the addition of a third dimension was less than one percent in all three groups. Hence the addition of an extra dimension was not considered parsimonious. Furthermore, using two dimensions permits the two different MDS analyses (those with and those without the algorithm adjusting for individual differences in categorization) to be compared (see Figures 3.6 to 3.8). The S-stress at 2-dimensions for all three participant groups was fair (Everitt and Dunn, 1991).

Figure 3.5: S-stress against number of dimensions for card sort data for each group (adjusting for differences in category size)



The RSQ values for the MDS models for each of the three groups were as follows: for the pain matrix, RSQ = 0.970; for the gardeners matrix, RSQ = 0.969; and for the controls matrix, RSQ=0.963 and show that in all three cases the MDS model accounted for over 96% of the variance in the data.

The use of the algorithm taking into account differences in the size of category in which two words are placed effectively adds greater complexity into the MDS analysis, and this is clear in the resulting scaling spaces. As can be seen in Figures 3.6-3.8, there is great spread among the words, notably among the 'filler' words, which vary more along the vertical axis than before and appear more closely integrated into the three main words groupings in some instances. For example, the words 'focusing' 'resounding' and 'adjoining' appear close to the affective pain words in the scaling space of the non-pain groups (both the gardening and the control subjects). However, in general the three main word groupings emerge as distinct clusters. In the pain group, (Figure 3.6) the filler words form a more distinct fourth cluster which does not appear in

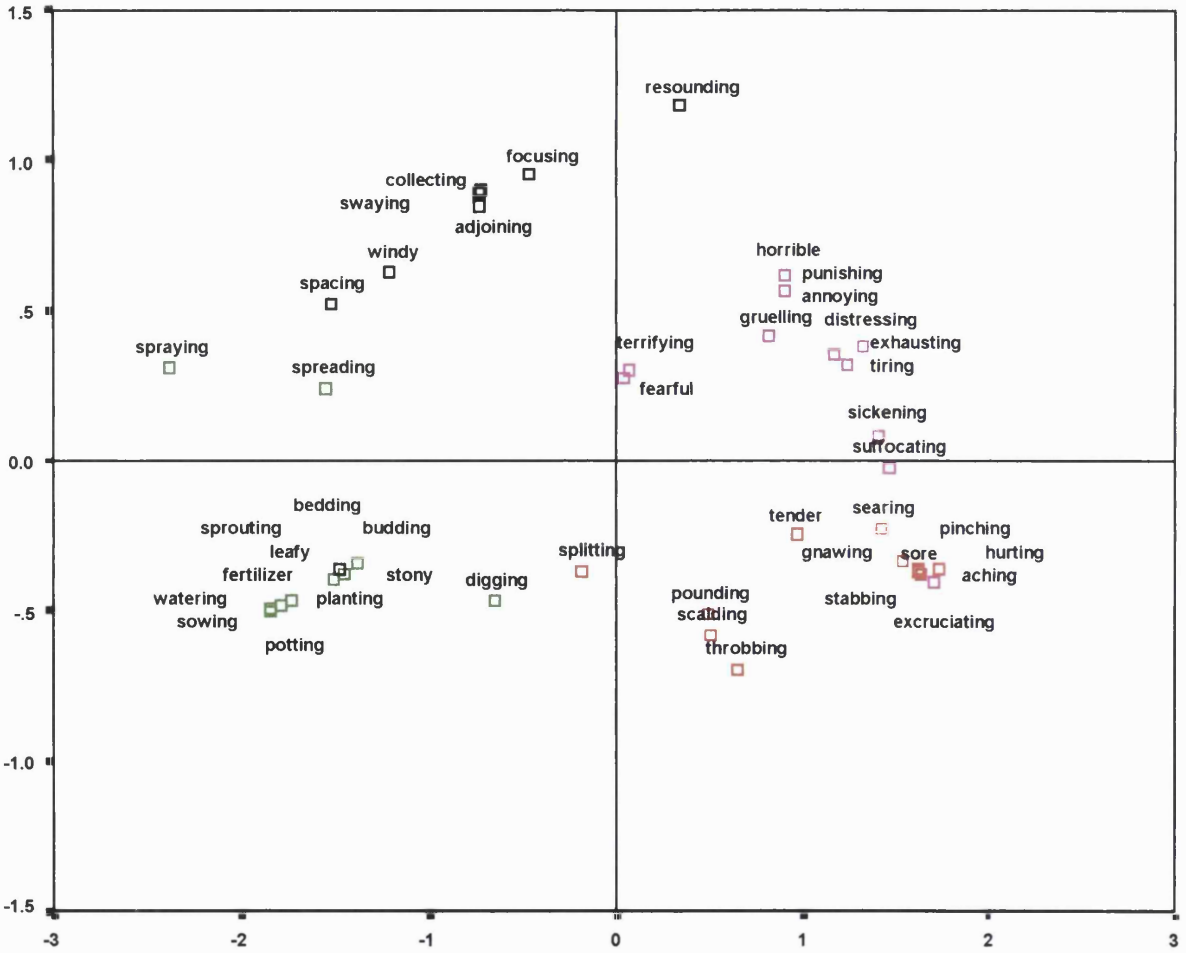
the two non-pain groups or in the original MDS analyses. In addition in the pain group, the sensory pain and affective pain words are plotted as closer in space than occurs in either of the two non-pain groups where the distinction between the sensory pain and affective pain words is more apparent. This provides some tentative support for the view that the sensory and affective pain words are viewed differently in the pain as opposed to the non-pain groups. However, it is less clear in Figures 3.6-3.8 what the dimensions might relate to. The relevant dimensions can occur at any angle (that is they do not necessarily correspond to the horizontal and vertical axes) however the horizontal axes can still be seen as reflecting a pain - non-pain dimension. The meaning of the vertical axis is less clear as the filler words now appear along it, although again it can broadly be seen as corresponding to a sensory-pain – affective-pain dimension.

3.4.4 Content analysis

The MDS reported in the previous section only takes account of which words are put together and produces a higher order (aggregate) pattern based on all participants within one group. Although the dimensions that appeared seemed similar across the three groups the MDS does not indicate anything about the category labels participants attached to these words, and hence what the words and the dimensions of the MDS actually mean to the individual participants. This higher order pattern shows which words participants viewed as similar but does not reveal the *meaning* that they attached to those words.

As stated earlier, this study aimed to analyze differences in perceived word meaning between the three participant groups, and how meaning might vary by group status. Joint subject and stimulus spaces within multidimensional scaling can be used to plot individuals and stimuli in the same space and demonstrate the relationship between

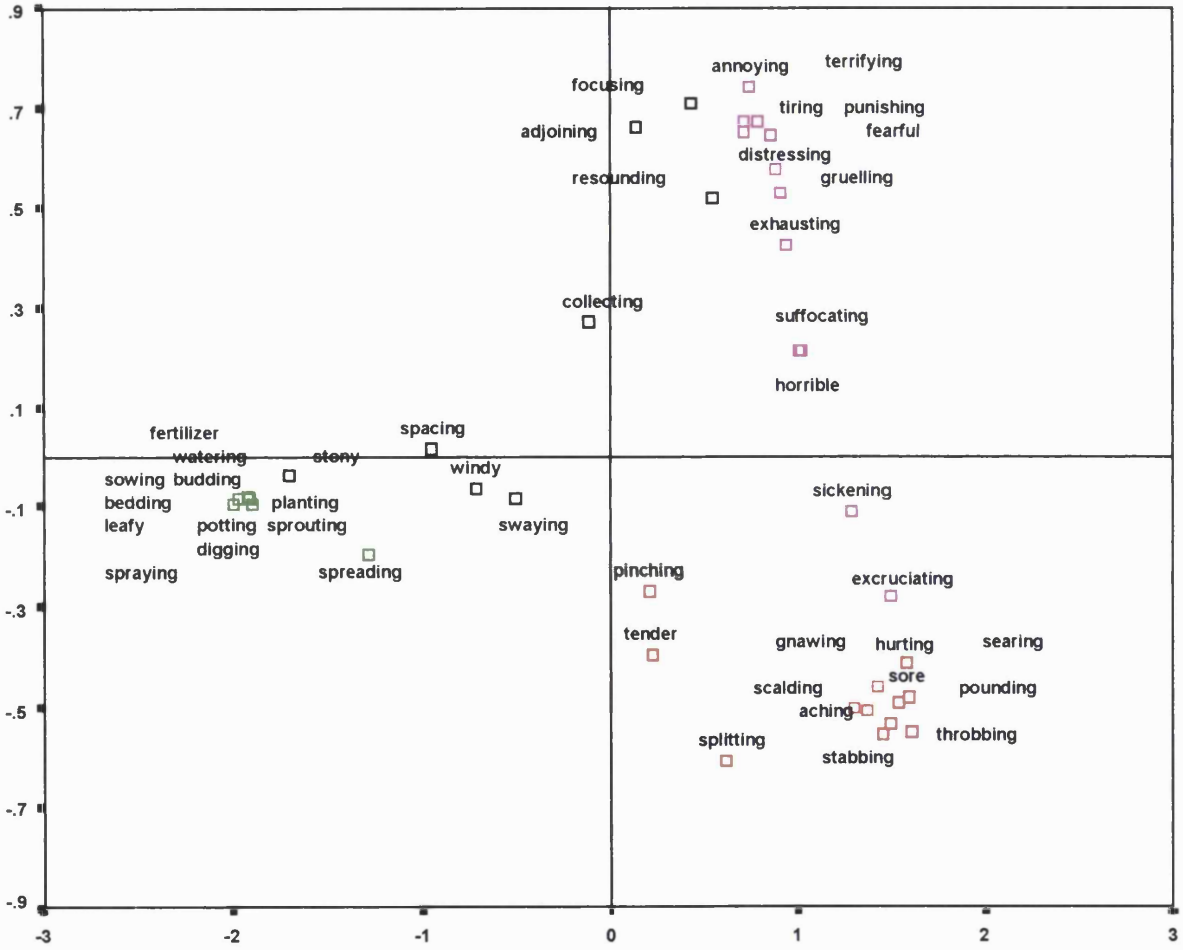
Figure 3.6: Position of word types for the Pain group in 2-dimensional space (adjusting for differences in category size)



KEY

- Sensory pain words
- Affective pain words
- Gardening words
- Filler words

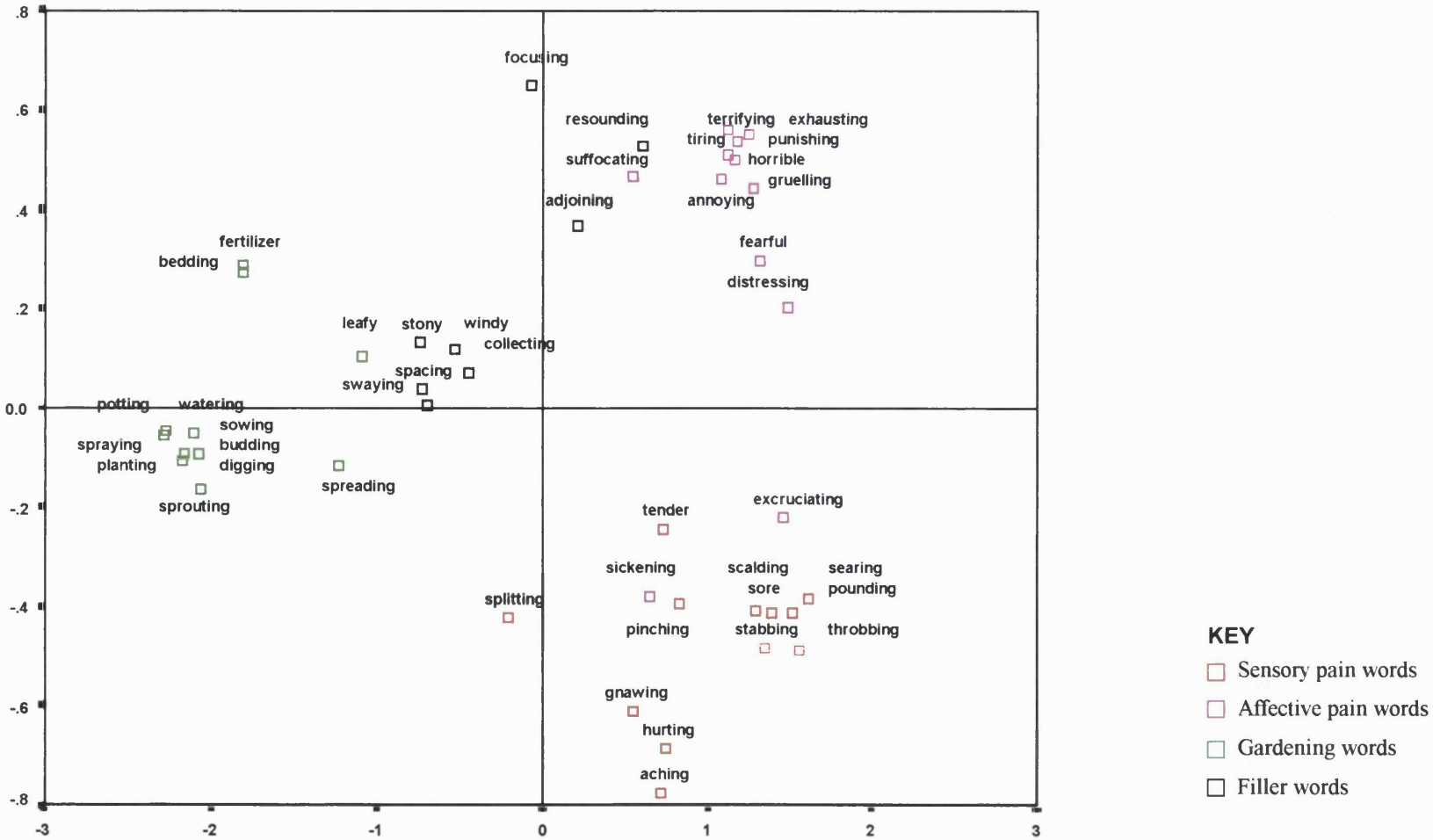
Figure 3.7: Position of word types for the Amateur gardener group in 2-dimensional space (adjusting for differences in category size)



KEY

- Sensory pain words
- Affective pain words
- Gardening words
- Filler words

Figure 3.8: Position of word types for the Control group in 2-dimensional space (adjusting for differences in category size)



KEY

- Sensory pain words
- Affective pain words
- Gardening words
- Filler words

the judgements individuals make and the individuals themselves. This technique is often used to plot preference data whereby people are placed near to stimuli they like and far from stimuli they do not like. However, this analysis is not used here. This is because the use of joint subject and stimulus spaces with the data in the present study would show whether there was a relationship between stimuli similarity and group status. Hence people would appear close to words they thought were similar and far from words they thought were dissimilar. This analysis would not be able to illustrate participant variability in *why* people felt words were similar i.e. their similarity in terms of perceived word meaning. It would not, therefore, reveal anything about differences in perceived word meaning, which is the focus of the present study. Had the data consisted of judgments about word meaning (e.g. how good an exemplar of a pain descriptor each word was), then joint subject and stimulus spacing would have been appropriate as it could have given an indication of the relationship between perceived meaning and group status.

In the current study, the meaning of the words is captured in the category title assigned to the groups. Participants' category labels were therefore content analyzed according to whether they broadly fitted into one of the following three categories: pain, negative emotions, and gardening. The category of negative emotions was used rather than affective-pain because few of the participants in the Gardening group or the Control group categorized the affective pain words as pain-related.

The content analysis was done by two independent researchers who were blind to the group status of the participants. The inter-rater agreement was initially 96%. Discrepancies were resolved through discussion between the two raters. A number of categories did not fit into any of the three main categories and were hence labelled separately. The most common other category label was 'Physical activity'. For example, one participant labelled the group of words 'exhausting, tiring, gruelling, punishing': as

'adjectives relating to tiring physical activity'; another participant labelled the groups of words: 'gruelling, excruciating, tiring, punishing, exhausting, suffocating' as 'stamina' words. Words which did not fit into one of the three main categories were excluded from the following analyses.

3.4.5 Word meaning and group status

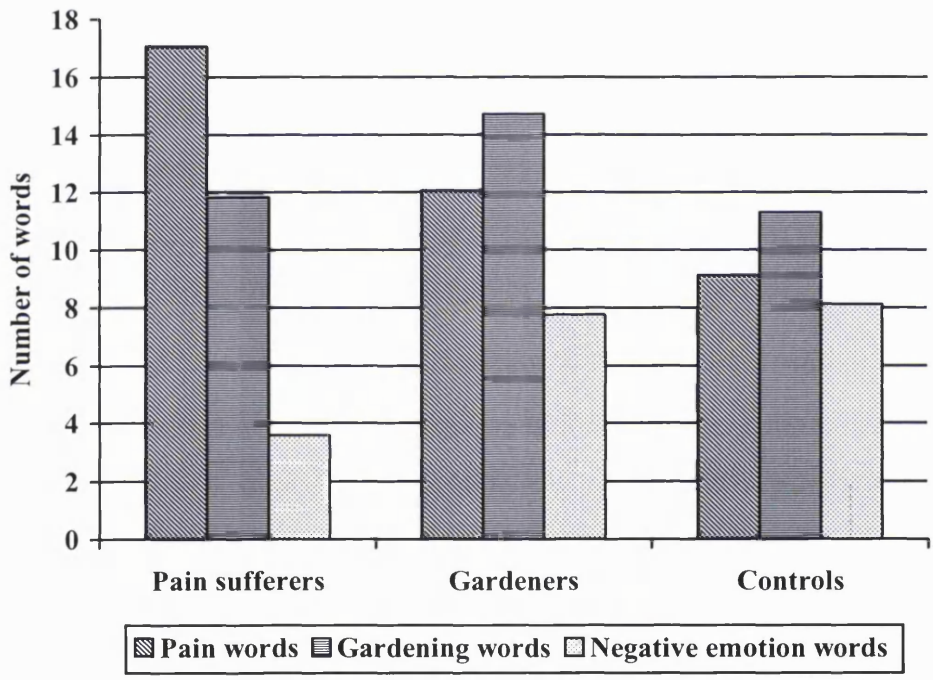
In order to test whether there were group differences in the numbers of words which were categorized as pain-related, a two-way split plot ANOVA was computed with one between subjects variable (*Group*: pain, amateur gardener, control) and one within subjects variable (*Word Type*: pain, negative emotive, gardening). There was no main effect of Group ($F_{2,48}$=2.23; NS) indicating that the groups did not differ in terms of the total number of words that they placed in one or other of these three categories. There was a main effect of Word type ($F_{2,96}$=30.63; $p<0.001$), and a significant interaction between Group and Word type ($F_{4,96}$=9.10; $p<0.001$).

The means for number of words placed in each of the three main categories collapsed across participant groups were as follows: for pain words the mean (and standard deviation) was 12.75 (6.30), for negative emotion words: 6.49 (4.73) and for gardening words: 12.61 (4.42). Dependent t-tests showed that the main effect of Word type is due to the smaller number of words being placed in a negative emotion category, as there were significant differences between number of negative emotion words and pain words people categorized ($t_{1,50}$=4.90; $p<0.001$), and between negative emotion words and gardening words ($t_{1,50}$=7.14; $p<0.001$) but no significant difference between number of pain words and number of gardening words categorized overall ($t_{1,50}$=0.12; NS). Figure 3.9 shows the means for these word types broken down for participant groups.

To explore the significant interaction, *a priori* contrasts were used in the between-subjects analyses, and one-way repeated measures ANOVAs and dependent t-

tests were used for the within-subjects analyses. This follows recommendations about using the overall error term for between-subjects analyses but using individual error terms for within-subjects analyses: the former because it is a better estimate of the error with more degrees of freedom, and the latter because of the pooled error term is inappropriate when partitioning variance in repeated measures analyses (Howell, 1997).

Figure 3.9: Mean number of words placed in the three word type categories by pain sufferers, gardeners and controls



To cut down on the number of comparisons computed, rather than computing simple effect analyses followed by contrasts or pair-wise comparisons, the latter were used directly. The only exception was for the comparison of word types within the Control group. For this comparison, no difference across the three word types was predicted and hence, rather than computing three pair-wise comparisons to demonstrate this, a one-way repeated measures ANOVA was used instead. In addition to keeping the number of tested comparisons to a minimum, the criterion for significance was set at

0.01 (Howell, 1997) to protect against the increase in familywise error rate following multiple comparisons.

A one-way repeated measures ANOVA of word type within the Control group was computed. As predicted, it was not significant ($F_{2,32} = 1.79$), demonstrating there was no evidence that the Control group categorized the words as relating to any one of the three themes more than any other.

A between-subjects *a priori* contrast was computed to test the hypothesis that the Pain sufferers categorized more words as pain-related than either of the other two groups. Weights were set at 2 for the Pain group and -1 for both the Amateur gardeners and Controls. The contrast was significant ($F_{1,48} = 19.77$, $p<0.01$). Related t-tests were computed on the word types within the Pain sufferer group. This showed that the number of words categorized by the Pain sufferers as 'pain words' was greater than those categorized as 'gardening words' ($t_{1,16} = 2.97$; $p<0.01$), and that the number of words categorized as 'pain words' was greater than those categorized as 'negative emotion words' ($t_{1,16} = 6.01$; $p<0.001$). These results together support the principal hypothesis that Pain sufferers viewed more of the words as pain-related than either of the other two word types, and to a greater extent than either of the other two groups. However, the pain sufferers also scored higher on the BDI measure. To check whether this result was associated with levels of depression, the number of words placed in a pain category was correlated with BDI scores. No significant correlation was found between number of words perceived as pain-related and BDI scores, either among the whole sample ($r=0.09$, $N=51$, NS) or among the pain sufferers alone ($r=0.18$, $N=17$, NS). This suggests that the tendency to view these words as pain-related is a function of pain status rather than depressive status.

Related t-tests within the gardener group demonstrated that the Amateur gardeners categorized more words as 'gardening words' than as 'pain words' ($t_{1,16} = 2.64$; $p<0.01$), and more words as 'gardening words' than as 'negative emotion words'

($t_{1,16}$=6.15; p<0.001). *A priori* contrasts were computed comparing the number of words categorized as 'gardening words' by the Gardeners with the number of words categorized as 'gardening words' by the other two participant groups. The weights used were the same as before. Although there was a trend towards the Amateur gardeners categorizing more words as 'gardening words' than either of the other two participant groups, this was not significant at the adjusted level of 0.01 ($F_{1,48}$=4.70; p<0.05).

3.5 DISCUSSION

The main hypothesis that pain sufferers would view more of the words as pain related than pain free controls was supported. There was a significant interaction between Group and Word type, and *a priori* contrasts and t-tests demonstrated that pain sufferers perceived more of the words as pain-related than as either negative emotion (unrelated to pain), or to gardening. In addition pain sufferers grouped more of the words as pain-related than either of the other two participant groups. The gardeners also classified more words as being related to gardening than to either of the other two dominant themes, although the tendency to do this more than the other two participant groups only approached significance.

The results relating to pain sufferers has implications for understanding previously published work on recall biases towards sensory words in chronic pain sufferers. The larger pain category in chronic pain sufferers was mainly at the expense of a negative emotion group unrelated to pain. However the tendency to form a large pain category did not correlate significantly with BDI scores suggesting that this result is not due to higher depression in this group, but to pain status.

The work that has demonstrated a recall bias towards sensory-pain words in chronic pain sufferers has typically used three word categories, two of which have typically been sensory-pain and affective-pain, and the third an uncategorized neutral word group (e.g. Edwards *et al.*, 1992; Pincus *et al.*, 1993). The result of the current

study illustrates that the effect of categorization on recall is not a factor that can be 'controlled for' by having a categorized neutral group of words in the word list, as has been argued previously (Edwards, 1992). Rather, these results demonstrate that issues of categorization and category size cannot be assumed fixed, rather they are subject to an interpretational bias, which is itself a product of group membership and associated personal interest.

It has been demonstrated that presenting interrelated words (e.g. ones that come from the same category or categories) leads to higher recall levels than presenting unrelated words (e.g. Puff, 1979). The finding that pain sufferers perceive more words as pain-related means the pain category is larger for this participant group. Larger category size may contribute to enhanced recall of these words. For example, Hunt and Seta (1984) demonstrated that increasing the category size by 2 words can produce improvements in category recall of between 0 and 20%, depending on the initial category size, which varied from 1 to 16 words. This percentage difference is comparable with the recall advantage typically shown by chronic pain sufferers towards pain-related words (e.g. Edwards *et al.*, 1992). In addition, the category sizes explored in the Hunt and Seta paper is comparable with the category size typically used in studies of this kind (e.g. Edwards *et al.*, 1992; Pincus *et al.*, 1993) and used in the present study.

The implications of these findings are that issues in categorization theory and research should be considered within work on information processing biases and emotional disorders, particularly when studies involve manipulations such as self *versus* other encoding strategies and forget/remember recall instructions. For example, research has explored the role of self *versus* other encoding on recall biases in chronic pain sufferers and depressed people (Pincus *et al.*, 1993; Bradley and Mathews, 1983, respectively). However, the words used in cognition and emotion studies are typically abstract words, as opposed to concrete nouns, hence their allegiance to a particular category is likely to be ambguous. The way that participants in such studies perceive the

words may therefore become of crucial importance. Hunt and Seta (1984), for example, have demonstrated that free recall of words from small categories was enhanced by sorting cards, a procedure which enhanced relational encoding. In contrast, recall from larger categories was enhanced by differentiating items e.g. by rating them for pleasantness. Studies which have shown enhanced recall for material encoded in relation to the self (e.g. Pincus *et al.*, 1993; Bradley and Mathews, 1983) may therefore be demonstrating a combination of relational and distinctiveness encoding. For example, the pain-sufferers may have perceived more of the words as pain related (forming a larger category) and the self-encoding strategy may have led to superior distinctiveness encoding compared to an 'other-reference' encoding manipulation (Bellezza, 1984), thereby resulting in enhanced recall of pain-related material encoded self-referentially.

The non-pain control group may not have formed such a large pain category, meaning that a self-referential encoding manipulation did not result in the combination of relational and distinctiveness encoding required to enhance recall levels to those equivalent to the pain group. This means these and similar results do not necessarily reflect the content of a self-related pain-schema, a schema which is arguably playing an important role at pre-conscious levels of processing in the continuation of chronic pain and distress. Rather, these results may merely be reflecting the operation of well-documented encoding manipulations (categorization and item differentiation) on recall levels, although it could be argued that this interpretative bias is schema guided.

The present study demonstrates that pain-related meanings are clearly salient for pain sufferers. However there was considerable intra-group variation in category sizes and so this should not be understood as applying to all pain sufferers. In addition, in so far as this is a demonstration of the salience of pain-related meanings, a similar finding was also demonstrated in relation to gardeners and the perception of gardening-related meanings. It would not be argued that the salience of gardening-related meanings

contributes to the continuation of gardening being a hobby, but rather as a reflection of gardening as a source of interest or concern. Likewise the salience of pain-related meanings cannot necessarily be seen as explaining anything substantive about the continuation of chronic pain, but merely as demonstrating that this is a source of interest or concern. As such it may serve by way of a description rather than an explanation. The role of personal relevance of information on recall has been demonstrated previously. For example, Bradshaw, Ley, Kincey and Bradshaw (1975) have shown that perceived importance has a strong effect on recall levels when studying recall of medical information given to patients.

In addition, whilst it could be argued that the differences in categorization shown in the present study may be insufficiently large to produce recall differences, it should be noted that the effect size of recall biases in chronic pain sufferers is of a comparable magnitude. The present study has demonstrated an average difference in pain category size of 3 words. The recall advantage typically shown by chronic pain sufferers towards sensory-pain material has ranged from 0.3 of a word to 1 word (e.g. Pincus *et al.*, 1993; Edwards *et al.*, 1992).

However, the conditions in which categorization decisions are made in a recall task clearly differ in a number of ways from those experienced by participants in the present study. In the present study, participants were given as long as they felt necessary to categorize the material. In addition, they were able to see all the words at the same time and revize their category decisions in light of this. In a recall task, participants are usually given a few seconds to view each word, only see each word once and do not see all the words together. Category decisions are therefore made quickly and without the benefit of seeing all the words in total. However, it is argued that the present study raises sufficient doubt about the validity of the assumption that people perceive equal categories sizes in word list studies to warrant greater caution in the interpretation of both previous and future results in this area.

An additional issue is the extent to which the current findings are generalizable to other studies that have used different word lists. Some of the words used in the present study are clearly ambiguous, for example, the words digging, pinching, splitting can be seen as either gardening-related or pain-related. However it seems reasonable to suggest that all the words used in studies into pain and emotion are by nature relatively ambiguous. Words used in previous pain research and counted within a pain category include 'pressing, boring, tugging, crushing' and are arguably no less ambiguous than the ones used in the current study. Hence the current study demonstrates the need to explore categorization processes in information processing biases.

3.5.1 Commentary in relation to previous work using MDS

The purpose of the MDS in the current study was to illustrate that, at a broad level, three different groups corresponding to the three different word types emerged. Previous research on the scaling of pain words has had very different aims, namely to unravel the dimensions implicit in the experience of pain in order to contribute to theoretical understandings of pain, and its measurement and treatment. With these aims in mind, this previous work has focused on understanding the dimensions underlying the experience of both experimental and clinical pain (e.g. Clark, 1984; Janal *et al.*, 1993), and has tested some of the underlying assumptions of pain measurement tools such as the McGill Pain Questionnaire (Clark *et al.*, 1995) and Tursky's Pain Perception Profile (Morley, 1989). Given these differing aims, the results of these studies and those of the present study are not directly comparable, particularly because the present study was concerned with discovering the extent to which words were viewed as pain-related. In contrast, the question as to whether the words were seen as pain-related or not, was not directly addressed in the research noted above. Rather, it was the numbers of dimensions underlying the similarity judgements participants made which was considered central, and these dimensions were labelled by the researchers involved rather than the

individual participants. Another key difference between the present study and previous work is that the words used in the current study were very different to those used in previous work. In the present study non-pain gardening words were used because the study aimed at testing a key assumption of Study 1 and hence the materials used in Study 1 were used here. The dimensions and clusters that emerge in MDS are dependent on the stimuli chosen, in particular the range of stimuli which are included in the analysis. If objects which are very different are analysed together, the more obvious differences between them will tend to dominate the scaling space, leaving more subtle differences obscured (Schiffman *et al.*, 1981). In the current study the scaling space was dominated by the distinction between pain and gardening, and, amongst the pain words, by the distinction between sensory and affective pain words. This latter distinction is consistent with the findings of Clark *et al.* (1989) who also used words from the McGill Pain Questionnaire, and found a distinction between somatosensory words (sensory) and words describing the emotional quality of pain (affective). However, the study by Morley (1989) showed that affective words (although not taken from the McGill Pain Questionnaire) had more than one dimension when they were analysed on their own. It is possible that more than two pain-related dimensions might have emerged had the gardening words not been included in the multidimensional scaling analysis, or had the sensory and affective words been judged separately by the participants and analysed separately.

Differences in study aims not withstanding, previous studies looking at similiarity judgments given by pain and non-pain participants have shown that non-pain groups tend to view pain words as more uni-dimensional than pain groups. For example, in a study looking at the similarity judgements of pain descriptors in cancer-pain and pain-free volunteers Clark *et al.* (1989) found that the primary dimension in the pain-free group was the emotional quality dimension and that the pain intensity dimension

was less salient, whilst for the cancer-pain group the dimensions of pain intensity and emotional quality were equally salient. Furthermore, Morley (1989) found that non-pain volunteers were more reliable in their scaling of affective words than the pain group, and that the non-pain volunteers viewed the affective words as more uni-dimensional than the pain group, who viewed them as three-dimensional. Whether these results reflect group differences in perceived word meaning is, however, unclear. The study by Clark *et al.* (1995) does provide some evidence that pain words may not necessarily be viewed as pain-related when other non-pain words are included alongside them, such as positive words. In the present study MDS was not used to assess the meanings of the words used, instead this was assessed using a content analysis of the category labels.

In the MDS analysis used here an apparently similar pain dimension (sensory-affective) emerged across the three participants groups, although from the category labels participants gave it was clear that the affective pole meant different things to the different participants: only the sensory-pain words tended to be viewed as pain-related by the non-pain groups. In order to demonstrate that affective-pain words are not necessarily viewed as pain-related but are related to negative emotional words using MDS, other non-pain emotional words would perhaps need to be used in order to display this difference in perceived word meanings.

In summary, the current study has demonstrated that the use of word lists to assess recall biases in chronic pain sufferers does not necessarily offer the levels of experimental control previously assumed. Assuming that schema will not affect word interpretation is contrary both to the original conception of schema and to the empirical evidence presented here. The current study has provided evidence that perceived word category size and group status may be confounded. This makes inferences based on further experimental manipulations at encoding or retrieval potentially problematic. Whilst personal relevance is clearly a central factor in any alternative explanations based

on categorization differences across groups, personal relevance has long been known to affect recall. Whether personal relevance provides anything by way of explanation of continued mood and pain complaints, or is just descriptive of group status remains a key question in cognition and emotion research.

3.5.2 Relevance of the current findings for the previous study

3.5.2.1 The pain-related recall bias

The study in Chapter 2 found no evidence of a pain-related recall bias. Given that the present study demonstrated a tendency for pain sufferers to categorize more words as pain-related than either of the other two groups, why did this fail to result in a recall bias in the first study? A number of potential explanations were forwarded in section 2.8.3, however the results of the present study provide a further possible explanation.

The multidimensional scaling analysis illustrates that there was greater consensus about which words fell into a 'gardening' category than into either of the other two categories. This is demonstrated by the fact that the gardening words are plotted very close to one another. These high levels of agreement among participants about which words formed a gardening category suggests that this was a tighter category. In the multidimensional scaling analysis these words not only group more closely together but they sit in a distinct half of the stimulus configuration, at a greater distance from the pain and negative emotive categories compared with the distance between the latter two. As highly related words are usually recalled better than unrelated words, this suggests that one of the reasons for the superior recall of gardening words demonstrated in all participant groups in Study 1 may well have been, at least in part, due to these words forming a more coherent and also distinct category.

3.5.2.2 Retrieval inhibition

The confounding of group status and category size presents particular problems when attempting to discover the processes causing recall biases e.g. the operation of self-schema, or the failure of retrieval inhibition. As discussed above, the use of self *versus* other encoding strategies offers up the possibility for different levels of 'distinctiveness' encoding. The exploration of retrieval inhibition presents similar difficulties. As discussed in Chapter 2, there are clear encoding differences that may exist between remember and forget instructed participants. However, not only might there be differences across groups in the number of words they categorize as a given type, but this may be further confounded by the forget/remember instruction as remember instructed participants are effectively shown one long list and the forget instructed participants two short ones. This is almost certain to further compound the difficulties of differential categorization, as this may be occurring not only across groups (pain, non-pain) as demonstrated by the present study, but also across forget/remember instructed participants, with smaller categories being formed in the 'forget' groups than the 'remember' groups. These issues clearly present problems when one attempts to address issues of *retrieval* explicitly and independently from issues of encoding as the study in Chapter 2 attempted to do.

The results of this study provided some evidence that pain sufferers tend to perceive more words as pain-related than non-pain sufferers, i.e. that chronic pain sufferers showed a bias towards understanding words as relating to pain, compared to pain-free controls. This finding suggests that one aspect of schema function which might contribute to information processing biases in chronic pain groups is an interpretative bias. The directed forgetting paradigm (which is meant to assess retrieval inhibition) may not be able to clearly tease apart processes of encoding from processes of retrieval, and demonstrate an effect which is due to failure of retrieval inhibition rather than due to enhanced encoding, when semantically related words are used (as they

were here). This is because an interpretative bias could potentially cause an apparent lack of retrieval inhibition, which is in fact caused by encoding biases arising from the biased interpretation of word meanings rather than retrieval inhibition. More specifically, category size (caused by an interpretative bias) may vary along with the directed forgetting manipulation (the instruction either to 'forget' or 'remember' the first list of words that has been seen).

More generally, these results also raise questions about the value of using word lists to study schema. Although biased recall may not necessarily demonstrate the presence of pain-related schema, it does appear to demonstrate a conceptual influence on the understanding, grouping and hence subsequent recall of pain-related words. Whilst this could arguably be interpreted as reflecting a schematically-guided process, this differential interpretation of word meaning across participant groups appears to go unacknowledged by many researchers who use word lists to explore cognitive biases in emotional disorders. These theoretical issues will be discussed in more detail in the next chapter.

3.6 SUMMARY

Words differing in affective valence have been widely used to study the role of schema and memory in chronic mood and pain complaints. Whilst schema are conceptualized as structures which guide people's understanding and perception of events, the possibility that they may affect perceived word meaning has been largely neglected and word lists are implicitly assumed to contain words of fixed meaning. This study investigated the validity of this assumption in chronic pain research.

Chronic pain, amateur gardener and non-pain non-gardening controls completed an unrestrained card sorting task on the words used in the previous study (sensory pain, affective pain, gardening and filler words). Perceived word meaning was demonstrated

as varying according to Group membership. Pain sufferers perceived more of the words as pain-related and gardeners perceived more of the words as gardening-related.

Chapter 4

A Theoretical Review of Schema Theory

4.1 DO CATEGORIZATION EFFECTS EXPLAIN RECALL BIASES IN EMOTIONAL DISORDERS?

Enhanced recall of pain-related material in pain sufferers has typically been interpreted as evidence that pain sufferers possess an elaborate sensory pain schema which has aided the encoding, search and/or retrieval of this material in and from memory. It has not been interpreted as the result of categorization processes. However, there is no strong evidence to support the view that categorization processes are not involved in these findings. The published results demonstrating a recall bias have not used a categorized neutral control group of words such as gardening words (Edwards *et al.*, 1992; Pincus *et al.*, 1993). Whilst other word categories have been used along with pain words (e.g. positive and social threat words) they have related to emotive themes and hence may not form a particularly cohesive category (compare, for example, the cohesiveness of the gardening word category as compared with the two pain word categories shown in Chapter 3). In one study which did use gardening words as a categorized neutral word group there was no demonstrated difference in recall of the categorized neutral words compared with a group of uncategorized neutral words, but this study did not demonstrate a pain-related recall bias either. In spite of this, it was interpreted as evidence that the pain-related recall bias does not arise from enhanced categorization of pain material (Edwards, 1992). However without the demonstration of a recall bias in this same study, such a conclusion is premature. For example, the use of an uncategorized group forming a fourth 'category' of words may have made both the pain words and gardening words less obvious, and hence lessened the use of categorization strategies to aid recall.

Research into recall biases and chronic pain has generally tended to assume that participants will categorize the words in an equivalent manner and that they will perceive an equal number of words from each category. However, the results of Chapter 3 demonstrate that this assumption is not necessarily valid. In addition, it renders the interpretation of recall data problematic, not least when additional encoding strategies are brought into the equation, as for example in a self- other-referential encoding manipulation and directed forgetting. The possibility remains, therefore, that the pain-related recall bias may be the result of categorization processes.

The extent to which categorization aids recall depends to some extent upon category size. For example, Hunt and Seta (1984) demonstrated that free recall of words from small categories was enhanced by sorting cards, which enhanced relational encoding, but that recall from larger categories was enhanced by differentiating items e.g. by rating them for pleasantness. Their research clearly demonstrates the difficulties in interpreting recall data when category size varies both across word-types and across participant groups. Hence interpretation of recall results becomes problematic when it is unclear, firstly, how many category groups participants are forming, and secondly, what other strategies they might be using in conjunction with category formation that might constitute a method of differentiating items within those categories. This raises an issue about the distinction that exists between the theoretical concepts of categorization and of schema, and hence the extent to which the results of biased recall of pain-related words in pain sufferers could be conceptualized within a categorization framework.

4.1.1 Similarities and Differences between Categorization Theory and Schema Theory.

A pain-associated recall bias in pain sufferers could be the result of this group having, or being able to generate, a more cohesive category re: pain-related words, compared to non-pain controls. A cohesive category would arise through more repeated

use of pain descriptors together.

Barsalou (1983) has demonstrated in his work on ad-hoc categories, that categories can be constructed that are task specific. For example, people can construct a category relating to 'things you would take on holiday'. However, whilst such categories display some of the characteristics of other so-called 'natural categories', ad-hoc categories have weaker instance-to-concept and concept-to-instance links. This means such an ad-hoc category concept will be less effective as both an encoding and as a retrieval aid. However, if this were a category of objects, or in this case descriptions, that was frequently used (i.e. it was a well-established category), there would be stronger instance-to-concept and concept-to-instance links, which would lead to better recall of material were this concept used as an encoding and retrieval aid.

The notion of well-established categories has clear parallels with the concept of schema: those for whom 'pain' is an ad-hoc category, that is, a category generated on the spot (perhaps for the specific task of enabling recall of material in a memory test), would be those who rarely used pain words together in a category (e.g. those people who rarely use pain words to describe symptoms, such as those without chronic pain or little pain experience). Those with repeated pain experience may, however, have linked such pain descriptors together when describing symptoms to others, such as doctors, family or friends. Hence their pain category may be well-established as opposed to ad-hoc. The notion of an ad-hoc category can therefore be seen as analogous to having a minimal pain schema, and the notion of an established category as analogous to a well-established and elaborate pain schema.

However the extent to which categorization theory and schema theory are considered commensurable depends upon the understanding of schema and categorization adopted. Whilst they both relate to the organization of material in memory, categorization theory typically refers to the mental representation of *verbal* material and knowledge, whereas schema theory may not (as is the case, for example, in

Leventhal and Everhart's use of the term schema).

Assuming for a moment that schema theory and categorization theory are substantially different and that whilst they both describe factors which may enhance recall of verbal material they do so in different ways, the results demonstrated in Chapters 2 and 3 together suggest that consensus regarding categorization (which is interpreted here as reflecting tighter categorization) was sufficiently strong to over-ride any contributions towards enhanced recall offered by elaborate schematic representations of pain material or enhanced facilitated retrieval, meaning a recall bias was demonstrated towards gardening and not pain words. This suggests that categorization processes may potentially be more important than schema in governing recall performance.

However, the results reported in Chapter 3 could be interpreted as an interpretative bias towards pain-related meanings in chronic pain sufferers. Whilst schema theory suggests schema act to influence the interpretation of material, categorization theory typically either focuses on issues of structure, or issues of inferences formed on the basis of given categories, rather than on the dynamic interplay between the construction of a category in a particular context that may differ for differing participants (Barsalou, 1990). The exception to this is the work of Barsalou himself. But, although he has looked at the issue of generating an ad-hoc category for on the spot demands, he has not explored how these may differ for people differing in their interest or experience in particular areas.

It is precisely this sort of dynamic category construction which may occur in a memory task. In Chapter 2 some participants reported noticing categories after so many words of a particular type seemed to arise and then using this knowledge to help them remember the words. But, as the results of Chapter 3 demonstrate, people notice different categories and different numbers of categories, and this in turn appears to be

influenced by issues of personal interest or involvement.

Whether this points to a definite role of schema in this result rather than categorization processes is unclear. Barsalou, for example, has also demonstrated differences in categorization that arise when participants are invited to take different perspectives, for example, a typical American *vs.* a typical Japanese in the generation of typical examples of birds. Hence categorization processes could potentially be used to explain differences in recall that may occur with differences in perspectives/interests.

4.2 SCHEMA CONTENT

Whether the results of the previous study can be adequately conceptualized within categorization theory or not, there are issues regarding schema theory which should be considered, most notably, the extent to which word lists can adequately be seen as addressing schema content. Word lists appeal to a notion of schema content that is arguably overly reductive (e.g. at the level of individual words) and not at the more holistic level of which schema theory usually speaks. The conclusion that word lists are problematic in studying memory in general is not new. Neisser (1987), for example, argues the assumption that:

> "all forms of memory are basically the same, ... (and) attractive possibilities of experimental control led to a preference for meaningless materials and unnatural learning tasks" (p. 1)

i.e. "lists of syllables or words" (p. 1) rather than memory for stories, friends, places or life experiences. However, despite advocating a new cognitive psychology that used terms such as schema to describe and explain the subject's active role in understanding the world (Neisser, 1966), there seems to have been a theoretical change in the meaning of the term 'schema'. For example, in their book "Cognitive Psychology and Emotional Disorders", Williams *et al.* (1997) argue that:

> "it is helpful to present a specially constructed list of words which are relevant to a depressed mood state. Using slightly artificial materials of this kind results in an experiment that is less ambiguous to interpret" (p. 9).

The results presented in Chapter 2 would suggest this view is overly optimistic. However this view seems to have arisen from their reducing the notion of schema, which were originally conceptualized as generic and abstract entities (e.g. Leventhal and Everhart, 1979) summarizing entire situations or experiences, to a notion of schema as referring to the representation of an individual word. Hence, abstract meaning which might be captured in a schematic representation of a 'typical pain experience' gets reduced to meaning at the level of an individual word. The result of this has been an acceptance of word lists as adequately tapping schema because a schema=one word.

However this theoretical reduction in the understanding of the term schema by Williams *et al.* (1997) was to some extent a necessary one. It was done in order to account for the differences in patterns of information processing biases associated with different mood states (discussed in Chapter 2). By hypothesizing that schematic representations existed of individual words, rather than generic experiences relating to pain, depression or anxiety, this meant that priming could be distinguished from elaboration. That is, schema activation could now theoretically occur without resulting in the activation of other pain-related or mood-related concepts. If the concept of schema was understood in the broader sense, then activation of the schema would mean if one element within it was activated, other related concepts would be activated as well. Hence this theoretical shift in the understanding of the term schema has contributed in part to the possibility that word meaning might vary across participant groups being overlooked. Accepting for the moment that this assumption about word meaning was unproblematic, using word lists nevertheless tends to result in a focus on issues of schema content (pain-related, depressive) and how schema influence memory and attentional processes at the expense of focusing on other factors that may play a more central role in the *meaning* pain symptoms have for individual pain sufferers.

4.3 CONTENT AND STRUCTURE IN SCHEMA

Schema have been conceptualized in many different ways. Most versions make reference to the beliefs and hypotheses the individual holds about the pain, for example, as structures which may drive (or be driven by) schema (e.g. Leventhal and Everhart, 1979), or as being something which actually provide structure to the schema in the first place (e.g. Lacroix, 1991). Different researchers, for example, use the term schema to refer to different things and the assumption that sensory words alone adequately access such pain schema is not necessarily in keeping with these different conceptualizations of schema content. For example, Fiske and Linville (1980) (cited by Lacroix 1991) define schemata as:

> "cognitive structures of organized prior knowledge, abstracted from experience with specific instances" (p. 197).

In the case of pain, a specific instance is going to refer to more than just a sensory experience but include details such as the accompanying emotional reaction, and details of the environment in which it occurred, and the implications of the event itself. Lacroix, Martin, Avendano and Goldstein (1991) define a schema as:

> "a distinct, meaningfully integrated cognitive structure that encompasses 1) a belief in the relatedness of a variety of physiological and psychological functions, which may or may not be objectively accurate; 2) a cluster of sensations, symptoms, emotions and physical limitations in keeping with that belief; 3) a naïve theory about the mechanisms that underlie the relatedness of the elements identified in 2); and 4) implicit or explicit prescriptions for corrective action" (p. 268).

In categorization theory there is a similar debate. For example, Neisser (1987) states:

> "no adequate theory of categorization can be based only on characteristics of the categorized objects themselves" (p. 3).

For example, to say that an object is a dog, is to do more than just compare the object with an internalized prototypical image, such an act also "appeals to our underlying intuitions and beliefs about the nature of animals." (p. 3). Furthermore, these

beliefs serve to make certain similarities between objects relevant and others irrelevant, as he goes on to say:

> "To categorize an object... is to assert that it bears a particular relation to a particular set of ideas." (p. 4).

Hence schema theories frequently assert that schema contain not just information about sensations, for example, but also information relating to theories and hypotheses about how these symptoms relate together. It seems problematic, therefore, to consider pain words in isolation from issues relating to beliefs, understandings, and hypotheses about what those words mean.

All of the theorists mentioned above therefore propose elements which relate to pain-sufferers' understandings, explanations and possible coping efforts in association with the pain and not just the sensations of the pain experience itself.

However, assuming for the moment that pain symptoms were the sole or primary content of pain schema, previous research has used words from the McGill pain questionnaire to tap this schema content. However some researchers have challenged the adequacy of using the words from the McGill Pain Questionnaire as descriptors of sensory pain experience. For example Skevington (1995) criticises it for being a summary of pain sensations produced by researchers rather than by the patients themselves. Harré (1991) has described the MPQ as:

> "a semantic theory for the Canadian English pain lexicon" (p.101)

He argues that only if the words on the McGill happen to match "the structure of the person's native resources" (p. 103) (i.e. the words they have learned and used to describe their own symptoms) is it an acceptable instrument. Skevington also cites a series of other studies which challenge the MPQ's validity, such as Ehrlich's demonstration that pain description can be phrases or words, or may even be expressed in terms of a narrative or story rather than a series of attributes such as throbbing or stabbing (Ehrlich, 1985). In addition Holroyd, Holm, Keefe, Turner, Bradley, Murphy,

Johnson, Anderson, Hinkle and Omalley (1992) have demonstrated the apparent presence of more than one sensory class of words, whilst the MPQ allows for only one general one.

However, assuming for the moment that this was a minor criticism, there is direct evidence using McGill pain words that previous work on information processing biases in chronic pain sufferers has not adequately tapped sensory pain schema of the type put forward by Leventhal and Everhart.

According to Leventhal and Everhart's model, complex mental representations of previous pain experience (pain schema) play a role in the interpretation of peripheral input. Hence, activation of these pain schema may contribute to the continuation of subjective pain experience when there is little or no peripheral input.

Previous work has found evidence consistent with the view that chronic pain sufferers possess more complex pain-related schema than pain-free controls. However, no link has yet been demonstrated between the degree of schema complexity (inferred from strength of information processing bias) and intensity of subjective pain experienced. For example, if the pain-related recall bias demonstrated in chronic pain sufferers is the effect of the operation of a pain schema, the more complex that pain schema, the greater the recall bias should be. In addition, the more complex the pain schema the greater the pain intensity experienced should be, because the more complex the schema, the greater the likelihood of interpreting sensations as pain-related should be. The fact that no such relationship between strength of information processing bias and pain intensity has been found raises the question of whether such methods (e.g. memory for word lists and stem completion tasks) tap the unconscious schematic level.

4.3.1 Different levels of pain representation

Leventhal and Everhart do not draw a clear-cut distinction between what is represented at the conceptual-verbal and the schematic levels. Their emphasis is primarily on the nature of the representation itself, i.e. whether it is a verbal representation or an analogue representation of the experience itself. For example, they suggest that whilst both the schematic and conceptual level contain memories, the memories in the latter are described as:

> 'flexible memories such as those involved in the conceptual system that produces speech' (p. 280),

in contrast to those of the schematic system which are described as 'more like image memories' (p. 280) and 'prototypes' (p. 279), stating that:

> "The investigations described here also make clear the need for differentiating between schematic and conceptual cognitive mediators. Whether these terms mark a simple qualitative dichotomy or define the ends of a continuum of controllable (conceptual-verbal) versus automatic and less controlled cognitive events is unclear. It is conceivable that a common memory structure underlies both systems and that the differences exist because of separate retrieval mechanisms. At present, however, we favour the former hypothesis of two relatively independent types of cognitive code" (p. 294).

The primary purpose of Leventhal and Everhart's distinction between schematic and conceptual level representations seems to be that it allows them to distinguish between 'hot' and 'cold' cognition. Cognition that is accompanied by emotion/pain is considered 'hot' and is represented at the schematic level, whilst cognition that is unaccompanied by emotion/pain is considered 'cold' and is represented at the conceptual-verbal level.

Furthermore, Leventhal, Meyer, and Nerenz (1980) state in an essay on Illness representations that the content of schematic and conceptual levels may be identical, the difference being one of accessibility:

> "These belief systems may be implicit rather than explicit. For example, the cognitive structures comprising the representation may be nonverbal perceptual memories that are difficult (or impossible) to represent verbally .... The ability to verbalize may emerge only with time ..... Because their cognitive structures are implicit, patients become aware of all its parts simultaneously, including his beliefs about cause, cure, underlying mechanisms and the effects of disease on his coping behaviour" (p. 294).

If we are to conceptualize the difference between the conceptual and schematic as lying along the verbal/non-verbal dichotomy, this poses a question as to what happens when verbal material is used to access non-verbal representations (which is what happens when word lists are used). Verbal material presumably cannot directly access non-verbal systems without first being transformed, if the verbal and non-verbal levels represent different types of code (as suggested above). Such a translation system is incorporated in Teasdale and Barnard's Interacting Cognitive Subsystems theory for example. The verbal material used must first be processed by a verbal system and then presumably translated into another (schematic) code. Hence the conceptual level cannot be ignored or left unassessed.

If we were to ignore the verbal/non-verbal distinction between the conceptual and schematic levels and hypothesize that they represented differences in terms of controlled and automatic processing instead, the results of information processing biases in chronic pain would suggest that the use of word lists and memory and attentional tasks have failed to tap schema in Leventhal *et al.*'s terms, as there is no evidence to support a pain-related bias in tasks that are typically thought to assess automatic processing (Pincus, 1993). For example, no recall bias has been demonstrated in attentional orientation towards pain-related material, instead the evidence is consistent with the involvement of more elaborate, controlled processes. In addition, although Leventhal and Everhart (1979) state in their 3-systems model that the three different levels all mutually interact, there is little evidence that interventions that aim to alter the conceptual level actually alter pain intensity levels, and little evidence of a link between enhanced memory for pain words and experienced pain intensity and yet the role of the

sensory schema was principally presented as a means by which ambiguous stimuli get quickly labelled as pain and hence potentially contribute to the continuation of chronic pain.

Previous work has therefore arguably not examined cognitive factors which play an important role in the pain-injury link. However, this may be in part because the meaning that the pain has for those suffering it has not been adequately explored. Previous work on information processing biases in chronic pain research has tended to examine schema content independently of the factors that provide it with its structure, yet it is these structural elements which arguably provide the schema content with its *meaning*.

Schema are considered to be organized around concepts of the cause and consequences of the symptoms being experienced, and it is arguably the implications of the symptoms and not the symptoms themselves which constitute the meaning of the pain.

Previous methods have provided no strong evidence that they tap pain schema and in addition can be interpreted as the result of conceptual processes alone. As schematic and conceptual levels of representation are thought to differ not in terms of their content but in terms of their code, an alternative conceptual-verbal method of addressing representations of pain symptoms will be used. However, rather than exploring issues relating to pain intensity, issues relating to the variable link between levels of pain and *adjustment* to it will be considered instead.

Chapter 5

An Exploration of Predictors of Adjustment in Chronic Pain Sufferers

5.1 INTRODUCTION

The third study in this thesis aimed to explore aspects of pain meanings more directly by using a method which assessed not just pain symptoms but people's hypotheses about what those symptoms meant. As such it aimed to explore the meanings surrounding pain and hence to examine aspects of schema content and structure rather than schema function. In addition it aimed to explore the conceptual-verbal as opposed to unconscious level of pain meanings, and hence to contribute to understandings of pain-adjustment rather than pain intensity.

As noted earlier, a great deal of research has focused on conceptual-verbal representations of pain and their role in pain adjustment. Furthermore a substantial proportion of these studies has focused on concepts from the depression literature, such as those of control, attributional style and cognitive errors (see section 1.4.4.2).

This study aimed to explore two aspects of pain meanings which have received little empirical attention to date, both of which relate to the limitations associated with pain, and which are also thought to relate to depression:

1) the accuracy of participant's understandings of their pain symptoms, which is considered to be a crucial precursor to acceptance of the limitations associated with illness (and hence adjustment to it), and
2) the losses (or actual limitations) associated with chronic pain. The latter was considered alongside the coping style of 'flexible goal adjustment' which has been found to moderate the impact of losses associated with chronic pain in previous research.

This chapter therefore discusses conceptual-verbal representations of pain which have been considered important in understanding pain-adjustment, and outlines the different measures of pain-adjustment which have been used in the pain literature, including depression. It then examines theoretical accounts of depression and discusses previous findings concerning the role of symptom understanding and role/goal losses in understanding depression in chronic pain and presents the rationale for the next study.

5.1.1 Conceptual-verbal representations

The role of psychological factors in chronic pain has received a great deal of attention in recent years in an attempt to account for the gap between 'disease' (medically recognized indictors of organic damage/disease) and 'illness' (the individual's presentation of symptoms). In particular, psychological theories have focused on people's cognitive models or 'schema' of their symptoms. These schema are considered to be organized sets of knowledge that are used to unite and make sense of symptom clusters. Hence schema are thought to play an important mediational role between 'disease' and 'illness', and account for variance in people's interpretation of sensations.

A number of different terms have been used to describe cognitive representations of illness and these include 'illness schema', 'illness perceptions', 'illness representations', 'illness beliefs' and 'illness cognitions'. Not withstanding the different emphases and methodologies that the differing terms may imply, a consistent finding about such representations is that they have five dimensions (Schober and Lacroix, 1991; Scharloo and Kaptein, 1997): identity, cause, consequences, time-line and controllability/possibilities for cure.

- *Identity* refers to both the disease label (e.g. rheumatoid arthritis) and symptoms arising from that disease (e.g. pain and stiffness);
- *Cause* refers to beliefs about why one has the disease (e.g. because of genetic inheritance);
- *Consequences* refer to both the short and long-term effects of the disease (e.g. the physical, social, emotional and economic consequences);
- *Time-line* refers to beliefs about how long the disease will last (e.g. whether it is acute or chronic); and
- *Controllability/curability* refers to beliefs about what can be done to get rid of the disease or modify its course in some way.

A large amount of research has been conducted into aspects of illness schema in chronic pain patients and their relationship to adjustment (Jensen *et al.,* 1991; Scharloo and Kaptein, 1997) and some of this research was discussed in Chapter 1 (section 1.4.4.2). In brief, there is evidence for the role of beliefs about cause, time-line and controllability/possibilities for cure and consequences in understanding variation in pain–adjustment. For example, scores on the Pain Beliefs and Perceptions Inventory (PBPI), which assesses patients' beliefs about issues related to the perceived causes and timeline of pain, have been associated with measures of pain and pain-adjustment. Williams, Robinson and Geisser (1994) found a significant relationship between a belief that the pain was constant and higher measures of pain intensity. They also found beliefs in the cause of pain as mysterious were associated with higher levels of psychological distress, such as anxiety and depression. In a study looking simultaneously at beliefs about identity (in this case, number of symptoms), timeline, consequences and control/cure, Murphy, Dickens, Creed and Bernstein (1999) found that depressed rheumatoid arthritis (RA) sufferers (as assessed by the depression scale of the HADS)

differed from non-depressed RA sufferers in their beliefs in the negative consequences of illness, and beliefs about having little control over their illness.

However, the most widely studied and consistent relationship that has been found is between the dimension of control and pain-adjustment (Scharloo and Kaptein, 1997). Beliefs that the pain is controllable have frequently been associated with positive adjustment (see Chapter 1, section 1.4.4.2). For example, Jensen and Karoly (1991) studied the role of control beliefs and coping efforts in psychological functioning, medical services utilization and activity level. They found that control beliefs related both to psychological well-being (depression and life satisfaction) and to activity levels: those with beliefs that they could control their pain and the impact it had on their lives reported lower levels of depression and higher levels of life satisfaction. Beliefs about control over the pain were also associated positively with activity levels but only for those patients reporting relatively low pain levels.

Whilst high levels of perceived control over pain have been found to relate to positive adjustment, a number of researchers have argued that high levels of desire for control over events which may be fundamentally uncontrollable, such as chronic pain, may be maladaptive. Knowing how people understand and respond to the limitations imposed by pain may be important predictors of adjustment, notably depression, and this issue is returned to in sections 5.1.5 and 5.1.6.

5.1.2 Measuring adjustment/adaptive functioning

There is considerable variability in the outcome or adjustment measures which have been used in chronic pain research. The term adjustment has been used to refer to a number of different outcomes. Leventhal and Nerenz for example have said:

> "Adjustment could mean not becoming emotionally upset, being able to continue everyday activities, maintaining closeness with family and friends, quitting a bad job, and so forth." (Leventhal and Nerenz, 1985; p. 535)

In their review of the literature on coping, Jensen *et al.* (1991) argue that, whilst

the term adjustment was often used to refer to psychological well-being or 'adaptive mental functioning', more recently, researchers have used a wider definition which includes the ability to carry out "normal physical and psychosocial activities" (Jensen *et al.*, 1991; p.250). Jensen *et al.* (1991) report that the following have been offered as different dimensions of adjustment in chronic pain by different researchers: pain behaviour, self-reported pain severity, activity level, physical strength and mobility, medication use, health services utilization, employment status and depression. In a factor analytic study, Jensen and Karoly (1991) suggest adjustment measures can be broadly categorized into three groups: psychological well-being, activity level and medication/professional services utilization, and that adjustment should be seen as multidimensional.

A variety of different measures have been used to assess these three categories of adjustment:

Psychological well-being (or psychological functioning) has been assessed using measures of depression such as the Center for Epidemiological Studies Depression Scale (Radloff, 1977) (e.g. Schiaffino and Revenson, 1992; Jensen and Karoly, 1991), the depression scale of the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) (e.g. Murphy *et al.*, 1999), the Beck Depression Inventory (e.g. Slater, Hall, Atkinson and Garfin, 1991) the Profile of Mood States (Affleck, Tennen, Pfeiffer and Fifield, 1987), and life satisfaction measures such as Satisfaction With Life Scale (Diener, Emmons, Larsen and Griffin, 1985) (see Jensen and Karoly, 1991)

Activity levels or disability have been measured using the activity subscales of the Multidimensional Pain Inventory (Kerns, Turk and Rudy, 1985) to measure activity levels (household chores, outdoor work, activities away from home and social activities) (e.g. Jensen and Karoly, 1991). Disability has been measured using the Health Assessment Questionnaire (Fries, Spitz and Young, 1982) which measures perceived disability in eight different areas of life such as walking and getting dressed (e.g. Jensen

and Karoly, 1991; Murphy *et al.*, 1999; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman and Rooijmans, 1998) and the Sickness Impact Profile (Follick, Smith and Ahern, 1985), (e.g. Slater *et al.*, 1991), a self-rated measure of functional impairment, which gives both an overall index and separate indices for physical, psychosocial and 'other' categories (e.g. work and recreational impairment). Disease-specific measures have also been used, such as the Arthritis Impact Measurement Scales (Meenan, Anderson, Kazis, Egger, Altz-Smith, Samuelson, Wilkins, Solsky, Hayes, Blocka, Weinstein, Guttadauria, Kaplan and Klippel, 1984) (e.g. Schiaffino and Revenson, 1992).

Use of medical resources has been assessed by asking people to document the frequency with which they have made pain-related visits to a doctor or other health-care professional (e.g. Jensen and Karoly, 1991), and treatment outcome has been assessed by asking about the frequency of use and perceived effectiveness of cognitive and behavioural coping strategies using the Coping Strategies Questionnaire (CSQ: Rosenstiel and Keefe, 1983). For example, Williams and Keefe (1991) examined the extent to which beliefs about time-line and cause relate to Coping Stratgies Questionnaire (Rosenstiel and Keefe, 1983) which contains subscales such as 'increasing behavioural activity' and 'ignoring pain sensations'.

Some researchers have explored both general and disease specific measures of adjustment, for example, Scharloo *et al.* (1998) measured the role of physical, role, and social functioning using three subscales of the Medical Outcomes Study Short Form General Health Survey (Stewart, Hays and Ware, 1988), alongside the disease-specific (rheumatoid arthritis) measure: the 24-item Health Assessment Questionnaire (Fries, Spitz, Kraines and Holman, 1980) which consists of eight categories of daily life activities each containing two or three items (such as walking and hygiene) with respondents being asked to rate how difficult it was for them to perform these activities.

5.1.2.1 Rationale for choice of adjustment measures

The focus of the present study was on testing the role of symptom understanding and role/goal losses in understanding pain-adjustment. Depression was used as the primary measure of adjustment for two reasons: 1) because it is a frequent correlate of the experience of chronic pain (e.g. Gamsa, 1994a; 1994b; Romano and Turner, 1985; Banks and Kerns, 1996) and has been extensively examined in chronic pain research, and 2) because depression has been noted as an important outcome variable in connection with both symptom understanding and role/goal loss, the two issues being explored in the current study.

5.1.3 Review of Theories of depression

Considerable debate has focused on the nature of the relationship between depression and chronic pain and much of this discussion has focused on their causal interrelationship, i.e. whether pain causes depression, depression causes pain, or pain and depression share a common underlying psychological or biological cause. Whilst there are, broadly speaking, three types of models of depression in chronic pain patients (reviewed by Romano and Turner, 1985) neurobiological models, psychodynamic models (Engel, 1959; Blumer and Heilbronn, 1982) and cognitive-behavioural models, it is the cognitive and behavioural models of depression that will be considered here as it is these which have received most attention in the field of chronic pain (Banks and Kerns, 1996), and this thesis is concerned with cognitive aspects of chronic pain.

5.1.3.1 The theories of Beck and Seligman

Both Beck's cognitive model of depression (Beck, 1970) and Seligman's learned helplessness theory (Seligman, 1975) and its reformulation (Abramson, *et al.*, 1978), argue that depression arises from cognitive distortions. For example, Beck's theory proposes that depression is the result of negative schema, which map onto events and

produce the pattern of negative thinking observed in clinically depressed people, which relate to negative thoughts about the self, world and future. Seligman's theory proposes that depression arises from the experience of uncontrollable negative events which lead to the (distorted) belief that future events will also be uncontrollable: "depression is the belief that action is futile" (Seligman, 1992; p. 93). These theories have been very influential in the field of depression but have been criticized. The limitations of Beck's theory have been fully documented elsewhere (e.g. Teasdale and Barnard, 1993). In brief, these include the fact that there is evidence dysfunctional attitudes return to normal levels with improved mood state, and that the model gives no account of the circumstances under which negative schema become operational and lead to a depression. In addition, the theory has been criticized for neglecting the importance of social and environmental factors in the etiology of depression, placing primary emphasis on the perception of events rather than their occurrence (cf. e.g. Brown and Harris, 1978).

Criticisms aimed at Seligman's theory include failing to offer an account of low self-esteem (a common depressive symptom) and not explaining why depressive episodes may vary in terms of their generality, chronicity and intensity following an uncontrollable outcome. As a result of such criticisms, this model was reformulated in 1978 by Abramson, Seligman and Teasdale, through the addition of the concept of 'causal attributions'. Abrahamson *et al.* hypothesized that the relationship between the experience of uncontrollable events and the development of helplessness and depression is mediated by these causal attributions, which are thought to vary along three dimensions:

i) *internality* (the extent to which the uncontrollable outcome was viewed as more likely or less likely to happen to oneself compared to others),

ii) *stability* (the extent to which the outcome was viewed as caused by unchanging/recurrent factors compared to temporary factors) and

iii) *globality* (the extent to which the outcome was viewed as caused by something which applied to numerous events as opposed to event specific).

Abramson *et al.* (1978) argued that the attributional style of people prone to depression was characterized by a tendency to believe that the cause of an uncontrollable event was internal, stable and global. Internal attributions were thought to result in lowered self esteem, stable attributions to result in prolonged periods of depression, and global attributions to feelings of depression which generalize across situations. However, despite addressing some of the key limitations of the original learned helplessness theory, significant criticisms still remain. Principally these concern the fact that the conditions which lead to internal stable global attributions are not delineated and that the theory therefore lacks predictive power. Furthermore, some researchers have argued that giving up may be an adaptive response if events truly are uncontrollable:

> "The negative affect that occurs when one begins to realize that he or she cannot influence an outcome might also be quite functional, even if it is relatively intense. Such depressions might serve the highly useful purpose of motivating a person to reevaluate his or her goals" (Wortman and Dintzer, 1978; p. 87)

and this issue of control is returned to in section 5.1.6.

5.1.3.2 The theory of Brown and Harris

In contrast to the models of Beck and Seligman, which focus largely on how individuals appraise particular events, the model of depression in women forwarded by Brown and Harris (1978) suggests that depression is dependent not solely on the

appraisal of events, but on their occurrence. In their research on depression in women, they found that depression was more likely to occur in those who had experienced a significant life event compared to those who had not. A key part of their theory of depression was therefore the consideration of *provoking agents* which were social in origin. However, they argued that depression was not the automatic consequence of such provoking agents, and proposed that these interacted with *vulnerability factors* to produce depression. The vulnerability factors listed included: loss of mother before 11 years old, absence of confiding relationship (particularly with their husband) and lack of a full or part-time job, with the reverse of these acting as protective factors against depression. Hence, whilst the vulnerability factors determined *whether* depression would occur in the face of provoking agents, the provoking agents determined *when* depression would occur.

Their theoretical account of the development of depression centers around the experience of hopelessness. Brown and Harris argue that hopelessness forms the central experience in depression (in contrast to Seligman who proposed that it was helplessness) and that this develops from the appraisal of particular life events which usually involve the loss, or threat of loss, of some kind. Vulnerability factors were seen as leading to feelings of hopelessness through their effect on self-esteem (or feelings of self-worth/mastery). If feelings of mastery were low prior to a life event, then feelings of hopelessness were viewed as more likely to generalize following this event. The actual losses experienced through the life events were conceptualized as ones which resulted in the loss of "sources of value or reward" (p.233), the significance of such loss was that:

> "it leads to an inability to hold good thoughts about ourselves, our lives, and those close to us" (Brown and Harris, 1978; p. 233)

> "a person's ongoing self-esteem is crucial in determining whether generalized hopelessness develops-that is, response to loss and disappointment is mediated by a sense of one's ability to control the world and thus to repair damage, a confidence that in the end alternative sources of value will become available" (Brown and Harris, 1978; p. 235)

Brown and Harris argue that role identities are key to understanding the generalization of feelings of loss and hopelessness, and that the challenge to these identities underpins the extent of vulnerability women may have towards developing depression. For example, they state:

> "The more a woman has committed herself to a given identity or cluster of identities the more her 'assumptive world'..... will be caught up in it and the greater the severity of a crisis that deprives her of an essential part of it." (Brown and Harris, 1978; p. 236)

> "It is possible that what is *left* of a role identity or identities after a provoking agent will determine vulnerability" (Brown and Harris, 1978; p. 237)

Hence the life event, or change in personal or social circumstances is not itself the key factor in depression, rather it is the meaningfulness of those events.

However, this theory has been criticized, in particular, the interaction between provoking agents and vulnerability factors has not been widely replicated and suggests the model may be limited. There is evidence, for example, that vulnerability factors may vary across cultures and hence may be community specific (Costello, 1982; Ndetei and Vadher, 1982) and that the model therefore lacks generality. However, aspects of this theory have been adopted by Champion and Power (1995) in their more recent model of depression.

5.1.3.3 The theory of Champion and Power: a socio-cognitive synthesis

Champion and Power (1995) have offered what they consider to be a synthesis of the cognitive vulnerability theory of Beck and the social vulnerability theory of Brown and Harris. They argue that previous cognitive theories, such as Beck's, failed to take into account certain features which they believe to be central to a theory of

depression i.e. "the concepts of goals, roles and options" (p. 485). They also argue that consideration of the latter necessarily involves consideration of the social world, involving the social relationships and circumstances in which these goals, roles and options take place.

This theory of depression proposes that an individual will be vulnerable to developing depression if an 'over-valued' role or goal becomes threatened or is lost. They argue that those individuals who are considered 'cognitively vulnerable' to developing depression are those who have what they term an 'ambivalent model of the self'. The latter are thought to derive meaning and purpose primarily from their life roles and goals, a meaning and purpose which occurs in the relative absence of an intrinsic belief in their own value. Whilst the latter would result in an individual's feelings of self-worth being relatively independent of external circumstances and rewards, the former means a dependency on social roles and goals for a feeling of self-worth. Champion and Power argue that if such people focus on and work towards these valued life goals they can inhibit negativity, self-doubt and self-depreciation. However, if these roles and goals become threatened or lost, depression may result. They further argue that this is particularly likely to occur if one area of life is valued over and above other areas, that is, if self-worth is defined almost exclusively in one domain and this domain comes under threat. For example, they state:

> "the vulnerable individual's self-esteem is overly bound up with the dominant goal or role and .... self-esteem is more vulnerable to external variation than is normal" (Champion and Power, 1995; p. 494)

The idea of an 'ambivalent model of self' clearly draws on previous models of depression such as Beck's, whereby depressed individuals tend to have negative self-schema considering themselves 'worthless' and 'stupid', and on Brown and Harris's view that low self-esteem is a vulnerability factor in developing depression. The focus on social roles also draws much from Brown and Harris's theory although it differs from the latter in its more detailed modeling of the cognitive processes thought to be involved

in depression. In contrast to Beck's model, Champion and Power argue for a mental models approach rather than a schematic one, as they argue this approach is better able to account for findings which suggest cognitive distortions in depressed persons do not appear to be stable and enduring across situations.

5.1.3.4 Behavioural models of depression

Lewinsohn's (1974) behavioural model of depression proposes that depression results from a decrease in response-contingent positive reinforcement, i.e. in positive rewards following action, which may occur for a number of reasons: i) positive reinforcers may actually become less available (or aversive reinforcers become more available), ii) the presence of reinforcers may not change but the impact that they have does, such that the impact of positive reinforcers decreases (or the impact of negative reinforcers increases), and/or iii) the individual may lack the skills required to gain positive reinforcement (or avoid negative reinforcement). As a result of reduced positive reinforcement, the number of behaviours, or responses, that the individual performs also reduce. This in turn makes positive reinforcement less likely and sets up a vicious cycle. The negative mood which accompanies depression is thought to be a direct result of the reduction in positive (and rewarding) activities, and differs from the learned helplessness model of depression as it argues that it is loss of reinforcers *per se* which causes depression rather than the loss of control over reinforcers. Behavioural models have been criticized, however, for arguing that depression is solely a function of environmental factors and not dependent on individual appraisals of the meanings of those environmental factors or stressors.

5.1.4 Theories of depression and chronic pain

The extent to which the above theories generalize to account for depression in chronic pain sufferers has been explored in a review paper by Banks and Kerns (1996). In brief, there is some evidence to support their applicability to understanding

depression in chronic pain, although relatively little theorizing specific to depression in chronic pain has been conducted to date, Williams (1998). For example, in line with Beck's model of depression there is evidence of cognitive distortions in chronic pain patients. Both pain-specific and more general cognitive distortions have been found to relate to depression among chronic pain sufferers (Lefebvre, 1981; Holzberg, Robinson and Geisser, 1993), although Flor and Turk (1988) found evidence for an association between pain-specific cognitive distortions and higher levels of reported disability in low back pain and arthritis patients, though not between general cognitive distortions and disability. There is also evidence from longitudinal studies in depression in chronic pain patients that such cognitive distortions appear to precede depression in chronic pain sufferers, suggesting they may play an etiological role in its deveopment (Keefe, Brown, Wallston and Caldwell, 1989).

Consistent with the learned helplessness theory of depression, chronic pain can be conceptualized as an uncontrollable negative event, as pain usually cannot be alleviated and is considered aversive. Low levels of perceived control have been linked to measures of pain-adjustment in general, and depression in particular. For example, there is considerable evidence that feelings of control both over the pain specifically and over life more generally have been linked to enhanced adjustment as measured by feelings of helplessness, depression and activity levels (Crisson and Keefe, 1988; Rudy *et al.*, 1988; Jensen and Karoly, 1991, respectively). There is also evidence that perceived life control mediates the relationship between pain and depression (Rudy *et al.,* 1988). However applying the learned helplessness model of depression to depression in chronic pain patients has been criticized. For example, Williams (1998) has argued that chronic pain may be better characterized as associated with realistic assessments of limited control over pain rather than low feelings of control following repeated failure to control pain.

There is also some evidence to support the reformulated model which considers attributional style, although overall the results have been mixed. For example, whilst Love (1988) showed depressed chronic pain patients were more likely than non-depressed chronic pain patients to show the depressive attributional style whilst Ingram, Atkinson, Slater, Saccuzzo and Garfin (1990) found no difference between depressed and non-depressed chronic pain patients in attributional style.

Finally, in line with the behavioural model of depression, Fordyce has argued that pain can lead to a reduction in positive reinforcement, because activities which were previously rewarding are now followed by an increase in pain, or a fear that pain will increase. Both pain and fear of pain are seen as negative reinforcers which cause activity levels to diminish, and result in a lack of positive reinforcement, further reducing the opportunities for positive reinforcements, and setting up a vicious circle which can lead to depression. There is little doubt that one of the key features of chronic pain is a decrease in numerous activities such as work, social and recreational activities (Rudy *et al.,* 1988), and there is evidence that activity levels are lower in depressed as compared with non-depressed chronic pain patients (Kerns and Haythornthwaite, 1988). However little longitudinal research has been conducted on the relationship between reduced activity and depression and it is unclear whether reduced activity does play a role in the development of depression in chronic pain sufferers.

5.1.4.1 The Diathesis-Stress framework of Banks and Kerns.

In their discussion of theories of depression and their application to understanding depression in chronic pain patients, Banks and Kerns present an analysis of what they consider to be the fundamental communality among theories of depression. They argue that the key cognitive and behavioural theories of depression (i.e. Beck's negative cognitive triad, Abrahamson *et al.*'s causal attribution and Fordyce's behavioural model) can all be conceptualized as diathesis-stress models, where

'diathesis' refers to a vulnerability towards developing depression, typically considered to be any personal characteristic, biological and/or psychological in origin, that increases the probability of a particular person developing depression. For example, following Beck this might be the presence of negative cognitive schema, or following Abrahamson *et al.* the tendency to attribute the occurrence of uncontrollable outcomes to global, stable and internal factors. In such models, vulnerability factors are seen as giving rise to depression but only following the event of a stressor (e.g. experiencing an uncontrollable outcome).

Whilst Banks and Kerns do not discuss Brown and Harris's or Champion and Power's theories of depression, both of these can also be viewed in diathesis-stress terms. In the former, low self-esteem is considered to be the key vulnerability factor and stressful life events, such as unemployment and bereavement, as stressors, and in the latter the vulnerability factor is an ambivalent model of self and the stressor the loss of highly valued roles and/or goals.

Banks and Kerns (1996) argue that, not withstanding the difficulties in determining the incidence of depression in different populations, the available evidence suggests that the prevalence of major depressive disorder is higher in chronic pain sufferers than in those with other medical illness (such as coronary artery disease and cancer). They argue that because diatheses (premorbid vulnerability factors) should be randomly and hence evenly distributed among people, the apparently higher incidence of depression in chronic pain groups implies there must be something uniquely stressful about the experience of chronic pain.

> "the stressors of chronic pain, individually or in their composite, are either more severe, produce losses in a greater number of domains, elicit a greater sense of loss of control and helplessness, or in some yet unspecified ways more specifically, directly, reliably, or intensively match and activate cognitive and behavioral diatheses for depression." (Banks and Kerns, 1996; p. 106)

They document some of the unique ways in which pain might be seen as more

stressful than other chronic illnesses. Briefly, these are:

i) *The symptom of pain per se:* included here are factors associated with the inheritently aversive nature of pain such as its persistence and its effect on cognitive function, such as attention and concentration;

ii) *Associated losses accompanying pain:* following the WHO classification of impairments, disabilities, and handicaps (outlined in Chapter 1 section 1.4.4.2), Banks and Kerns categorize physical impairments, such as muscle weakness, and disability as coming under the category of primary losses associated with pain.

iii) *Secondary losses:* examples of these are the knock-on effects that the impairments and disability caused by pain has on social relationships, such as those with family friends and partners, and other factors which may accompany pain, such as financial strain and job loss.

iv) *Experience with the medical system:* Banks and Kerns argue that in comparison with other chronic illnesses, chronic pain often lacks a clear diagnosis and effective treatment which can significantly reduce the pain. As a result, they argue that the experience of chronic pain is often characterized by a lack of validation by medical profession.

Whilst Banks and Kerns recommend that future research explicitly test diathesis-stress models of depression in chronic pain, this view has been criticized (Williams, 1998). Williams questions the need to theorize vulnerability factors, which focus on a 'flaw' in the patient, arguing that the evidence for premorbid and post-morbid cognitive vulnerabilies is not always convincing. Instead Williams suggests that models describing stress without diathesis should be considered.

5.1.5 Understanding limitations associated with pain: Schema accuracy

The present study aimed to explore predictors of poor adjustment to pain, notably depression, which have not been widely explored to date, namely the role of symptom understanding and role/goal loss. Whilst Banks and Kerns identify role/goal loss as important in understanding depression in chronic pain, accurate symptom understanding does not feature in their discussion. However, accurate symptom understanding could be viewed as a 'cognitive distortion' (this is discussed more towards the end of the present section) or could be viewed as a measure of the extent to which the patient and doctor are in agreement about the cause and possibilities for cure of their symptoms and hence offers a measure of a stressor Banks and Kerns do discuss: that of validation from the medical profession.

Whilst a number of studies have found evidence that single dimensions of schema correlate with depression, relatively little research has examined global symptom understanding. There are a number of different measures that can be used to assess the different dimensions of illness schema and these have been reviewed by Scharloo and Kaptein (1997). They state that semi-structured or open-ended interviews are typically the only methods used to assess all five dimensions of schema. Questionnaire measures often assess one or two schema dimensions, with the exception of the Illness Perceptions Questionnaire (Weinman, Petrie, Moss-Morris and Horne, 1996) which assess all five. For example, the Survey of Pain Attitudes (Jensen, Karoly and Huger, 1987) assesses the dimensions of control over, and consequences of, illness through five subscales. The latter assess beliefs about control, potential curability of the pain, best treatment for pain and beliefs that pain has led to permanent disability. The West Haven-Yale Multidimensional Pain Inventory (Kerns *et al.*, 1985), which has been widely used in chronic pain research, consists of twelve subscales, one of which assess life control (the degree to which pain patients feel in control of their life) and one of which assesses pain consequences (the degree to which pain has interfered with social,

recreational and work activities).

There is considerable variability in measures of illness schema, most notably in terms of whether they assess general health beliefs (and therefore tap a general 'health schema') or assess pain specific beliefs (and therefore tap a 'pain schema'). For example, whilst the Multidimensional Health Locus of Control Scales assesses beliefs about control over health in general, the Multidimensional Health Locus of Pain Control Scales assesses beliefs about control specifically over pain. In addition to varying in terms of their level of specificity (general health vs. pain), measures also vary in terms of which particular aspect of the illness dimension is measured. For example, whilst some measures of beliefs about the causes of pain have focused on the extent to which people perceive their pain as caused by organic or psychological factors (Edwards, Pearce, Turner-Stokes and Jones, 1992), others have focused on the extent to which the pain is perceived as caused by internal or external factors (Crisson and Keefe, 1988).

Research which has measured multiple dimensions of illness schema and looked at more global measures of symptom understanding has tended to focus on how illness schema relate to treatment compliance and treatment outcome. For example, degree of correspondence between patients' and doctors' understanding of symptoms has been linked to treatment compliance in hypertensive patients (Meyer, Leventhal and Gutmann, 1985). Relatively little research has explored the relationship between global symptom understanding and psychological wellbeing or disability in chronic pain sufferers, although the work of Lacroix, Powell, Lloyd, Doxey, Mitson and Aldam (1990) is a notable exception.

Lacroix *et al.* (1991) argue that "*the patient's illness schema is conceptualized as the link between disease and illness*" (p. 269) and that, by shifting the focus from diagnosis to prognosis, it may also "*be conceptualized as the link between medical pathology and disability*" (p. 269). In support of this view Lacroix *et al.* (1991), in a

study on people with chronic respiratory disorders, found that those patients who had a better understanding of their symptoms, measured by high levels of agreement with their doctors:

> "functioned at a higher level in their daily lives than did less-informed patients. Well-informed patients pursued hobbies and interests, were socially responsive, and generally were more active than the less-informed patients, who seemed more depressed, inactive, and socially isolated" (p. 272).

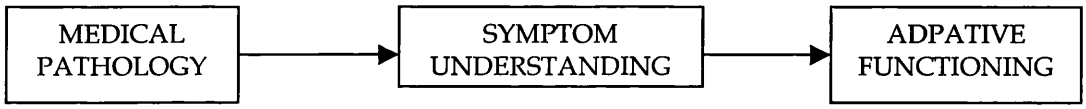
Hence, according to Lacroix *et al.*, the role of illness schema extends beyond issues of treatment compliance and outcome (in Lacroix's terms, factors associated with 'illness') to more global issues of disability or what they term 'adaptive functioning' (in Lacroix's terms, factors associated with 'prognosis'). There is some evidence to support this view.

In a study examining people who had sustained a work-related back injury which had resulted in levels of pain sufficient to stop them from working, Lacroix *et al.* (1990) found that better symptom understanding was significantly associated with work status: those who tended to concur with the doctor's assessment of their symptoms were more likely to return to work, compared to those who did not. Further, this relationship was independent of factors relating to the severity of the injury sustained. Accuracy of symptom understanding was also associated with English proficiency (assessed on a 1-4 scale from 'Nil' to 'Good'), whereby those with higher levels of English had higher levels of symptom understanding. Participants were examined 3 to 6 months following their injury, at which time they were given both an orthopaedic examination and a psychological assessment. At this point Lacroix *et al.* assessed the pain sufferers' understandings of their symptoms. Work status was assessed some time after this, between 6 to 12 months after the initial injury.

Lacroix *et al.*'s (1991) claim that illness schema affect 'adaptive functioning'

has not yet been tested in chronic pain sufferers except with regard to return to work. However, Lacroix *et al.* clearly state that accuracy of symptom understanding should predict factors such as level of current involvement in hobbies and other lifestyle activities, and levels of depression (see previous page). Lacroix's model of the relationship between medical pathology, illness schema and adaptive functioning is shown in Figure 5.1.

Figure 5.1: Lacroix *et al.*'s model of the relationship between medical pathology, symptom understanding and adaptive functioning



Although it is never explicitly stated in his work, Lacroix's assumption that the doctor holds the 'correct' view of the patient's symptoms implies that the measure of agreement between patient and doctor regarding the patient's symptoms is a measure of the degree of distortion of the patient's illness schema. Hence it is this schematic distortion which results in general 'maladjustment' or poor 'adaptive functioning'. Lacroix *et al.*, however, do argue that agreement in symptom understanding between doctor and patient may point to key mediators such as compliance with treatment, which in itself may improve levels of adaptive functioning, and/or level of understanding about the limitations associated with their illness (in this instance chronic pain).

> "The patients who better understood their physical conditions may also have assessed their limitations more realistically. Coming to terms with one's limitations is an essential requirement for successfully (sic) adaptation to chronic illness. This implies, however, that a patient gains an accurate understanding of what those limitations are." (p. 272)

Hence correct understanding is viewed as a crucial precursor to acceptance of the limitations associated with that illness and hence adjustment. Whilst their own research has presented some evidence consistent with the idea that symptom understanding may

predict adjustment, as noted above, their claim has not been widely tested within chronic pain groups. The view that accurate symptom understanding might predict adjustment receives support from recent work by Geisser and Roth (1998). They showed a significant relationship between people's awareness of the physiological cause of pain which was in agreement with their clinical diagnosis, and reduced reports of pain intensity, pain distress and disability in chronic neck and back pain sufferers. This provides evidence that symptom understanding may play an important role in understanding the link between pain and emotional response to the pain (in this instance, pain distress), and pain and perceived disability.

5.1.5.1 The Schema Assessment Instrument

Lacroix's Schema Assessment Instrument (SAI) uses the pain sufferer's own symptoms and assesses their own hypotheses about the meaning of these symptoms. This method of schema assessment directly matches the description of schema given by Lacroix *et al.* (noted in Chapter 4, section 4.3) (Lacroix *et al.*, 1991), assessing as it does the individual's symptoms, the belief in the relatedness of those symptoms and a theory about the mechanisms underlying this relatedness. This method was chosen because it addressed some of the criticisms of schema assessment used in Study 1 (word lists) which were noted in Chapter 4: firstly it uses the patients' own symptoms as the basis of the measure of schema, and secondly it arguably also goes some way to assessing the meaning of pain symptoms through an assessment of the patient's hypotheses about the inter-relatedness of those symptoms. The SAI principally addresses the identity and cause dimensions of schema. However, the measure also includes questions about time-line and curability and hence includes the final element of their definition of schema: implicit or explicit prescriptions for corrective action. It therefore omits only the consequences dimension of schema. In contrast to the majority of other questionnaire measures, which typically assess only one schema dimension, the SAI offers a global measure of symptom understanding. It does this by comparing the patient's

understanding of their symptoms with that of their clinician, generating a measure which is a measure of schema accuracy.

Lacroix *et al.* (1991) suggest that symptom understanding or illness schema may play an important role in predicting depression. However in their test of the predictive power of illness schema using their Schema Assessment Instrument on different measures of adjustment (e.g. return to work and the Global Assessment Scale) only univariate analyses (correlations) were performed. The unique predictive power of illness schema, as assessed by the SAI, has therefore not been demonstrated in previously published work to date. In the present study, other factors which have been hypothesized as predicting depression in chronic pain sufferers were therefore also considered: namely the losses that are associated with it and how people might deal with these losses (i.e. general coping style).

5.1.6 Actual limitations associated with pain: role/goal loss and flexible goal adjustment

A number of theories of depression focus on loss and, in particular, on the loss of roles and goals (e.g. Brown and Harris, 1978; Champion and Power, 1995; Oatley and Bolton, 1985). Such losses have been conceptualized as causing depression by triggering an individual's vulnerability towards developing depression, whether this is theorized as low self-esteem (Brown and Harris), an ambivalent model of self (Champion and Power) or an inability to seek reinforcement from other areas of life (Lewinsohn, 1974). Whilst it is clear that a large number of losses accompany the experience of chronic pain, such as in work, social and recreational activities, and there has been widespread research into these sorts of restrictions that accompany pain, there has been relatively little research which explicitly conceptualizes these losses as losses in roles or goals. The significance of conceptualizing losses as losses in roles and goals lies in placing these losses as related to an individual's identity. For example, in their

discussion of the theory underpinning their Roles and Goals Questionnaire, Lam and Power (1991) state that the theories of depression of both Oatley and Bolton (1985) and Power (1987) which focus on role/goal loss predict:

> "that a stressful event increases the risk of depression if the event poses a threat to a highly valued characteristic of the self" (Lam and Power, 1991; p. 359)

Banks and Kerns suggest that future research into aspects of chronic pain and depression could either focus on examining the match between diathesis and stress and/or on:

> "examination of the meaningfulness of the pain experience and accompanying losses-meaningfulness in terms of the significance of the losses to the patient's self-concept or perceived life purpose, " (Banks and Kerns, 1996; p. 106)

Whilst there has been little work on role/goal loss and the resulting challenge to identity it may pose in chronic pain patients, research into pain as presenting an *obstacle* to life goals in general has been conducted.

Schmitz, Saile and Nilges (1996) have argued that chronic pain can be conceptualized as an impediment to pursuing life goals and that depression can be seen as resulting from chronic pain primarily because chronic pain presents an obstacle to their pursuit. The idea of pain as an obstacle has clear parallels with the idea of loss or threat of loss as proposed by the theorists noted above. However, following the work of Brandtstädter (discussed in section 5.1.6), rather than focusing on the specific nature of the losses *per se*, Schmitz *et al.* propose that the key to understanding depression in chronic pain lies in how people cope with impediments to pursuing goals in general. For example, they state:

> "The experience, that certain personal goals may no longer be attainable due to chronic pain, can be understood in terms of a discrepancy between a factual and a desired state; such discrepancies trigger coping processes that serve to neutralize anticipated threat or avoid loss." (Schmitz *et al.*, 1996; p.43)

Schmitz *et al.* assume that chronic pain by definition causes goal pursuit impediments, but rather than theorizing a vulnerability factor centred on self-esteem (such as Brown and Harris) or an ambivalent model of self (such as Champion and Power), coping style of flexible goal adjustment (FGA) is viewed as the crucial moderator of the relationship between role/goal loss in chronic pain and depression. Nevertheless, FGA could be conceptualised as a vulnerability factor within a diathesis-stress framework. For example, the originators of the coping style flexible goal adjustment state that the:

> "buffering effect of flexible goal adjustment on the impact of perceived developmental deficits on dissatisfaction with personal development... indicates a lower vulnerability of flexible individuals to developmental stress." (Brandtstädter and Renner, 1990; p. 65)

The concept of FGA was developed to account for individual differences in how people adjust to enforced changes in activity and lifestyle brought about by the ageing process, and alongside the coping style of Tenacious Goal Pursuit (TGP) forms part of a larger model termed 'personal self-regulation of development' which outlines coping appraisals, control beliefs and emotions (Brandtstädter and Renner, 1990; Brandtstädter and Rothermund, 1994). These two coping styles, FGA and TGP, are measured by a questionnaire developed by Brandtstädter and Renner (1990) (see Appendix C). Both types of coping are directed towards reducing the discrepancy between desired goals and actual levels of achievement of those goals. However, the two methods of coping refer to two very different attempts to reduce such goal discrepancy.

Assimilative coping (FGA) refers to active attempts to achieve personal goals and aspirations. In the context of chronic pain these may include instrumental activities such as trying to get surgical treatment, and compensation strategies to deal with the

impediment caused by the pain, such as sitting rather than standing to achieve particular tasks if standing makes the pain worse.

Accommodative coping, (TGP) on the other hand, refers to relinquishing or altering personal goals that have not been achieved, through a process of self-revision. This process may include the following: a downgrading of personal standards, setting up more 'realistic' goals which, for example, accept the limitations on normal life imposed by pain, and the development of new goals to replace the relinquished ones. In this way the perceived discrepancy between desired goals and achievement is effectively dissolved. Brandtstädter and Renner suggest this is seen as a 'neutralization' of the problem rather than an 'active solution' (p. 58).

FGA was used by Schmitz *et al.* because they considered chronic pain is "more or less associated with broad limitations in important areas of life and daily functioning" (p. 43), and as such, active-assimilative coping efforts will not generally be effective in dealing either with the pain and/or its associated stressors. They argue there is evidence both that chronic pain patients adopt few problem-focused coping strategies (which involve taking personal control over the pain) and that perceived control over pain is typically low. As a result, they argue that theories of coping which centre on active-offensive coping as leading to positive adjustment are limited in their ability to account for relatively high levels of adjustment despite low levels of perceived control.

Using the FGA scale, Schmitz *et al.* demonstrated that FGA significantly moderated both the relationship between pain intensity and depression, and the relationship between pain-related disability and depression. Hence, when FGA was high, both the relationship between pain intensity and depression and that between pain disability and depression was attenuated. Schmitz *et al.* also found that the relationship between disability and different pain-specific coping strategies, such as cognitive restructuring, action planning, self-efficacy, diverting attention, distracting activities and

relaxation, were only significant in the case of distracting activities, however when FGA was entered as a moderator variable (i.e. the interaction between the particular coping strategy and FGA was entered as a predictor) the relationship was significant at the 0.05 level, or approached significance, in every instance. They interpreted these results as suggesting that specific coping strategies are only effective in reducing the perception of pain-related disability if accompanied by accommodative coping. Whilst some evidence was found to support Tenacious Goal Pursuit as a useful strategy, it was not found to relate to depression in the same consistent way that FGA did. Hence these findings suggest that accommodative coping, or FGA, may be a useful concept in understanding people's adjustment to chronic pain.

However, in line with Banks and Kerns' criticisms of work on depression and pain, this research can be seen as having focused more on the vulnerability factor (low levels of FGA) rather than the specific stressors. For example, whilst Schmitz *et al.* (1996) assume that chronic pain presents a general obstacle, no test has been made of whether there are particular life domains which, when impeded by pain, are more likely to lead to depression than others. Thus no assessment has been made of particular role/goal impediments or stressors and how they relate to depression in chronic pain patients.

5.1.6.1 The relationship of FGA to theories of depression

As noted in section 5.1.6 Brandtstädter and Renner's (1990) model offers a partial critique of learned helplessness theory in that it challenges the view that high levels of internal control are always linked with positive psychological wellbeing. They argue that there is evidence that:

i) depressed people view fewer events as requiring acceptance, and

ii) desire for control over what are realistically uncontrollable events might aggravate the problems of a depressed person, for example by exposing them to perpetual failure.

Brandtstädter and Renner therefore argue that these:

> "assumptions and findings do not easily fit with theoretical accounts of depression that primarily center on perceived control and learned helplessness" (Brandtstädter and Renner, 1990; p. 61)

However, they do not dismiss the role of control as important in understanding depression, but rather argue that depression depends *not only* on attributional style and beliefs about control but on the "individual's readiness or capability to revise and readjust personal preferences." (p. 59) which they suggest becomes important when goals become difficult to attain.

Whilst they do not discuss other theories of depression, there are marked similarities between Brandtstädter and Renner's model and the theories of depression of Champion and Power, and Brown and Harris. Although the details of each theory of depression differ in terms of the stresses and vulnerabilities which are hypothesized, at a broad level there are the following similarities: they all focus on loss (as opposed to helplessness for example), however, whilst the theories of Champion and Power, and Brown and Harris both focus on vulnerability factors which center around concepts related to feelings of self-worth, Brandtstädter and Renner focus on lack of flexibility, i.e. the inability to relinquish unfeasible goals and develop new ones. However, the revision of personal preferences is viewed as linked with aspects central to a person, for example, Brandtstädter and Renner state that whether depression follows the blocking of a goal:

> "depends on the importance of the blocked goal perspectives with regard to the person's basic life themes and value orientations" (Brandtstädter and Renner, 1990; p.59)

and that the inability to change a situation in which developmental life roles and goals are challenged results in an identity crisis which precipitates accommodative reappraisal (p.60). Hence whilst they do not invoke ideas of low self-esteem as a vulnerability factor, the notion of a 'threat to self' is present in their theory. A further

similarity between Brandtstädter and Renner's theory and Champion and Power's is the focus on the availability of alternative goals following an obstacle. For example, Lam and Power propose that depression arises in part because people:

> "have a limited range of self-related roles and goals and thus have no alternative roles that can fulfill the sense of selfness once the dominant role is lost." (Lam and Power, 1991; p. 360)

and Champion and Power mention flexibility as a key to understanding the availability of alternatives:

> "the flexibility to find new meaning in either new or previously neglected areas of experience is likely to be a crucial factor in cognitive vulnerability to depression. The more flexible that the individual can be in this way, the lower the vulnerability in the face of stress" (Champion and Power, 1995; p. 490)

Hence, Lam and Power/Champion and Power discuss the lack of alternatives following over-commitment to one or another life domain, and Brandtstädter and Renner discuss the individual's readiness or capability to revise and readjust personal preferences. The two theories therefore arguably converge on notions of over-involvement/tenacity towards certain goals and a lack of ability/willingness to establish new goals.

The concepts of loss and the ability to find alternatives to supplement this loss also appear in Brown and Harris's theory. For example, they state:

> "it is not just loss of a particular 'object' that has to be dealt with, so much as its implications for our ability to find satisfactory alternatives" (Brown and Harris, 1978; p.234)

5.1.6.2 The relationship of FGA to other coping measures

FGA represents a different measure of coping to that used in much of the research on coping with chronic pain (see Jensen *et al.*, 1991 for a review), principally in terms of the stressor it identifies as the object of coping efforts. The majority of coping research in chronic pain has tended to focus on how people cope with the pain

per se. For example, the Coping Strategies Questionnaire has been widely used in chronic pain research (Jensen *et al.*, 1991) and assesses seven types of strategy for coping with pain, such as diverting attention, reinterpreting pain sensations and increasing activities. However, chronic pain involves multiple stressors which include not only the pain itself, but associated lifestyle changes such as loss of work (Keefe, Salley and Lefebvre, 1992; Williams, 1998). The Ways of Coping checklist allows either the respondent or the researcher to specify the stressor they consider to be primary and hence is not necessarily restricted to studying pain *per se*. In contrast, FGA specifies the stressor but considers it to be obstacles to the pursuit of valued life goals. FGA also differs from other coping measures in its stance on other key issues within the coping field.

Key distinctions in the coping literature include those between 'passive' vs. 'active' (Brown and Nicassio, 1987) and 'problem-focused' vs. 'emotion-focused' coping strategies (Folkman and Lazarus, 1985), and whether coping strategies are viewed as stable over time ('trait') or as varying across time and/or across situations ('state') (Folkman and Lazarus, 1985; Carver, Scheier and Weintraub, 1989). A further issue is the extent to which such strategies must be seen as effortful in order to count as coping strategies. The construct of FGA does not draw on the distinction between active and passive strategies so that distinction will not be discussed further here, however, it does draw on the other distinctions and its position in relation to these will now be outlined.

The distinction between FGA and TGP mirrors that drawn between problem-focused vs. emotion-focused coping by Folkman and Lazarus (1985) and measured by the Ways of Coping Questionnaire (Folkman and Lazarus, 1988). Folkman and Lazarus view stress as arising from a problematic person-environment relationship, and their distinction between problem-focused and emotion-focused coping revolves around whether anything can be done to change the person-environment situation. Problem-

focused coping refers to coping efforts which aim to change the person-environment relationship by changing the environment and/or changing oneself. In contrast, emotion-focused coping refers to coping efforts directed at changing the meaning of the stressor and hence are typically used when nothing can be done to change the presence of the stressor. The aim of emotion-focused coping is to control the meaning of event and thereby regulate the accompanying distress.

> "there is ample evidence that under certain conditions - particularly, those in which nothing useful can be done to change the situation - rational problem-solving efforts can be counterproductive" (Lazarus, 1993; p. 238)

Tenacious goal pursuit (TGP) is viewed as a coping strategy which is primarily focused on 'active, instrumental efforts at control' (p. 59). This coping style therefore focuses on changing the situation. Flexible goal adjustment, on the other hand, is viewed as focused on 'adaption of personal preferences and life designs' (p.59) to situational demands, and, like emotion-focused coping, focuses more on reappraisal of a situation which cannot be changed, such as the presence of chronic pain.

FGA is conceptualised by Brandtstädter and Renner (1990) to be a trait-like disposition. They argue that flexible goal adjustment and tenacious goal pursuit can be assessed as "habitualized styles or tendencies of coping on a dispositional level" (p. 61). However they also argue that the use of such coping strategies are the result of situational demands alongside generalized behavioural tendencies (based on prior learning/personality traits, for example). Following criticisms of past trait-like measures, they attempt to draw a distinction between the coping style and its adaptive qualities, so they do not equate accommodative coping with 'good' outcomes and assimilative coping with 'poor' outcomes. Instead they argue that the success of one or other style of coping relates to the particular situation at hand, and that in certain situations active-offensive coping efforts may be associated with good outcomes, whilst in others it may not.

Theories concerned with the stability of coping, focus on what Folkman and Lazarus (1985) refer to as 'structure' i.e. stable factors such as personality traits and/or stable features of the environment, such as social support networks, whilst those which focus on the variability in coping focus on how coping varies across time and situations. A number of researchers have suggested that personality traits determine coping (e.g. Epstein and Meier, 1989; Bandura, 1982; Antonovsky, 1987) (Cited in Lazarus (1993) article.). However the personality trait view of coping has been criticizied. Lazarus argues that what people *actually* think and do in response to a stressful event should be measured, rather than what they *usually* or *typically* do, as the latter may be subject to memory biases, and it is more important to focus on the 'particular threats of immediate concern' (Lazarus, 1993; p. 236). Despite this criticism, Folkman and Lazarus (1985) argue that coping is transactional process between the person and the environment, and that whilst coping varies over time and according to the specific stressor under consideration, "....stable coping styles do exist and are important...." (Lazarus, 1993; p. 8). For example, there is evidence that some strategies appear to vary little over time, such as the use of positive reappraisal (Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen, 1986a; Folkman, Lazarus, Gruen and Delongis, 1986b). Furthermore, Scheier, Weintraub and Carver (1986) have shown that the tendency towards optimism or pessimism influences people's coping strategies suggesting that personality traits might play an important role in the selection of coping strategies. Carver *et al.* (1989) however have gone further. They argue that the rejection of trait-like approaches rests on data showing that the coping styles of 'monitoring' and 'blunting' did not predict the course of recovery from surgery, and argue that:

> "We are not.... ready to assume that individual differences play no role in determining the degree to which a given coping strategy is engaged at any given point....The fact that trait measure were poor predictors in the past may tell us more about the predictive value of specific personality differences than it tells about the role of individual differences in general" (Carver *et al.*, 1989; p. 270).

Further, they suggest that both state and trait coping styles be assessed such that both coping dispositions and situational coping responses can be assessed.

However, given Brandtstädter and Renner's definition of coping as 'habitualized', some might reject the idea that FGA is a coping strategy. Jensen *et al.* (1991) have defined coping as a "purposeful effort to manage or vitiate the negative impact of stress" (p. 250), and the view that coping strategies need to be 'purposeful' by definition is endorsed by a number of researchers (e.g. Lazarus and Folkman, 1984; Tennen and Affleck, 1997). However, Coyne and Gottlieb (1996) argue that a definition of coping as necessarily effortful is too restrictive as it excludes automatized thoughts and behaviours, which may be particularly important in chronic medical conditions where coping efforts may become routinized over time.

5.2 AIMS

This study aimed to explore aspects of schema content associated with pain-adjustment, particularly depression, which have received little empirical attention to date: namely symptom understanding and the role/goal losses which frequently accompany the experience of chronic pain. These aspects of schema content concern the *accuracy* of individual's understandings of their pain symptoms (considered to be a crucial precursor to acceptance of the limitations associated with illness, and hence adjustment to it), and secondly the *losses* (or actual limitations) associated with chronic pain and the coping style of 'flexible goal adjustment' which has been found to moderate the impact of losses associated with chronic pain in previous research. Both are thought to predict acceptance of the limitations of illness.

This study therefore aimed to explore:

i) the role of symptom understanding in predicting pain-adjustment, particularly depression,

ii) the role of pre-pain life involvement in different life domains in predicting pain-adjustment, and the role of general coping style (Flexible Goal Adjustment (FGA)) in moderating the impact of this.

The present study also aimed to replicate the findings of Lacroix *et al.* and of Schmitz *et al.*. This was so that some assessment could be made as to the generalizability of the results found in the main analyses outlined above. Hence the subsidiary aims of the current study were to:

1) see whether the results of Lacroix *et al.*, linking symptom agreement with work status, would be replicated in a group of pain sufferers who had had pain for more than 3 to 6 months, and hence applied to people who had had pain beyond the relatively acute phase of 3 to 6 months,

2) see whether FGA significantly moderated the relationship between pain intensity and depression.

5.3 METHOD

5.3.1 Participants

Forty-four pain sufferers took part in the present study. Of these, four had incomplete data due to either not having a significant personal relationship or not having a significant hobby that they could speak of. All analyses reported here were therefore conducted on those remaining forty who had a complete data set.

Chronic pain was defined as present if it was linked to a benign condition, was ongoing and had persisted for more than 6 months despite medical treatment. The other inclusion criteria were:

- No visual and/or auditory problems
- An ability to read and write English
- Aged over 18 years.

The pain sufferers were recruited from the outpatient Anaesthetic pain clinic at the Northwick Park Hospital where they were attending appointments for routine medical management. The study was approved by the Institutional ethical committee and all participants gave written, informed consent (see Appendix C).

5.3.2 Design

The study employed a survey/questionnaire design to test regression and path analytic models of the relationship between symptom understanding, pre-pain activity involvement, flexible goal adjustment and adjustment to pain.

5.3.3 Materials

Lacroix's method of schema assessment: The Schema Assessment Instrument (SAI)

Lacroix (1991) has argued that symptom schema contain information about the time-line of the symptoms, their cause, consequences and possibilities for their cure. His Schema Assessment Instrument (SAI) enables an evaluation to be made of:

i) the patients' understanding or schemata of their symptoms, and

ii) a means of evaluating the 'accuracy' of this understanding with respect to objective medical evidence".

This instrument offers a measure of the agreement between doctor and patient about the patient's symptoms. The first stage involves gaining detailed information from the pain sufferer themselves about their symptoms, i.e. a list of the typical symptoms they experience. Both the pain sufferer and a doctor familiar with the patient's medical condition, are independently asked to group the symptoms according to which they think are caused by the same thing. They are asked three questions about the groupings: why they felt these symptoms were related, what was the cause of these symptoms and what was the physiological basis of these symptoms. The patient was also asked how

long they thought their symptoms would last for and whether they thought there was a possible cure for their symptoms. The doctor gave ratings of both:

i) the *Organic symptom severity* of the patient's medical condition and

ii) their functional *Prognosis.*

Both of these measures are given on the basis of physical/organic findings only and both are on a scale of 1-7 where '1' represents major physical findings and extremely poor prognosis, and '7' indicates no major physical findings (only "some spasm/tender points") and excellent prognosis, respectively.

These two symptom groupings were then compared by independent doctors and judged in terms of similarity of:

i) the differentiation of the symptoms into clusters,

ii) the content of the symptom clusters, and

iii) the causal explanations given to the symptom clusters.

An overall score was then given based on these assessments, of between 1 and 7, where 1 refers to a "completely inappropriate, purely arbitrary" groupings of symptoms by the patient and 7 refers to a "perfect" grouping, identical to that given by the doctor (see Appendix C). This overall score is called the 'Global' measure, but will be referred to as *symptom understanding* in the thesis for the sake of clarity.

Other questionnaire measures

Other questionnaire measures obtained were as follows:

Pain measures

i) Four 101 mm Visual Analogue Scales of pain intensity were used: present pain, average pain over the last week, worse pain over the last week and least pain over the last week. They were anchored 'No pain'/'Worst pain imaginable'. (See Appendix A)

ii) Details of whether the pain was continuous or intermittent, its chronicity in years, its location and whether they took medication for their pain or for depression were taken.

Depression measure: the Beck Depression Inventory (BDI; Beck *et al.*, 1979) was chosen to measure depression. (See Appendix A). The problems of measuring depression in chronic pain groups have been widely discussed (Williams and Richardson, 1993; Novy, Nelson, Berry and Averill, 1995; Williams, 1998). The inclusion of somatic items in measures of depression, such as the BDI, is problematic because significant overlap can exist between problems associated with pain and symptoms of depression (e.g. sleep disturbance and work inhibition) and lead to inflated scores. The BDI was chosen in the present study because it has been widely used in chronic pain research, and has a range of non-somatic items which form a scale with good internal reliabilities when completed by outpatient chronic pain patients, for example the total BDI scale has an internal reliability of 0.87 and the affective subscale an internal reliability of 0.85 (Miles, McManus, Feinmann, Glover, Harrison and Pearce, 2001). In the present study both the total BDI score was used, as well as the affective subscale excluding somatic items, to see whether somatic item inclusion altered the pattern of results.

Involvement in different life domains: the Roles and Goals Questionnaire (Lam and Power, 1991) was chosen to assess role/goal losses because, whilst there are pain-specific measures, such as Multidimensional Pain Inventory, which assess the disruption caused by pain in different life domains, such as work, social and recreational domains, Lam and Power's measure attempts to grasp not simply the disruption caused by pain but the meaning of that disruption to the individual by offering a measure of involvement and hence importance to the person, rather than simply a measure of whether or not that particular role can still be performed. As noted in sections 5.1.3 and 5.1.4 it is importance to the person's sense of self which is thought to play a key role in

depression by a number of theorists. This questionnaire has been shown to predict relapse in a prospective study of 30 adult depressed patients (Lam, Green, Power and Checkley, 1996), although to date it has not been used in a chronic pain sample.

The questionnaire assesses involvement in each of the following five life domains: work, most important hobby or interest, most important relationship, health and independence. The questionnaire asks the same five questions to assess involvement in each of these five life domains and includes questions about how central each activity is to the individual's sense of well-being, how unhappy life would feel if this activity had to stop, and to what extent success in that activity determined successes in other areas of life. Each question is judged on a scale ranging from 1 (very little involvement) to 4 (a great deal of involvement) (see Appendix C). In their preliminary study using this questionnaire, Lam and Power (1991) studied two samples: one younger (18-65 year olds) and one older group of adults (65-85 years old). The whole scale had reasonably good internal reliability in both the older adult (Cronbach alpha = 0.85) and the younger adult samples (Cronbach alpha = 0.67). For each of the separate domains the internal reliabilities were found to be reasonable, with Cronbach alpha coefficients ranging from 0. 81 – 0.66 in the older adults sample and from 0.73 - 0.62 in the younger adults sample. Test-retest reliabilities (conducted only on the younger adults, three months later) were reasonable at 0.79 for the scale as a whole, although ranged from 0.55 to 0.72 for the separate domains.

In the current study this questionnaire was filled in twice: firstly relating to before the pain began, and secondly relating to the present time. Involvement scores for people who had given up their work and/or hobby due to the pain, due to retirement, or for other reasons, gave a present involvement score for alternative work and/or hobby activity (e.g. in the case of work, this would be for housework, or voluntary work; in the case of their hobby this would be for a second hobby or one taken up after the pain). If

no alternative working activity or hobby was available, a score of '1' for involvement was given, i.e. the lowest score possible.

This method of gaining measures for current involvement in work and/or hobby by using substituted activities, rather than assigning a value of '1' if they had given up their pre-pain work and/or hobby, was used because it was considered a more appropriate measure of current 'adjustment'. However, it should be noted that assigning a score of '1' for involvement for those people who had no current work-related activity or hobby is slightly problematic. The Roles and Goals Questionnaire is not simply a measure of physical involvement in an activity, but more a measure of emotional involvement in an activity, as inspection of the items reveals. However, the measure clearly presupposes that people are engaged in an activity for them to complete the questions about it. Giving people not engaged in an activity a score of '1' is therefore not entirely in keeping with the aims of the Questionnaire, as people may still feel an emotional involvement with a particular domain even though they can no longer be actively involved in it. Hence, in the results two analyses will be presented: one using a measure of '1' for those not engaged in an activity within a particular domain and one omitting these people from that analysis.

This questionnaire therefore offers a means of assessing aspects of pre-pain life by altering the questions to ask about pre-pain levels of involvement in different life domains, and also of assessing current levels of 'adjustment', by asking about current levels of involvement in different life domains.

Coping measure: Flexible goal adjustment (Brandtstädter and Renner, 1990). This measure was chosen because it offers a measure of coping which describes how people might cope with challenges to role/goal attainment and hence offers measure of coping which matches role/goal loss. Previous work has shown it relates to depression in chronic pain patients.

Each question is answered using a 0-4 scale, and the scale contain 15 items each.

The scores for each item within the scale are summed, hence possible scores range from 0-60 (see Appendix C). The construction of the scale was theoretically driven. Accommodative coping was considered, a priori, to consist of factors such as disengagement, reorientation to new goals, and 'acceptance'. The latter was considered to be reflected in 'palliative comparisons', 'selective focusing of favourable effects', 'compromising and rescaling of aspirational levels' and 'flexible disengagement from blocked goals'. This measure has reasonable levels of internal reliability (Cronbach's alpha =0.83), although no test-re-test reliabilities have been reported.

English proficiency measure: In Lacroix *et al.*'s study, English proficiency was assessed according to a four point scale where 1=Nil, 2=Poor, 3=Fair and 4=Good. Participants in the current study were given a score, using this 1-4 scale, by two independent assessors on the basis of the taped interviews.

5.3.4 Procedure

All participants were instructed that the study was an investigation into pain sufferers understanding of their symptoms, however, they were not aware of the specific hypothesis under test.

Participants were given the following instructions verbally prior to the start of the task:

> "This is a study about people's understanding of the symptoms they usually suffer from that relate to their pain. I'll be asking you to give me a list of the symptoms you usually suffer from that relate to your pain. I will then ask you to tell me what you think the cause of these symptoms is or are. I will then ask you to group together the symptoms that you think are caused by the same thing. I will then be asking you about each group of symptoms. I will be asking why you feel each group of symptoms are related, what you think the cause of these symptoms is and what you think the physiological basis of these symptoms is. The list of symptoms you have given me will also be given to the clinic doctor. She will be asked to group the symptoms according to which symptoms she thinks are caused by the same thing. At no time will she see your symptom groupings."

The symptoms that the pain sufferers' reported having were written down on cards. These cards were then presented to the pain sufferers and they were asked to group the symptoms together that they believed were caused by the same thing. For each symptom group they were then asked the following three questions:

i) why they felt these symptoms were related,

ii) what the cause of these symptoms was, and

iii) what the physiological basis of these symptoms was.

Following this they were asked to complete the remaining battery of questionnaires, outlined in the above section, in the following fixed order: Roles and Goals Questionnaire, demographic, pain chronicity and location, and medication details, pain intensity measures, BDI, and FGA. The discussion about symptom cause was tape recorded.

The doctor familiar with the patient's condition (the Consultant Anaesthetist at the Pain Clinic) was given the list of symptoms generated by the patient and asked to group them into symptom clusters according to which were caused by the same thing. The doctor assessed the cause and the physiological basis of the symptom clusters, and rated both the severity of the patient's medical condition and their functional prognosis on the basis of physical/organic findings only.

Neither the patient nor the doctor saw the symptom groupings given by the other person.

Agreement between the patient and doctor symptom groupings was then assessed for each participant by two independent doctors using the SAI. Where there was disagreement between the two doctors, this was resolved between them through discussion.

5.4 HYPOTHESES

1) Symptom understanding will be related to people's work status (Lacroix *et al.*'s (1990) result will be replicated),

2) Flexible Goal Adjustment (FGA) will significantly moderate the relationship between pain intensity and depression (the findings of Schmitz *et al.* 1996 will be replicated),

3) Symptom understanding will predict measures of adjustment (depression and current levels of involvement in different life domains), and

4) FGA will moderate the relationship between pre-pain life involvement and depression.

5.5 STATISTICAL ANALYSIS

All statistical analyses were computed using SPSSwin version 6.0.

5.5.1 Path Analyses

The principal form of analysis used was path analysis. Path analysis, which is a form a causal modelling, was computed using multiple regression analysis. The minimum accepted ratio of predictor variables entered into a regression equation, to number of participants, is usually 5:1, with a bare minimum ration of 3:1 (Tabachnick and Fidel, 1989). As the current study had a sample size of 40, this meant that a maximum of 8 variables could be entered into any one path model. As a result of this restriction each life domain is considered separately in the path analyses reported in this chapter. In addition two measures of adjustment will be considered separately: levels of depression, and current level of involvement in the relevant life domain. That means that ten models will be tested in total: five with depression as the measure of adjustment (each model using one of the different life domains) and five with each of the different life domains as the measure of adjustment. Whilst using separate models means that the

interrelationships between different life domains cannot be explored, it does mean that the models can be compared to see:

i) which model, and hence which life domain, helps account for the greater amount of variance in depression, and

ii) in which life domain current levels of involvement are best accounted for by the demographic, pain and coping variables measured in the present study.

Whilst some of the path models were conducted on a sub-sample of 31 participants (when excluding those who had no current work or hobby from the analysis), the use of 8 predictors still fell within the basic ratio required of 3 participants to each predictor.

The variables entered into the path analytic models were chosen on the grounds of theoretical importance and are outlined below. The method of regression used was hierarchical, and was chosen because it deals with the problem of multicollinearity (Cohen and Cohen, 1983). Multicollinearity arises when two or more independent variables correlate highly with one another. The coefficients tested in regression are partial coefficients. That means if a given independent variable (IV) emerges as a significant predictor of the dependent variable when another independent variable is also entered into the regression equation, then that IV uniquely accounts for variance in the dependent variable that is variance unique to itself, and not variance which is shared between it and the other independent variable.

If two independent variables are highly correlated this means that neither may emerge as significant predictors of the dependent variable, as the variance unique to each may be greatly reduced as a result of their being intercorrelated. This problem emerged in the present study principally in the case of the interaction term that was entered (FGA x pre-pain involvement in each life domain), testing whether Flexible Goal Adjustment acted as a significant moderator in the relationship between pre-pain importance of life domain and other measures in the path model. The interaction term

correlated very highly with both the main effect of FGA and the main effect of pre-pain importance of the given life domain. Hence the main effects were entered in one step and the interaction term in the next step, even though they appear at the same time point in the path models.

Variables were entered into the hierarchical regression in a pre-determined order. This order was based on a logical causal sequence whereby those variables thought to cause subsequent variables were entered first (Cohen and Cohen, 1983). Hence age and sex were entered in Step 1. Pre-pain involvement in life domain and FGA were entered in Step 2, the interaction between the latter was entered in Step 3. Present pain intensity and organic symptom severity were entered in Step 4. Symptom understanding was entered in Step 5.

The causal order of the variables entered in Steps 1 and 2 are relatively self-explanatory, in that sex and age are determined prior to pre-pain level of involvement in a given life domain. In addition, the coping style of FGA is assumed by Brandtstädter and Renner (1990) to be something that can be treated as a general disposition, hence it can be viewed to all intents and purposes to be a 'personality variable' and hence can be assumed to be fixed prior to the experience of having pain. As symptom understanding is viewed as reflecting the content of pain schema and pain schema are thought to mediate the pain-adjustment link, this was entered after pain intensity and organic severity and prior to depression/current involvement in life domain. Depression was the dependent variable because there is more evidence to support the view that depression is a consequence rather than a cause of chronic pain (Gamsa, 1994a; 1994b). Current levels of involvement are seen as subsequent to both pain and the patients' understanding of their pain, hence they were also seen as dependent variables rather than predictors.

The variables entered within the same stage were not correlated with one another, with the exception of sex and age. The correlation between these two variables

is indicated in the path models.

Entering variables in this hierarchical format means that those on the left side of the diagrams are given priority in the analysis, hence entering age and sex first means that those variables entered later have to account for significant variance over and above that already accounted for by age and sex, and so on. Hence the coefficients in all five models predicting depression for age and sex are the same, as they are independent of the variables entered later in the analysis. The order of entry means that for symptom understanding to be a significant predictor of measures of adjustment, it must account for variance that has not been accounted for by all the variables preceding it in the path model. The key difference between entering all the variables together and entering them hierarchically is that the latter attributes the variables entered in earlier stages both unique variance and also any overlapping variance which may exist between it and variables which are entered later. Hence they are given priority in the analysis. β coefficients are shown in the path models rather than bs. The β reflects the strength of the relationship between two variables but one which has been standardized, in comparison to the b coefficient which uses the original units of the scales employed. Using the β allows direct comparisons to be made between different models regarding the relative strength of links within each. As one of the aims of the current study was to compare different models and because the original units of the questionnaires are to some extent arbitrary as they are questionnaire scales, only βs will be printed on the models for the sake of clarity.

5.5.2 Correlational Analyses

Pearson Product Moment correlation coefficients were computed for correlations between variables judged to meet the assumptions of normal distribution and homogeneity of variance. Spearman's Rank Correlation coefficients were computed between those variables where the latter assumptions were not met (Howell, 1997).

Number of analyses

A number of analyses are conducted in the preceding section on the same variables hence Type 1 error rates are likely to be inflated most notably in the first section replicating Lacroiz *et al.*'s findings.

5.6 RESULTS

Demographic details of the participants and their scores on pain and mood are shown in Table 5.1.

Table 5.1: Characteristics of participants

Age Mean (SD)	53.43 (13.70)
Sex (% female)	53%
% using medication for pain relief	88%
% using antidepressant medication ***for pain relief:*** ***for depression:***	 17% 5%
Chronicity (years of pain) Mean (SD)	8.87 (8.90)
Primary Pain Site	Neck 7% Upper shoulders/arms 5% Lower back and legs 38% Legs 10% Pelvis 5% Multiple sites 35%
Present pain intensity	50.60 (22.93)
% with continuous pain	75%
BDI scores	14.20 (7.46)
English proficiency	3.85 (0.48)

Details of the participants' work and hobby status are shown in Figures 5.2 and 5.3. Whilst there are 9 participants who had no substitute work to give ratings for

'current work involvement', and 9 who had no substitute hobby or interest to give ratings for 'current hobby involvement', this is coincidental, as participants in each case were different people with the exception of one.

Figure 5.2: Break down of participants' work status

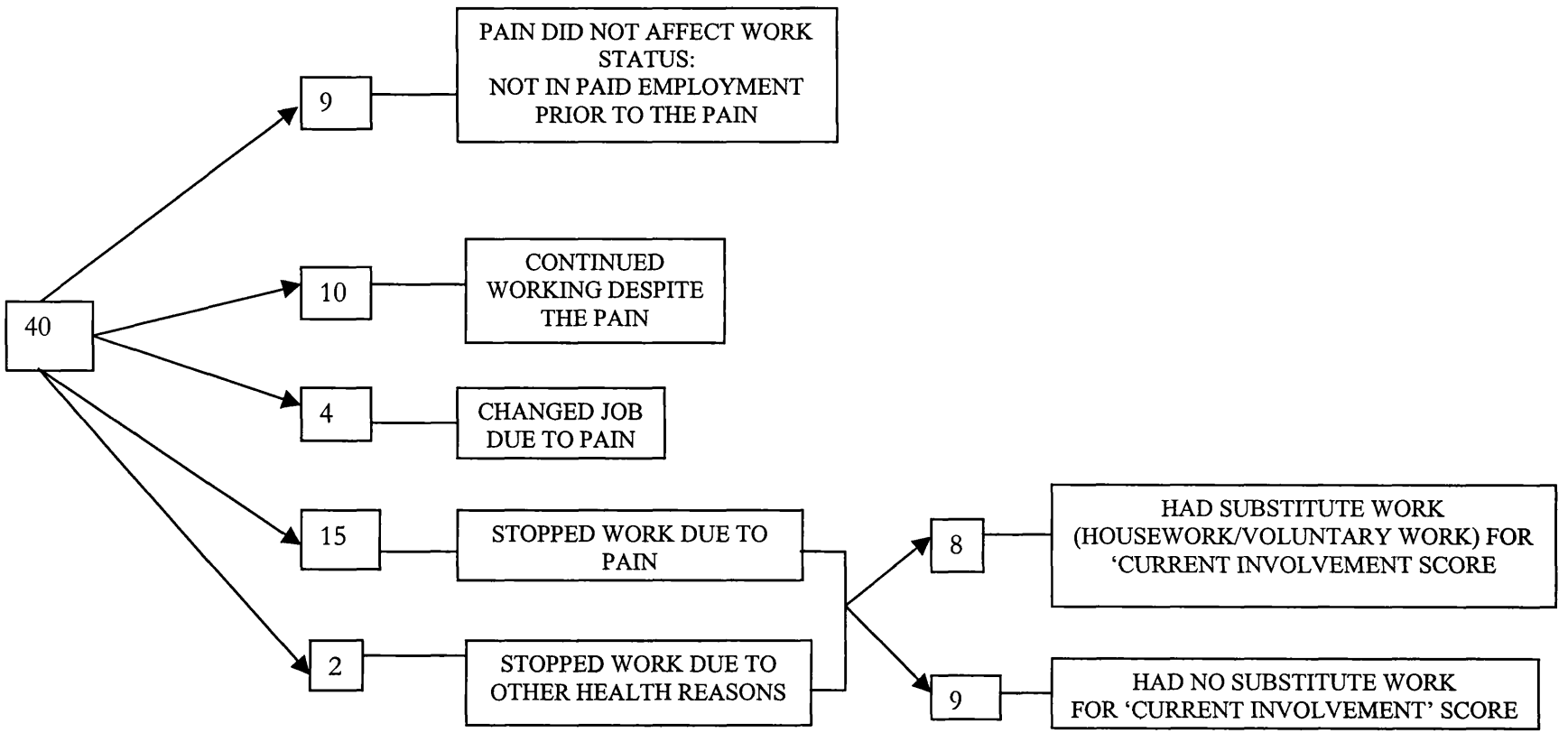
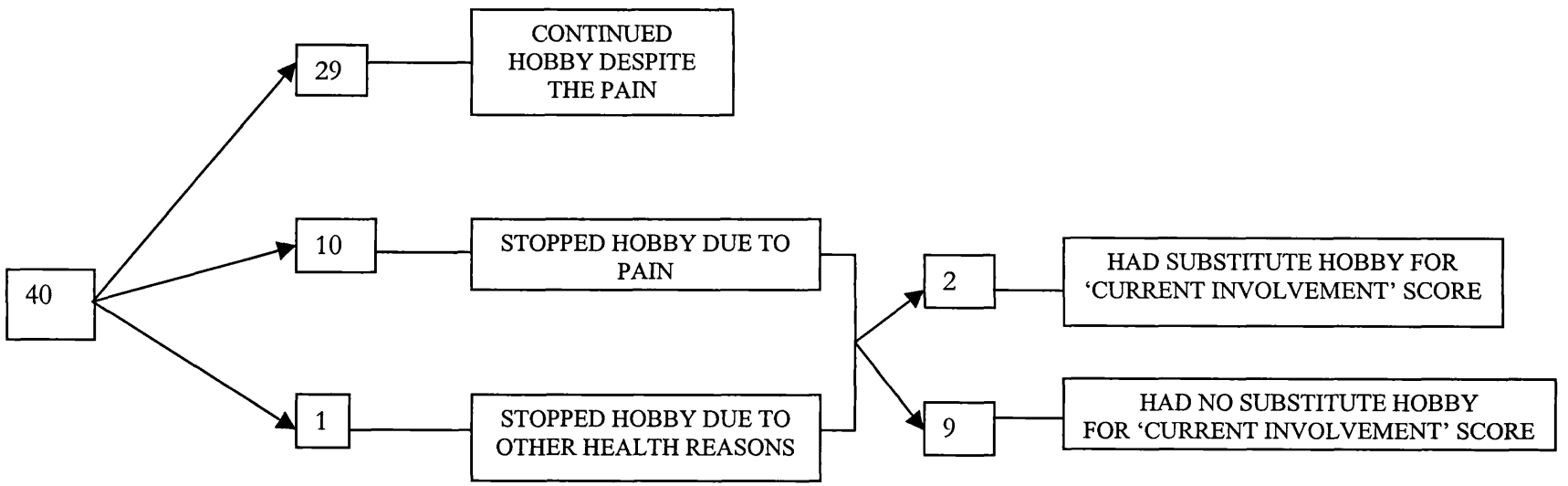


Figure 5.3: Break down of participants' hobby status



Spearman's Rank correlations were computed for correlations between Work Status, English proficiency and the other variables, whilst Pearson Product correlations were computed between the remaining variables.

As shown in Table 5.2, the results of Lacroix *et al.* were not fully replicated. Importantly, there was no correlation between symptom understanding and work status. In addition, whilst there was a significant correlation between English proficiency and symptom understanding, this was in the opposite direction to that found by Lacroix *et al.*, indicating that in the current study higher levels of symptom understanding was associated with *lower* levels of proficiency in English. Also in contrast to Lacroix *et al.*'s study, the correlations between organic symptom severity, prognosis and work status were significant, such that work status *was* associated with both fewer organic signs and better prognosis. Age also correlated significantly with work status, such that younger people were more likely to have stopped work or be on lighter duties than older people.

Consistent with Lacroix *et al.*'s findings there was a significant correlation between organic symptom severity and prognosis such that higher levels of organic symptom severity were associated with poorer prognosis. And whilst there was a trend towards higher levels of symptom understanding being correlated with lower levels of organic severity and better prognosis, this did not reach conventional levels of significance. Hence differences between patient and doctor understanding of the patient's symptoms were not merely a function of the severity or complexity of organic damage.

It seems plausible to suggest this pattern of results may be partially due to the inclusion of people whose pre-pain work status could not be changed following the onset of chronic pain i.e. those who were housewives or those who were already retired prior to the pain, and that this may have affected the association between age and work status. This analysis was therefore repeated excluding the 9 people for whom work

status could not be affected by the pain (see Figure 5.2). (None of those participants who were housewives prior to the pain reported giving up housework completely because of the pain, hence their inclusion in this group.)

Table 5.2: Correlations between measures of the SAI, age and English proficiency and Work Status: all participants

N=40	Work Status	Symptom understanding	Organic symptom Severity	Prognosis	Age
Symptom understanding	0.14				
Organic symptom Severity	0.42**	0.20+			
Prognosis	0.56***	0.21+	0.45**		
Age	-0.26*	-0.09	-0.44**	-0.22+	
English proficiency	0.23+	-0.28*	0.03	0.15	-0.15

(+p<0.10); *p<0.05; **p<0.01; ***p<0.001

This resulted in excluding nine participants and the resulting correlations are shown in Table 5.3. One-tailed significance was used again as it was predicted that the pattern of results would mirror those of Lacroix *et al.*.

Table 5.3: Correlations between measures of the SAI, age, English proficiency and Work Status: excluding those 9 participants for whom pain could not affect work status

N=31	Work Status	Symptom understanding	Organic symptom Severity	Prognosis	Age
Symptom understanding	0.19				
Organic symptom Severity	0.36*	0.19			
Prognosis	0.61***	0.11	0.43**		
Age	-0.03	-0.06	-0.35*	-0.24+	
English proficiency	0.22	-0.07	0.07	0.20	-0.26+

(+p<0.10); *p<0.05; **p<0.01; ***p<0.001

Excluding the 9 participants for whom pain could not affect work status resulted in some changes to the pattern of correlations. The correlation between age and work status fell to non-significant as did the correlation between symptom understanding and English proficiency. In addition the relationship between symptom understanding and both organic symptom severity and prognosis no longer approached significance. However, relationships between organic symptom severity and work status, and prognosis and work status, both remained significant.

Work involvement

Correlations between work involvement, measures from the SAI, age and English proficiency were computed. A one-tailed significance was selected as it was predicted that Lacroix *et al.*'s pattern of results would be replicated in the current study. Two analyses were run, one including all participants, assigning a score of '1' to those 9 participants who had no current work related activity, and one excluding these 9 participants (see Figure 5.2). For these correlations Pearson Product correlations were computed for all variables except those correlations between English proficiency and other variables. The results using all participants are shown in Table 5.4.

Table 5.4: Correlations between measures of the SAI, age, English proficiency and current levels of involvement in work: all participants

N=40	Current involvement In work	Symptom understanding	Organic symptom Severity	Prognosis	Age
Symptom understanding	0.26*				
Organic symptom Severity	0.24+	0.20+			
Prognosis	0.26*	0.21+	0.46**		
Age	-0.03	-0.07	-0.45**	-0.22+	
English Proficiency	0.10	-0.28*	0.03	0.15	-0.15

(+p<0.10); *p<0.05; **p<0.01; ***p<0.001

A significant relationship was found between current involvement in work and symptom understanding, with higher levels of agreement being associated with higher levels of involvement in work related activities.

However, in contrast to Lacroix *et al.*'s findings, in the current study higher levels of symptom understanding was again associated with *lower* levels of English proficiency. There was a significant correlation between prognosis and work involvement and the correlation between organic symptom severity and work involvement approached significance. To check whether symptom understanding uniquely predicted variance in work involvement, over and above organic symptom severity and prognosis, all the variables in Table 5.4 were entered into a linear regression. Age and English proficiency were entered in Step 1, organic symptom severity and prognosis in Step 2 and symptom understanding in Step 3.

Table 5.5: Predicting current levels of involvement in Work using measures of the SAI, age and English proficiency: all participants

Predicting 'Current involvement in work'	t
Step 1	$t_{(1,37)}$
Age	-0.22
English proficiency	0.14
Step 2	$t_{(1,35)}$
Organic symptom severity	1.00
Prognosis	1.05
Step 3	$t_{(1,34)}$
Symptom understanding	1.30

The t-tests computed on the regression coefficients are shown in Table 5.5 and illustrate that symptom understanding does not significantly predict current work involvement over and above organic symptom severity and prognosis. However it should be noted that neither organic symptom severity nor prognosis emerged as significant predictors of current work involvement.

The correlational analysis was repeated excluding those 9 participants who did not report having a current work-related activity (see Table 5.6).

Table 5.6: Correlations between measures of the SAI, age, English proficiency and current levels of involvement in work: excluding those 9 participants who reported no current work related activity

N=31	Work involvement 'now'	Symptom understanding	Organic symptom Severity	Prognosis	Age
Symptom understanding	0.38**				
Organic symptom Severity	0.33*	0.15			
Prognosis	0.26+	0.34*	0.51**		
Age	-0.23+	-0.04	-0.54***	-0.24+	
English Proficiency	-0.07	-0.37*	0.01	0.09	-0.04

(+p<0.10); *p<0.05; **p<0.01; ***p<0.001

Excluding the 9 participants altered the pattern of correlations only slightly. Most importantly the correlation between work involvement and symptom understanding remained significant. However organic symptom severity changed from approaching significance to significant in its relationship with current levels of involvement in work, whereas prognosis changed from significant to approaching significance in its relation to current levels of involvement in work. In addition, age changed from non-significant to approaching significance in its relationship with current levels of involvement in work. Further, prognosis became significantly correlated with symptom understanding whereas organic symptom severity moved from approaching significance to non-significant in its relation to symptom understanding. The five predictors were again regressed onto current levels of involvement in work to see whether symptom understanding uniquely predicted current levels of involvement in work over and above organic symptom severity and prognosis. The individual t-tests on the regression coefficients for each predictor are shown in Table 5.7.

Table 5.7: Predicting current levels of involvement in Work using measures of the SAI, age and English proficiency: excluding those 9 participants who reported no current work related activity

Predicting 'Current involvement in work'	t
Step 1	$t_{(1,28)}$
Age	-1.30
English proficiency	-0.35
Step 2	$t_{(1,26)}$
Organic symptom severity	0.88
Prognosis	0.65
Step 3	$t_{(1,25)}$
Symptom understanding	1.84+

(+p<0.10)

As shown in Table 5.7, symptom understanding approached significance in its ability to predict current levels of involvement in work, but neither organic symptom severity nor medical prognosis significantly predicted work involvement.

All the above results suggest that work status is not significantly and uniquely associated with symptom understanding, however there was a weak relationship between symptom understanding and current levels of involvement in work activities.

Hypothesis 2: Flexible Goal Adjustment (FGA) will significantly moderate the relationship between pain intensity and depression (the findings of Schmitz *et al.* will be replicated)

To test the hypothesis that FGA would significantly moderate the relationship between pain intensity and depression, the same form of analysis was used as that used by Schmitz *et al.* (1996), i.e. a hierarchical regression analysis, entering the main effects of FGA and pain intensity in one Step and the interaction term (FGA x pain intensity) in the subsequent Step. In addition, the same measure of pain intensity as that used by Schmitz *et al.* was used, that is, an average of the four pain intensity measures taken (see

section 5.3.3).

The background variables of age, sex and pain chronicity were entered in the first step of a hierarchical regression. Altogether, these three variables accounted for 10% of the variance although their joint contribution to predicting variance in depression only approached significance $F_{(3,36)}= 2.51$; $p<0.08$.

Individually, sex was a significant predictor of depression, $t_{(1,36)}=2.52$ $p<0.05$, with women being more likely to rate themselves as depressed than men. Age only approached significance as a predictor of depression, $t_{(1,36)}=1.77$; $p<0.08$, with the trend being towards younger participants reporting higher levels of depression. Chronicity was unrelated to depression ($t_{1,36}=.39$) meaning that the length of time participants had had their pain for did not contribute to the likelihood of them rating themselves as depressed.

Pain intensity and FGA were entered at the second step, and the product of pain intensity and FGA were entered at the third step to test for the role of FGA as a moderating variable in the pain-depression link. The change in R square, F values, individual t statistics and significance levels are shown in Table 5.8.

Table 5.8: Predicting depression using pain intensity and FGA

Predicting Depression	R^2 change	F change	Df	t
Step 2	0.23	7.25	2, 34	
Flexible Goal Adjustment (FGA)				-2.37*
Pain intensity				1.53
Step 3	-0.01	>1	1, 33	
FGA x Pain intensity				0.71

* $p<0.05$

As Table 5.8 shows, the addition of the two variables of FGA and pain intensity in Step 2 accounted for an additional 23% of the variance in depression, and this was significant ($F_{2,34} = 7.25$; $p<0.01$). FGA was significantly and negatively associated with depression ($t=-2.37$; $p<0.05$), demonstrating that high flexible goal adjustment is

associated with low depression scores, replicating previous findings. However, pain intensity did not significantly predict depression (t=1.53; NS). In addition, Step 3, the product of FGA and pain intensity was not significant, failing to account for any additional variance in depression. Thus no evidence was found that FGA significantly moderates the relationship between pain intensity and depression in the present study and the results of Schmitz *et al.* (1996) were not replicated.

One difference between the current study and that of Schmitz *et al.* was in the depression measure used. The one used in the Schmitz study contained fewer somatic items than the BDI. To test whether the failure to replicate the results of Schmitz *et al.* was due to using a measure with a relatively high number of somatic items, this analysis was repeated using BDI items 1-10 inclusive, items 12 and 14 to form the dependent variable. These are items which relate to affective items alone and which form a cohesive factor or 'scale' (Novy *et al.*, 1995).

However excluding somatic items in this way did not affect the main pattern of results (see Table 5.9). 21% of the variance was explained by those predictors entered in Step 2, though again, whilst flexible goal adjustment emerged as a significant predictor ($t_{1,36}$=-2.13; $p<0.05$), pain severity did not ($t_{1,36}$=1.42). More importantly, the interaction between pain severity and FGA remained non-significant. It therefore seems reasonable to suggest that the use of a different measure for depression is not the cause of the failure to replicate Schmitz's results. The possibility that the failure to find a significant effect was due to insufficient power in the analysis is discussed in section 5.7.5.

Table 5.9: Predicting depression using pain intensity and FGA, omitting somatic items from the BDI

Predicting Depression	R^2 change	F change	Df	t
Step 2				
Flexible Goal Adjustment (FGA)	0.21	5.47	2, 34	-2.14*
Pain intensity				1.42
Step 3	-0.02	>1	1, 33	
FGA x Pain intensity				0.56

*p<0.05

Hypotheses 3 and 4

3) Symptom understanding will predict adjustment.

4) FGA will play a moderating role in the relationship between pre-pain life involvement and depression.

Both of the above hypotheses were tested using path analyses. As noted in section 5.5.1, 8 independent variables could be entered into the regression analyses. The key variables in the analysis were: agreement about symptom understanding, a measure of physical pathology (severity of organic symptoms), pre-pain involvement in the given area of life, FGA and the interaction between FGA and pre-pain involvement. The three additional variables that were chosen were age, sex and present pain intensity. Age and sex were chosen because they represent standard demographic variables, often included in path models, and pain intensity was chosen because it is clearly of interest in a path model about adjustment to pain. However, rather than using the composite measure used by Schmitz *et al.* (1996), present pain intensity was used instead, principally because it is a measure of pain which is not dependent on recall and hence not susceptible to recall biases. However it should be noted that the pattern of results reported below were unaffected by using the composite score rather than the present pain score. The path models were run using both the total BDI score and the affective subscale of the BDI (mentioned on the previous page) to check whether the inclusion of

somatic items affected the results. The results reported will relate to total BDI scores unless explicitly stated otherwise.

Like the work of Schmitz *et al.*, the current study assumes that chronic pain presents an impediment to pursuing activities. However, in the current study this assumption was testable by comparing pre-pain involvement and current involvement in each of the five life domains, and seeing whether involvement ratings did decrease.

Table 5.10 shows the average scores for involvement in the five different life domains rated for 'pre-pain' and 'present' times and used a two-tailed test.

Related t-tests in Table 5.10 show that involvement ratings were significantly lower for 'present' compared to 'pre-pain' for all domains except most significant relationship, supporting the assumption that involvement in some life domains has indeed decreased, supporting Schmitz *et al.*'s assumption about the impact of pain on life goals. Excluding those participants who had no current work or hobby did not alter the pattern of results.

Table 5.10: Means, standard deviations and t-tests of pre-pain and present involvement in the five life domains

N=40	Pre-pain	Present	$t_{(1,39)}$
Work	2.81 (0.57)	2.14 (0.85)	4.85***
Hobby/interest	2.33 (0.56)	1.77 (0.68)	4.15***
Relationship	3.26 (0.61)	3.19 (0.66)	0.81
Health	3.01 (0.54)	2.79 (0.64)	2.05*
Independence	3.06 (0.77)	2.84 (0.81)	3.17**

*p<0.05; **p<0.01; ***p<0.001

Relationships emerged with the highest involvement score for both pre-pain and

present time, with health and independence following closely behind. As such, they replicate the findings of Lam and Power (1991) who demonstrated that relationships and health emerged with the highest involvement scores.

Support for Hypothesis 3

Hypothesis 3, that symptom understanding would predict adjustment (depression and current levels of involvement in each of the five life domains) was not supported by any of the models (Figures 5.4 to 5.13). Symptom understanding did not significantly predict depression in any of the five models (Figures 5.4 to 5.8), nor did it significantly predict current levels of involvement in any of the five life domains, with one exception: hobby, although the relationship is negative (see Figure 5.10a). Hence *lower* levels of symptom understanding was related to higher current levels of involvement in hobbies, running contrary to the prediction that *higher* levels of symptom understanding would be associated with higher levels of adjustment. However, in the path model computed excluding those 9 participants who had no current hobby, the path from symptom understanding to current levels of involvement in hobby disappeared. This suggests that the result shown in Figure 5.10a may have resulted from an association between higher levels of symptom understanding and having no current hobby. To check this, a Spearman's rank correlation was computed between having a hobby 'now' and symptom understanding. The correlation approached significance ($r= -0.29$; $p=.06$) such that there was a trend for people who had no current hobby to show higher levels of symptom understanding.

In summary, there was little evidence to support the view that symptom understanding predicts adjustment. The one exception was the model using current levels of involvement in hobby. However, this relationship was a weak one and the relationship was not in the predicted direction. The possibility that there was insufficient power in the analysis to detect a relationship between the SAI and measures of adjustment is discussed in section 5.7.2.

Figure 5.4: Predicting depression using pre-pain involvement in WORK

VARIANCE EXPLAINED = 31%; F(8,31) = 3.23; p<0.01

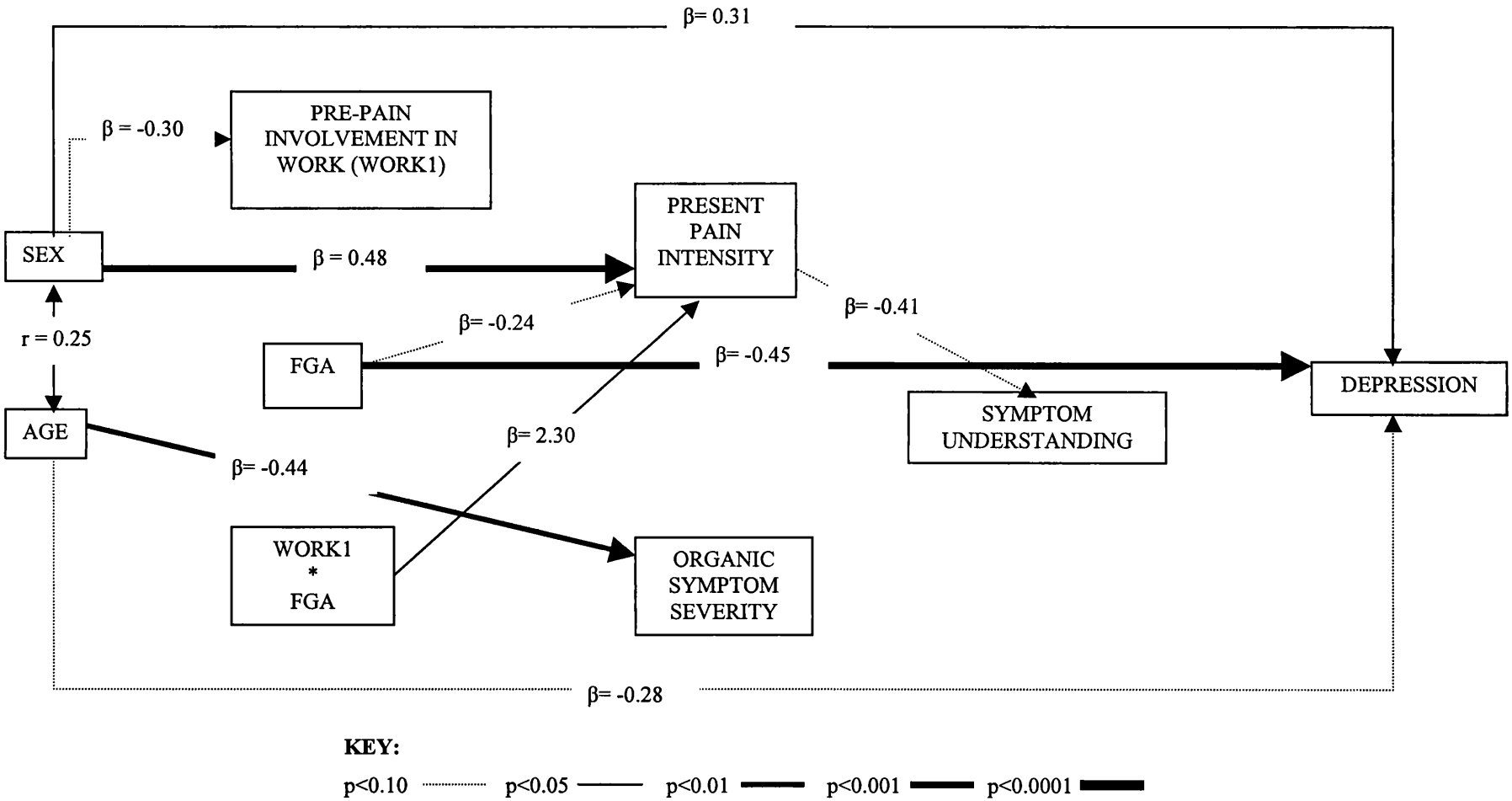


Figure 5.5: Predicting depression using pre-pain involvement in HOBBY

VARIANCE EXPLAINED = 45%; F(8,31) = 5.11; p<0.001

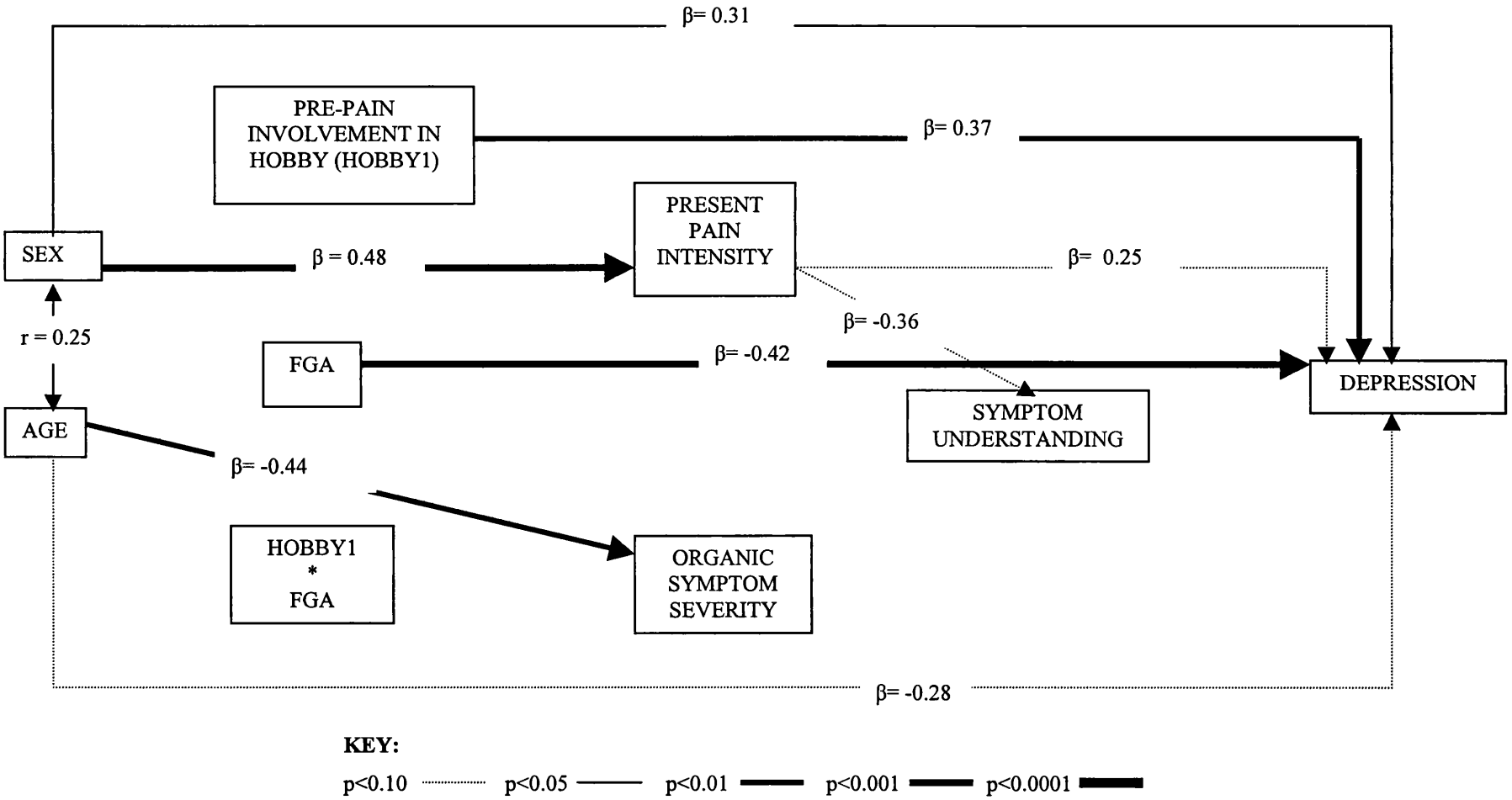


Figure 5.6: Predicting depression using pre-pain involvement in HEALTH

VARIANCE EXPLAINED = 40%; F(8,31) = 4.32; p<0.001

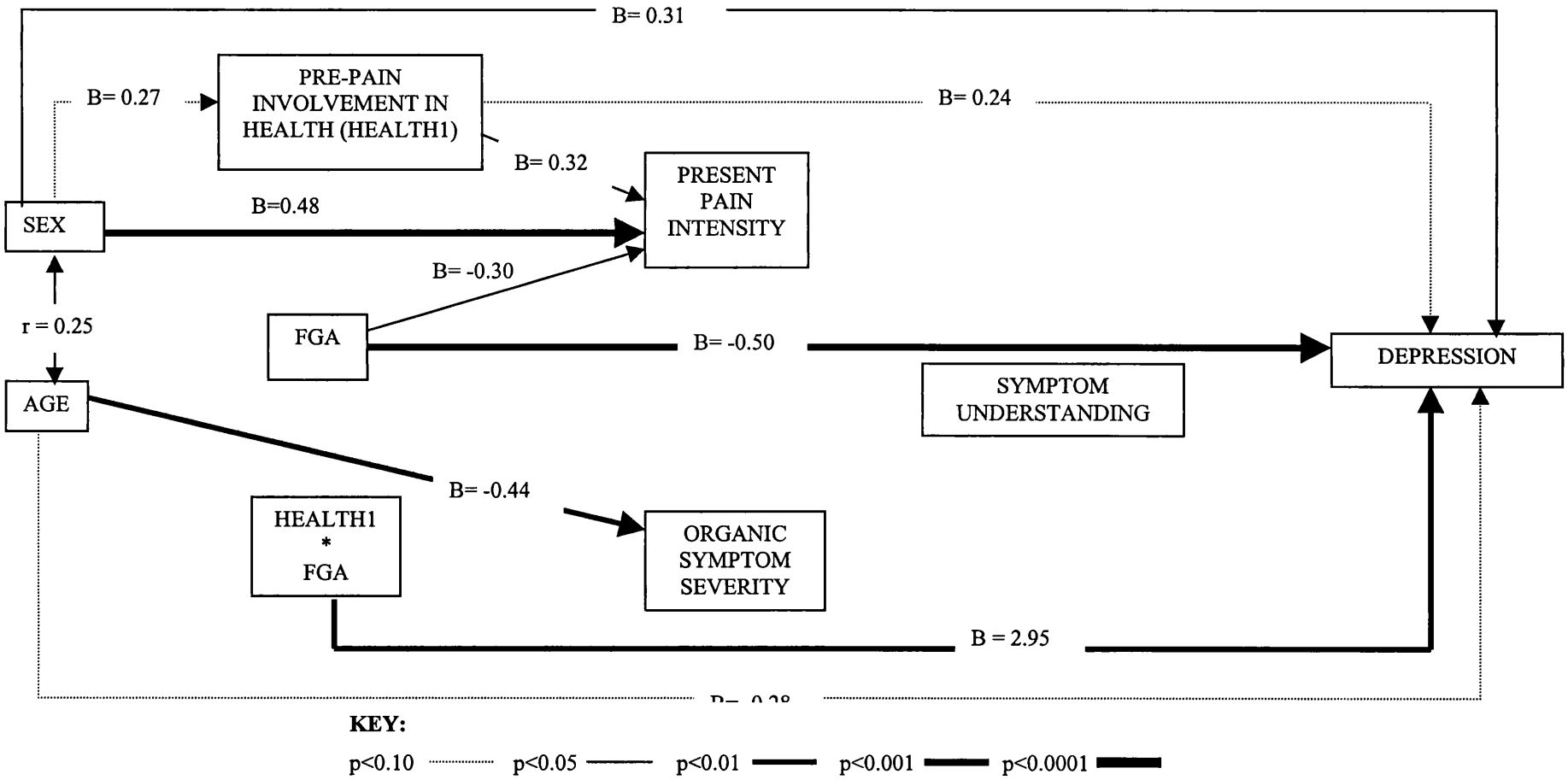


Figure 5.7: Predicting depression using pre-pain involvement in RELATIONSHIP

VARIANCE EXPLAINED = 29%; F(8,31) = 3.02; p<0.01

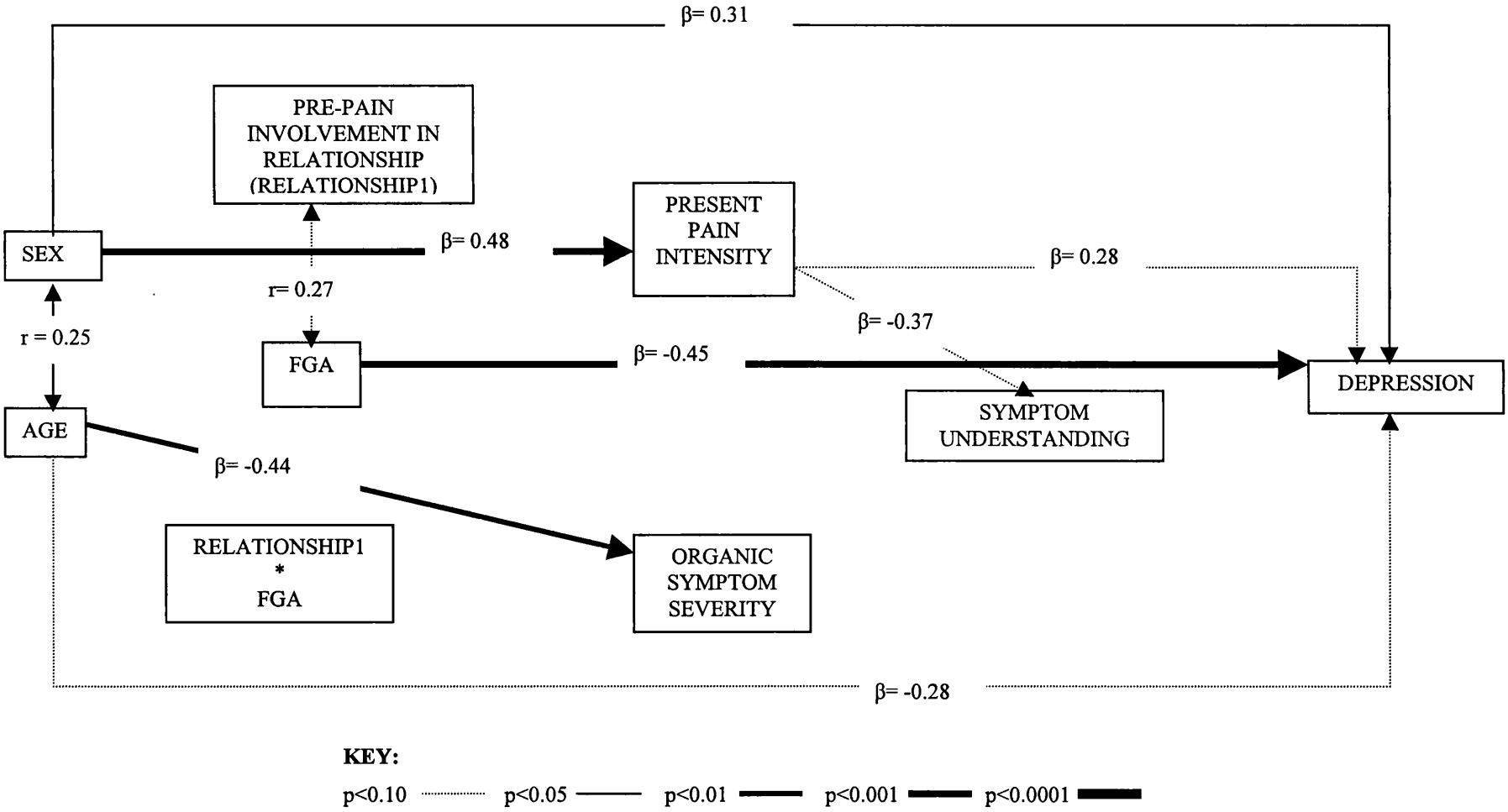
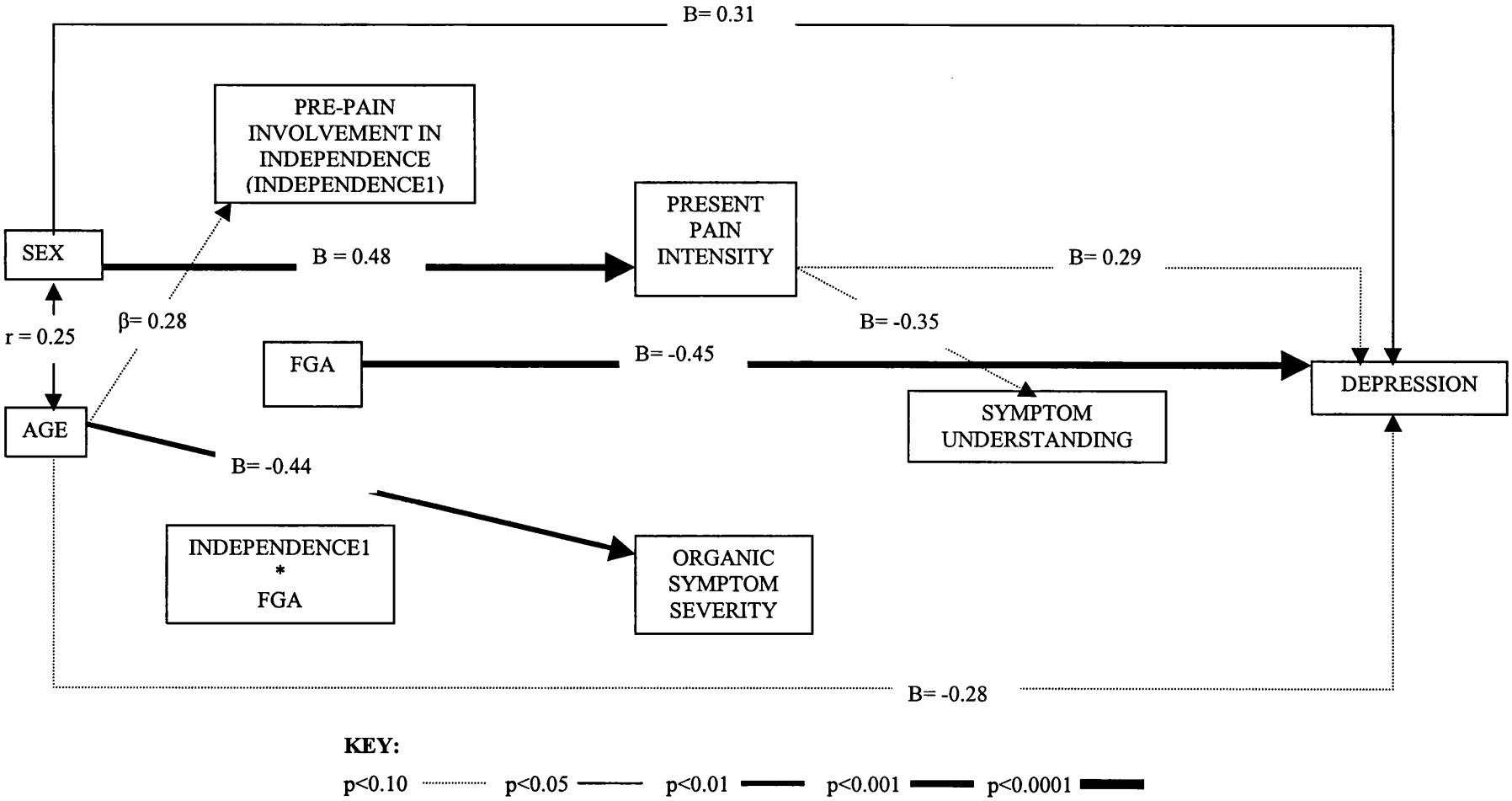


Figure 5.8: Predicting depression using pre-pain involvement in INDEPENDENCE

VARIANCE EXPLAINED = 31%; F(8,31) = 3.19; p<0.01



KEY:

p<0.10 ····· p<0.05 —— p<0.01 ▬ p<0.001 ▬ p<0.0001 ▬

Figure 5.9a: Predictors of current involvement in WORK (All participants)

VARIANCE EXPLAINED = 4%; F(8,31)=1.23; NS

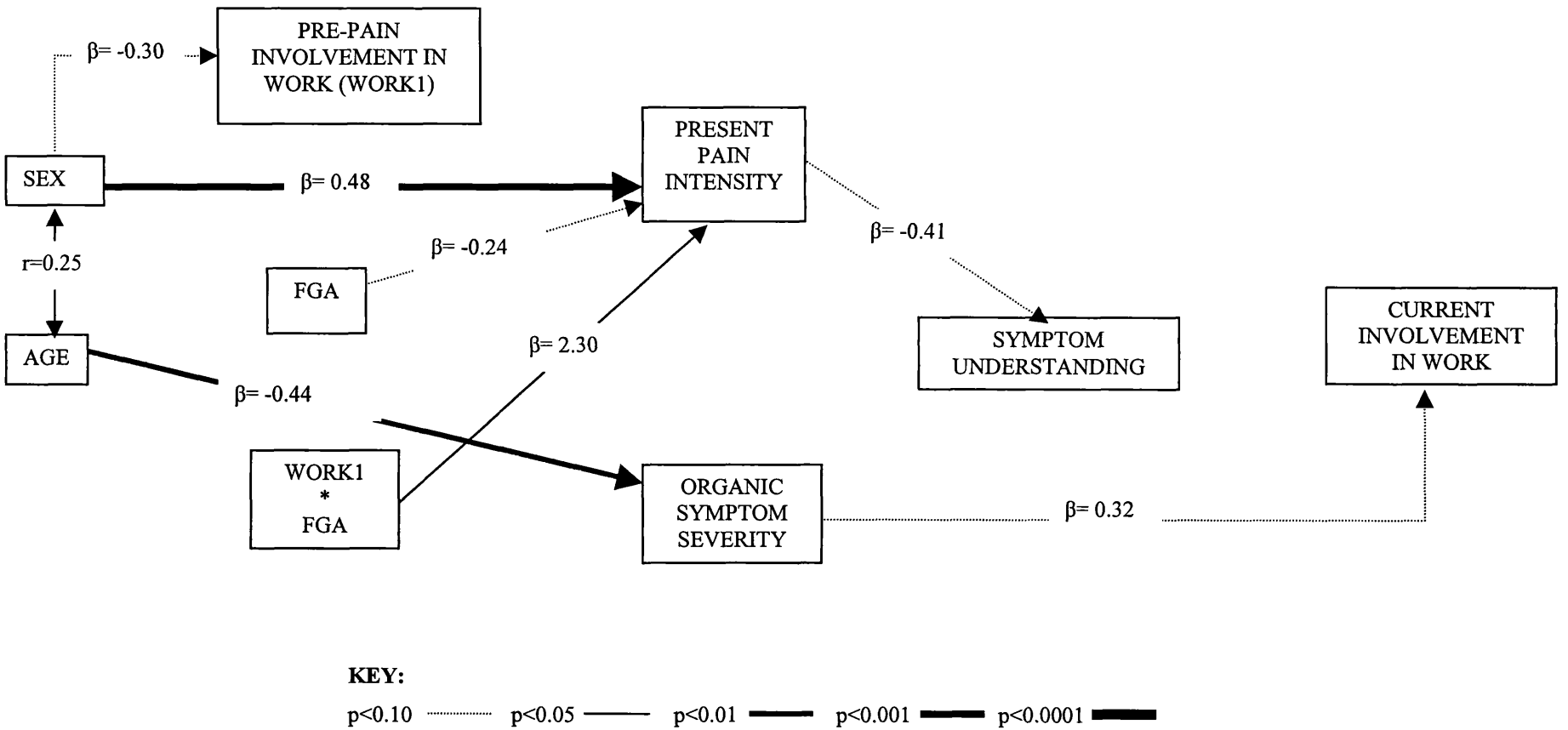
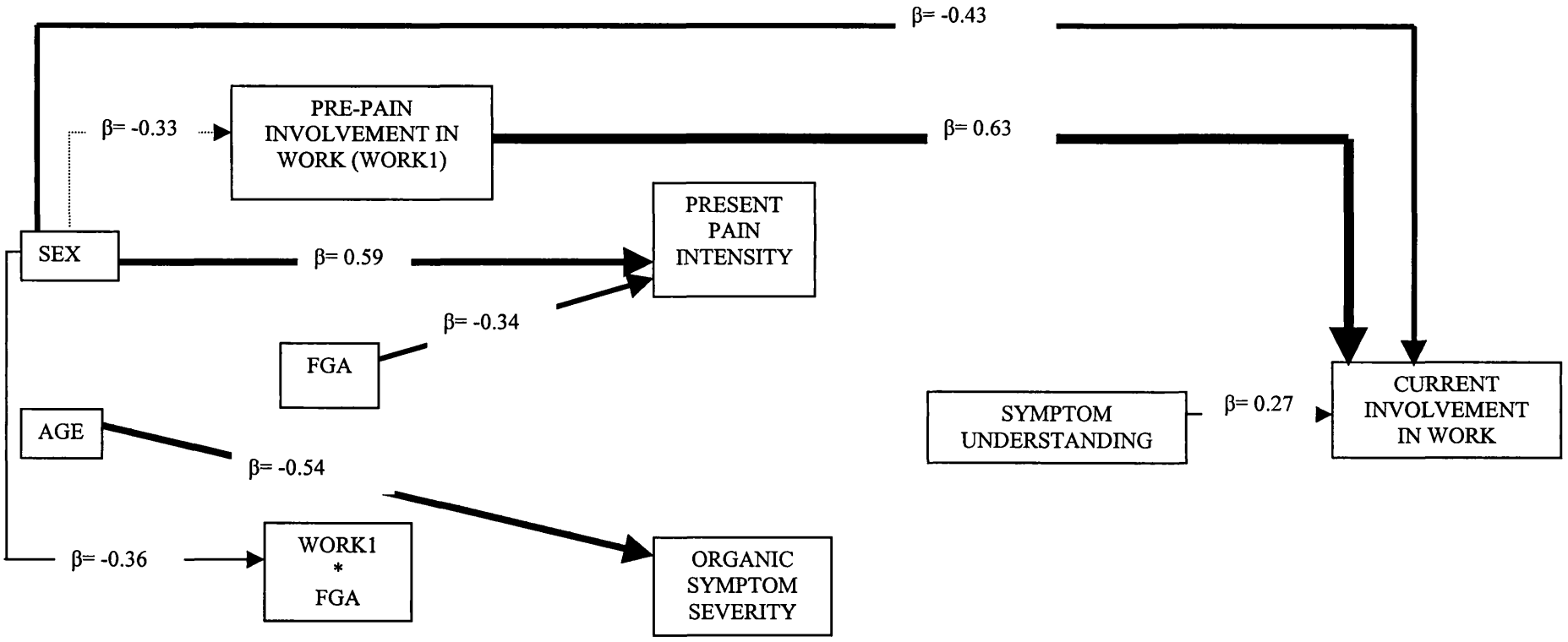


Figure 5.9b: Predictors of current involvement in WORK
(Excluding 9 participants with no current work)

VARIANCE EXPLAINED = 54%; F(8,22)=5.47; p<0.001



KEY:

p<0.10 ····· p<0.05 —— p<0.01 ▬ p<0.001 ▬ p<0.0001 ▬

Figure 5.10a: Predictors of current involvement in HOBBY (All participants)

VARIANCE EXPLAINED = 23%; $F(8,31) = 2.46$; $p<0.05$

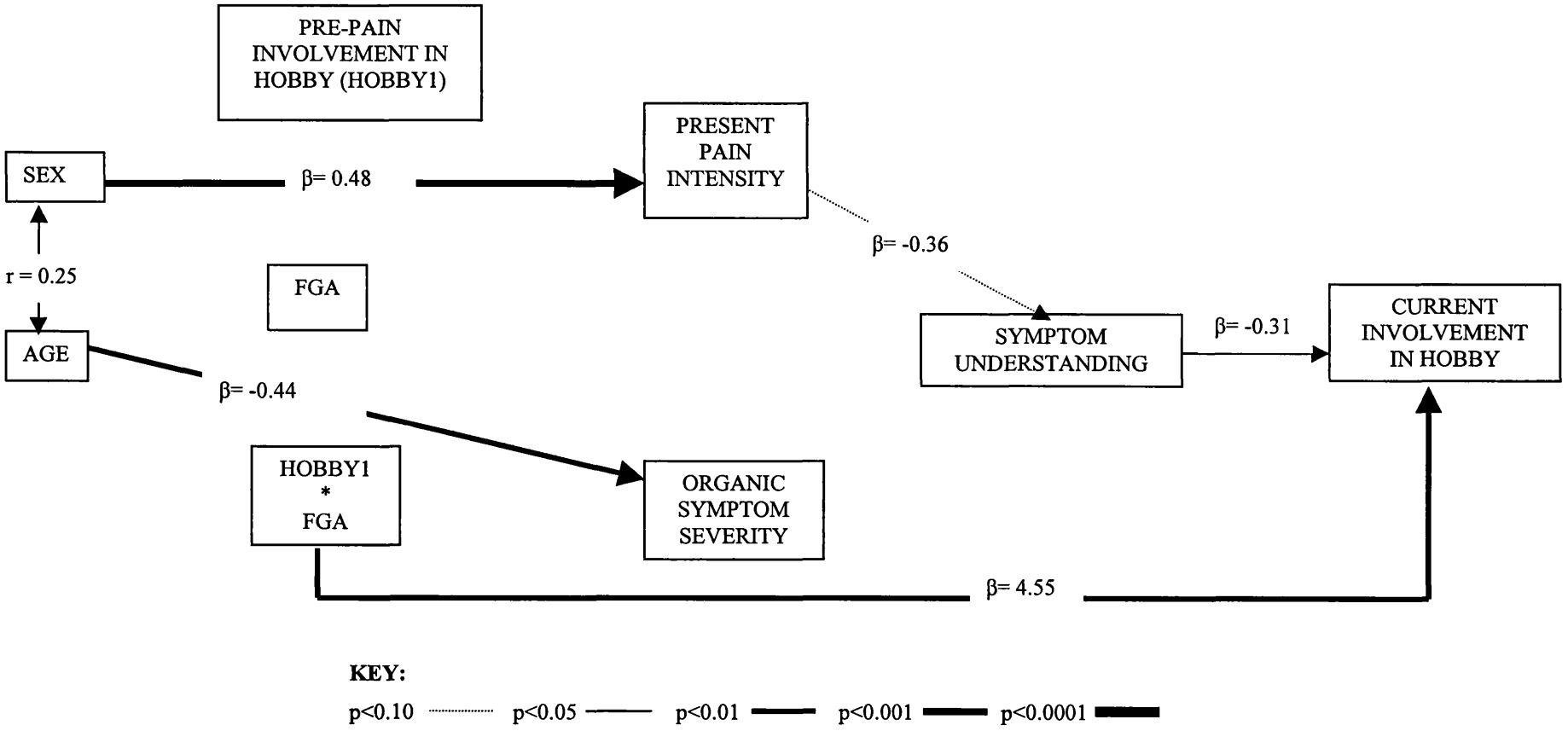


Figure 5.10b: Predictors of current involvement in HOBBY
(Excluding 9 participants with no current hobby)

VARIANCE EXPLAINED = 36%; $F(8,22) = 3.13$; $p<0.01$

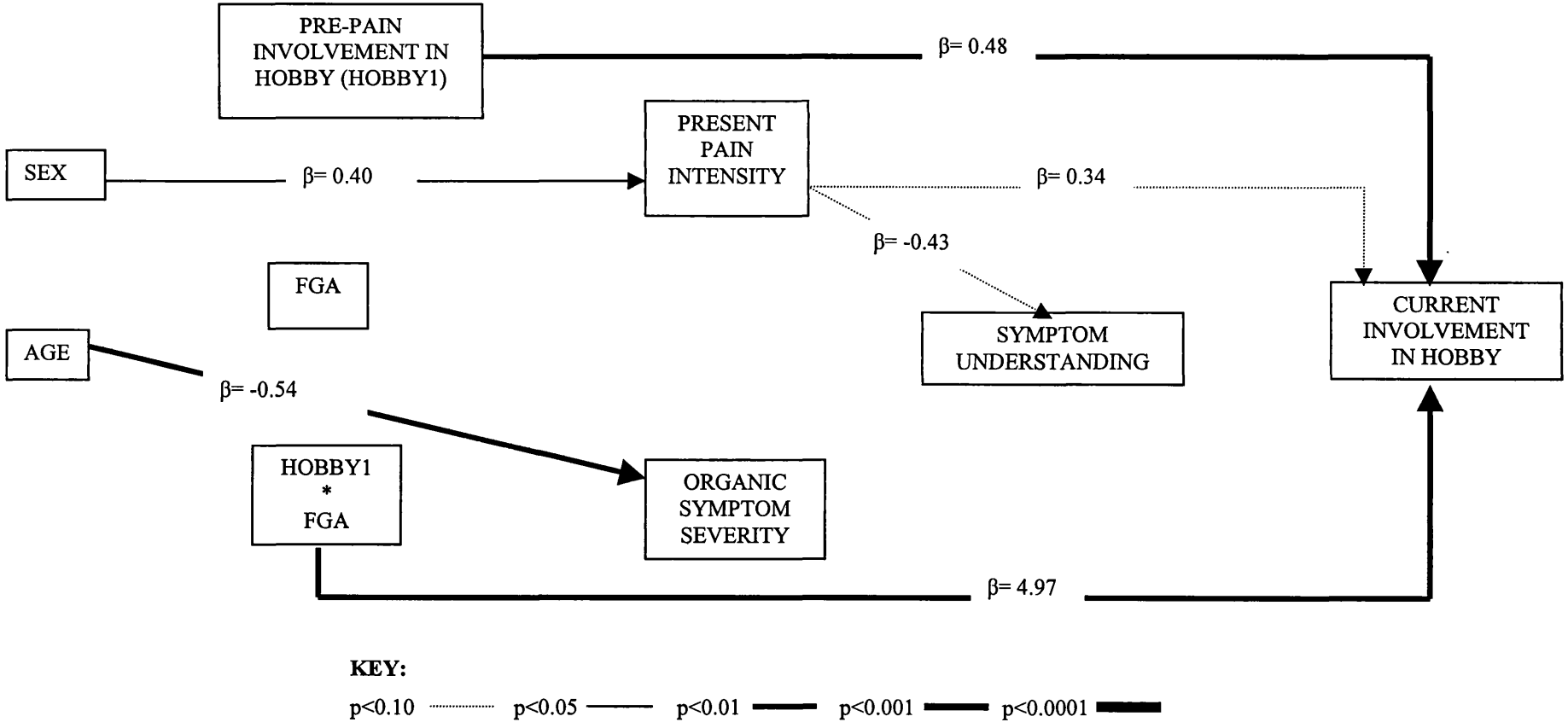
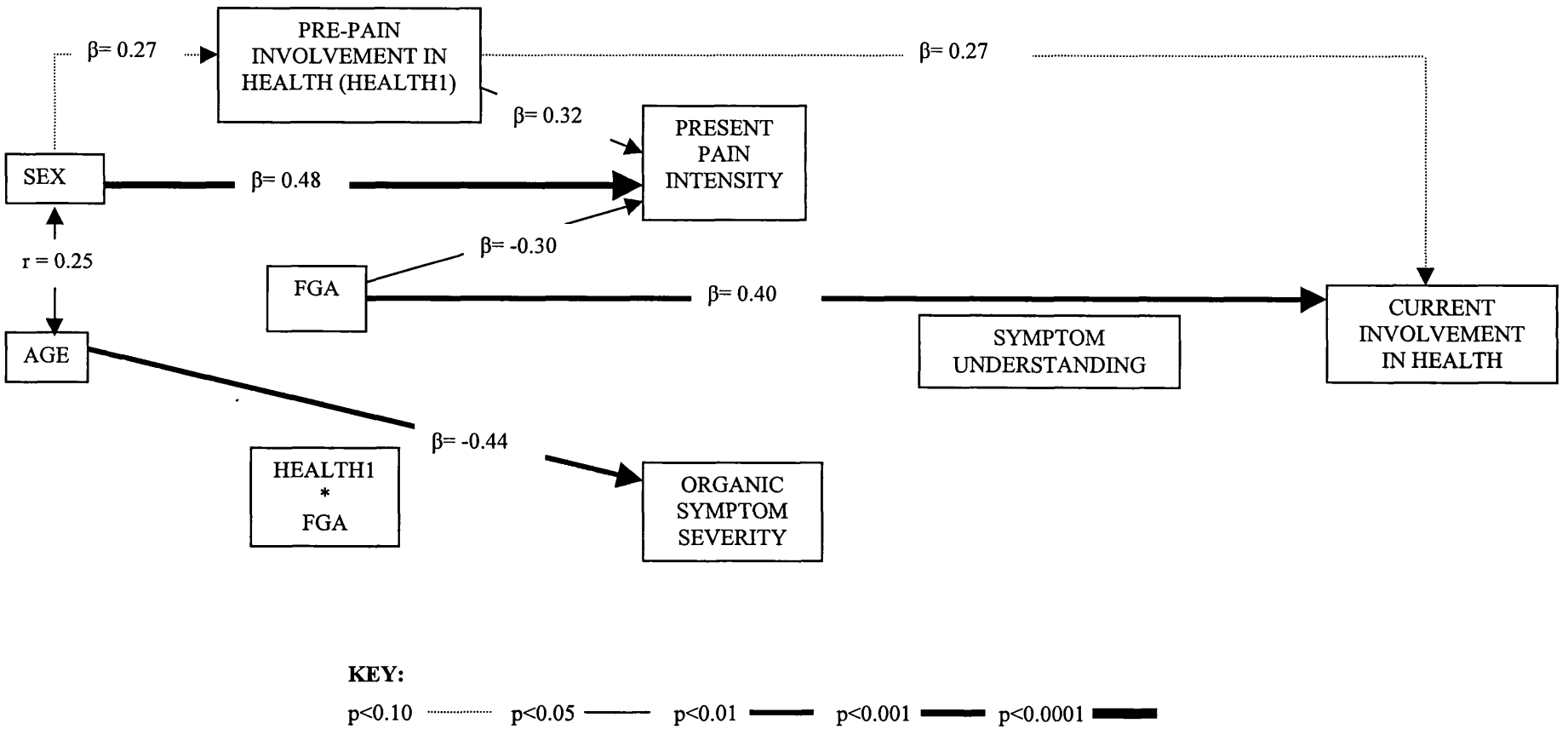


Figure 5.11: Predictors of current involvement in HEALTH

VARIANCE EXPLAINED = 10%; F(8,31) = 1.55; NS

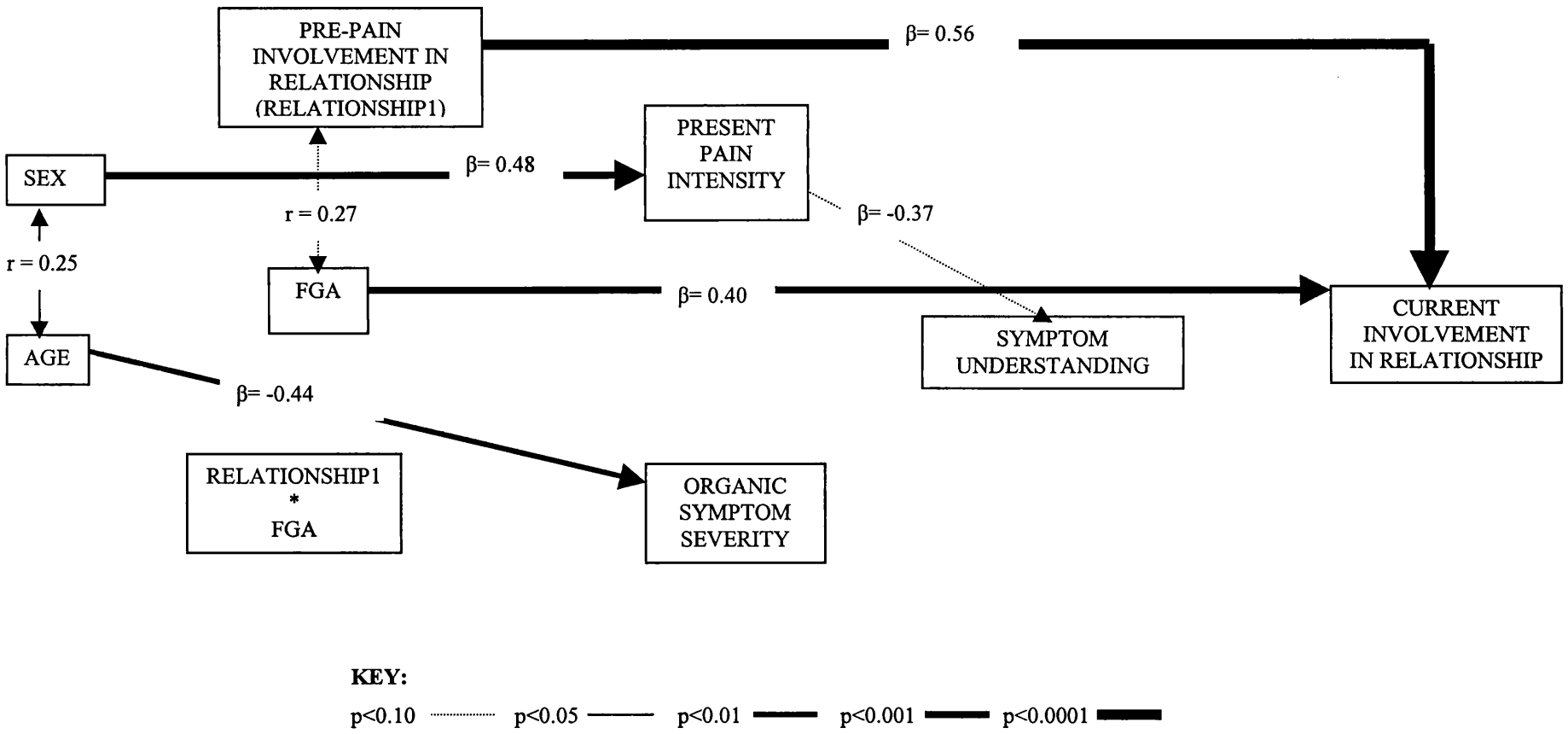


KEY:

p<0.10 ····· p<0.05 —— p<0.01 ▬ p<0.001 ▬ p<0.0001 ▬

Figure 5.12: Predictors of current involvement in RELATIONSHIP

VARIANCE EXPLAINED = 52%; F(8,31) = 6.38; p<0.0001

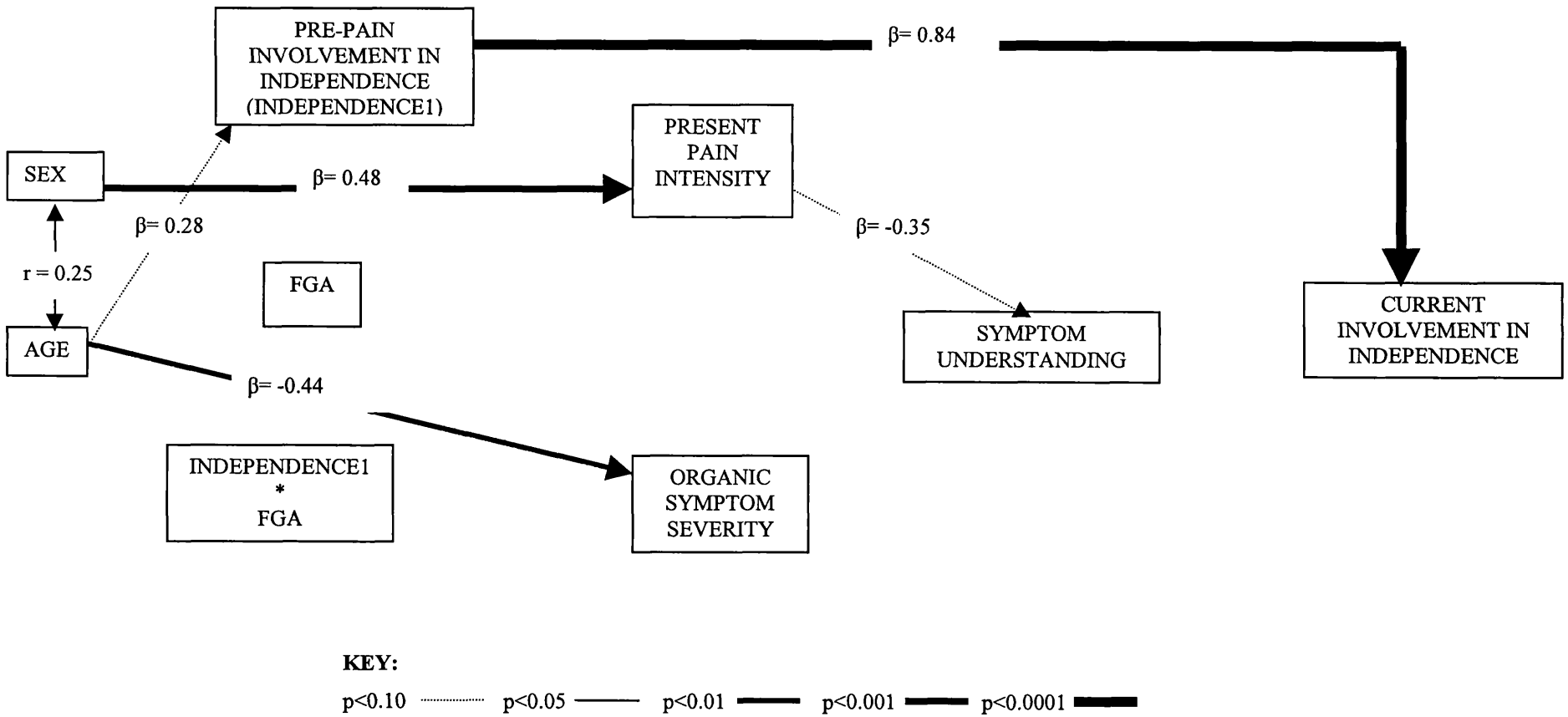


KEY:

p<0.10 ····· p<0.05 —— p<0.01 ▬ p<0.001 ▬ p<0.0001 ▬

Figure 5.13: Predictors of current involvement in INDEPENDENCE

VARIANCE EXPLAINED = 66%; F(8,31) = 10.81; p<0.0001



KEY:

p<0.10 ····· p<0.05 —— p<0.01 ▬ p<0.001 ▬ p<0.0001 ▬

Support for Hypothesis 4

Hypothesis 4, that FGA would play a moderating role in the relationship between pre-pain levels of involvement in the five different life domains, and depression also received little support (see Figures 5.4-5.8). The interaction term between FGA and pre-pain involvement levels in four out of the five domains of life did not significantly predict depression. The one exception was the domain of health (Figure 5.6).

As Figure 5.6 shows, there was a negative relationship between FGA and depression such that higher levels of flexible goal adjustment were associated with lower levels of depression. In addition there was a trend towards higher levels of pre-pain involvement in health being associated with higher levels of depression. However the relationship between the interaction term, pre-pain involvement in health x FGA, and depression, was *positive.* To explore this relationship more fully, people's scores on the FGA scale were split into three equally sized groups and labelled low (scoring 28-34) medium (scoring 35-39) and high (scoring 40-51). Pre-pain involvement in health was then plotted against BDI scores for each of these three groups. This is shown in Figure 5.14. This graph indicates that, contrary to predictions, FGA did not reduce the likelihood of becoming depressed when pre-pain levels of involvement in health were high, but rather *increased* it. Given the pattern of main effects was as predicted, this result is puzzling.

This result changed, however, when somatic items were excluded from the BDI and the relationship between pre-pain involvement in health x FGA and depression (Figure 5.6) became non-significant. This suggests that this relationship relates to the presence of somatic items in the BDI and this possibility will be discussed further in section 5.7.5.

5.6.1 Subsidiary findings

Other results involving FGA

Flexible Goal Adjustment emerged as a significant moderator in several path models. In Figure 5.14 predicting depression using the domain of work, the interaction between pre-pain levels of involvement in work and levels of FGA significantly predicted present pain intensity. The relationship between pre-pain levels of involvement in work and present pain intensity was plotted for the three levels of FGA and this is shown in Figure 5.15. The interaction arises from the different relationship between work and pain intensity shown by those scoring at relatively low levels of FGA. For this group, higher levels of involvement in work pre-pain is correlated with lower levels of pain intensity, whilst for those scoring relatively moderate to high on the FGA scale showed the reverse relationship whereby higher levels of involvement in pre-pain work were correlated with higher reported levels of present pain intensity.

Figure 5.14: Predicting depression using pre-pain health involvement, for low medium and high levels of flexible goal adjustment (FGA)

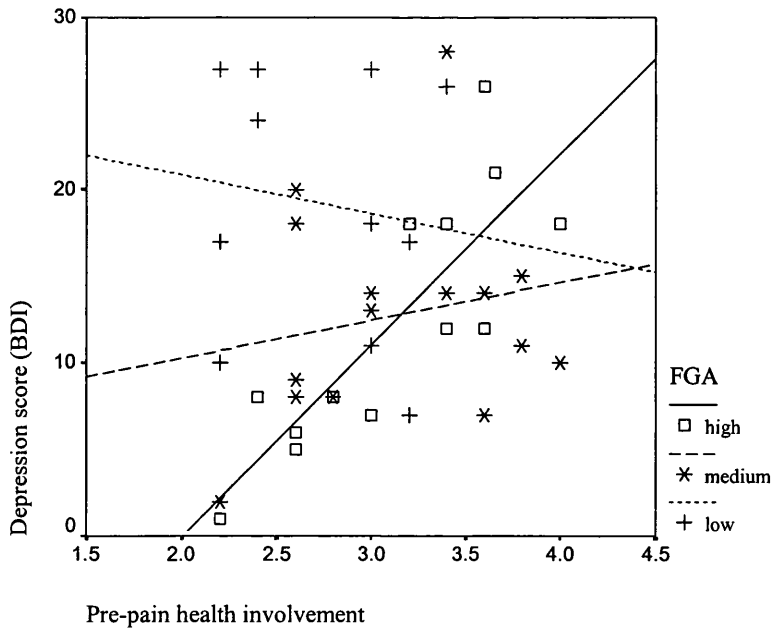
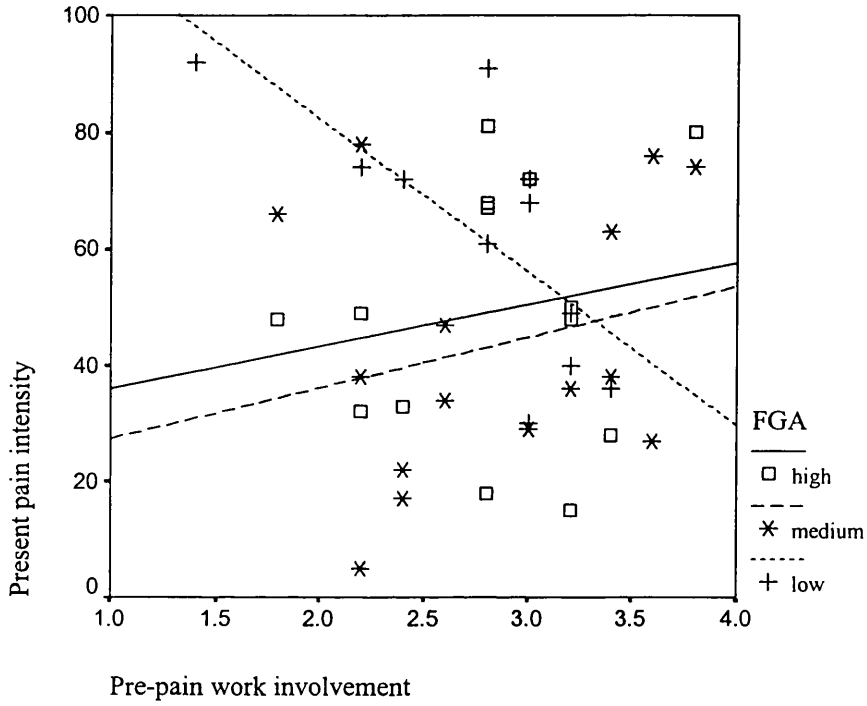
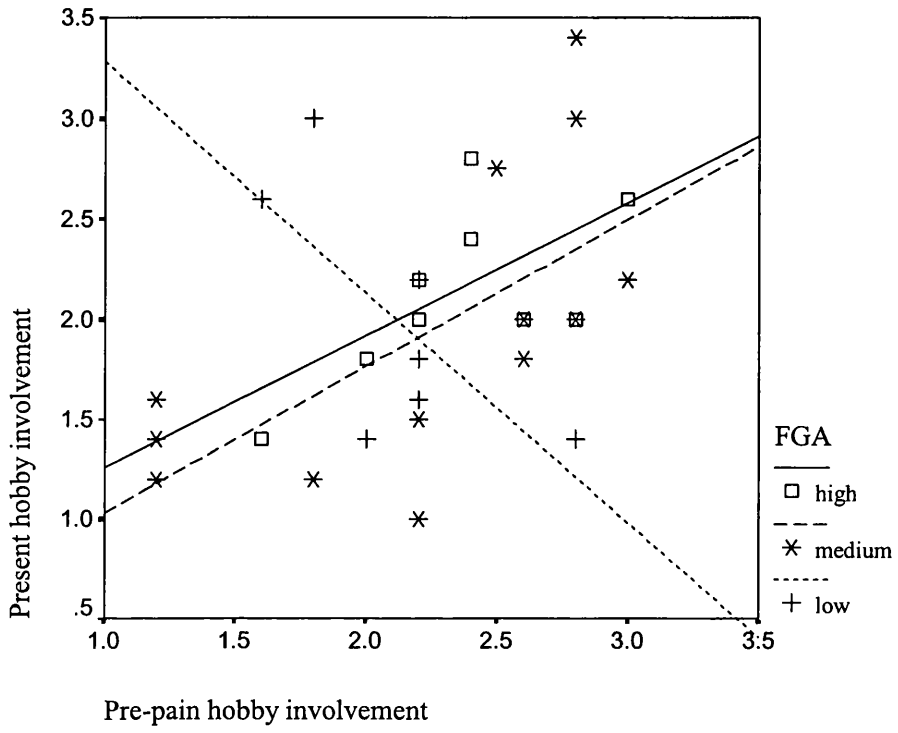


Figure 5.15: Predicting present pain intensity using pre-pain work involvement, for low, medium and high levels of flexible goal adjustment (FGA)



A significant relationship emerged in Figures 5.10a and 5.10b between the interaction between pre-pain levels of involvement in hobby x FGA, and current levels of involvement in hobby. Figure 5.16 shows the relationship between pre-pain and current levels of involvement in hobby graphed out for the three groups of FGA scores: low, medium and high. This shows that for those scoring relatively low on the FGA scale, high levels of pre-pain involvement are correlated with low levels of current involvement in their most important hobby or interest, whilst the reverse relationship holds for those scoring medium to high on the FGA scale. This provides some support for the view that FGA is an important variable in understanding adjustment to pain as it

Figure 5.16: Predicting current levels of hobby involvement using pre-pain hobby involvement, for low, medium and high levels of flexible goal adjustment



suggests that those scoring relatively highly on the FGA scale continue to engage in similarly high levels of involvement with their hobbies as they did before the pain began, compared to those low on FGA, who show a decrease in levels of involvement pre and post-pain. This may be because those who are high on FGA find ways of continuing a hobby despite the pain. Indeed correlations between whether people reported a different hobby for the present time compared to the one they reported on pre-pain correlated significantly with FGA demonstrating that those high on FGA were more likely to have replaced a pre-pain hobby with a new one ($r=0.34$, $p<0.05$).

Predicting depression

Comparison of the path models predicting depression (Figures 5.4-5.8) illustrates that all five models significantly predicted depression. The model containing the predictor pre-pain levels of involvement in people's most important hobby or interest accounted for the most variance (45%) followed by the model with health as a predictor, which accounted for 40% of the variance. The remaining three models were roughly equivalent in their ability to predict depression with the model containing involvement in work accounting for 31%, the model containing involvement in relationship accounting for 29%, and the model containing involvement in independence accounting for 31% of the variance in depression.

Two key variables that emerged as important predictors of depression were sex and FGA. Sex was significantly associated with depression such that women were more likely to rate themselves as depressed compared to men. However, this result only approached significance when the somatic items of the BDI were excluded. FGA was significantly and negatively associated with depression such that high levels of FGA were associated with lower levels of reported depression, in both path models including and excluding the somatic items of the BDI.

Predicting current levels of involvement in the five life domains.

The variables measured in the current study were best able to account for variance in current levels of involvement in both independence and most important relationship.

Current involvement in independence

Figure 5.13 shows that, in the case of independence, it is only pre-pain levels of involvement in independence that accounts for 66% of the variance in current levels of involvement in independence.

Current involvement in relationship

Both pre-pain levels of involvement in most important relationship and FGA

significantly predicted current levels of involvement people reported in their most important relationship. High levels of pre-pain involvement and high levels of FGA were both associated with high levels of current involvement, and together these two variables accounted for 52% of the variance (See Figure 5.12).

Current involvement in hobby

Current levels of involvement in people's most important hobby or interest were predicted by the interaction between pre-pain levels of involvement and FGA. When FGA levels were medium-high, the more involved people were in their hobby pre-pain, the more involved they were currently. Those with low levels of FGA, on the other hand, with high levels of involvement in hobby pre-pain showed lower levels of hobby involvement currently.

Current involvement in work

Significant predictors of current involvement in work critically depended on whether all participants were included in the analysis or only those who had a current work related activity. For the model containing all participants (Figure 5.9a) none of the variables emerged as significant predictors in current levels of involvement in work, although organic symptom severity approached significance as a predictor whereby higher scores on severity (indicating *less severe* organic signs) was associated with higher levels of involvement in work.

In the model excluding those 9 participants who had no current work related activity, sex, pre-pain levels of involvement in work and symptom understanding emerged as significant predictors of current levels of involvement in work. Men reported higher levels of work involvement than women, higher levels of pre-pain work involvement were associated with higher levels of current work involvement, and higher levels of symptom understanding were also associated with higher current levels of involvement in work.

Current involvement in health

Current levels of involvement in health was weakly associated with pre-pain levels of involvement in health and significantly associated with FGA such that those people higher on FGA also reported higher levels of current involvement with their health.

Other findings

Other relationships between the variables entered in the path models worthy of note are those of significant associations between sex and present pain intensity with women rating their pain as more intense than men, and a significant association between age and organic symptom severity with older adults being given lower, more severe organic damage ratings than younger adults. However, these results are not central to the aims of the study and will not be discussed further here.

5.7 DISCUSSION

The main aim of this study was to explore predictors of adjustment to chronic pain. An attempt was made to explore symptom understanding along with symptom consequences such as role/goal losses, thereby examining aspects of pain schema (symptom understanding and role/goal losses), and their role in adjustment, which have hitherto remained largely unexplored.

5.7.1 The SAI and prediction of pain--adjustment

There was little evidence in the current study to support the view that illness schema, as measured by the SAI, predicted 'adjustment' as measured by both depression and current levels of involvement in five different life domains. The correlations between total BDI scores and symptom understanding was –0.13 and reflects a small effect size. Hence there may have been insufficient power in the analysis to detect a

significant association, and this is discussed in more detail in section 5.7.2.

Whilst a significant association between symptom understanding and current levels of involvement in personal hobbies was found, this showed *higher* levels of symptom understanding was associated with *lower* levels of hobby involvement, suggesting higher agreement was associated with poorer adjustment. In the path model conducted excluding those 9 participants who had no current hobby, this relationship disappeared, suggesting that this result may have arisen because of an association between higher levels of symptom understanding and having no current hobby. Indeed the correlation between having a current hobby and levels of symptom understanding approached significance.

However, this result could reflect a number of factors, for example, it could be that it reflects some degree of 'motivated' misunderstanding whereby there is disagreement about symptom understanding between the patient and doctor because the patients are unwilling to reduce activities they enjoy that might be inadvisable, given their particular symptoms. Hence the doctor's understanding of their symptoms is rejected to legitimate their continuing the levels of involvement in their hobby they wish to pursue. However, there is no adequate way of testing this hypothesis with the current data because pain sufferers were not asked about how the doctor's view about their symptoms might relate to advice the doctor gave about the suitability of engaging in hobby type activities. In general, though, the results of the current study need to be interpreted with caution as the present study did not replicate the findings of Lacroix *et al.*.

5.7.2 Replication of Lacroix's findings

Lacroix *et al.*'s key finding in relation to chronic pain was that higher levels of agreement between doctor and patient about the patient's symptoms was correlated with return to work.

In the current study no correlation was demonstrated between symptom understanding and work status. However, although the key finding was not replicated, a similar pattern of internally consistent relationships among the measures of the SAI were demonstrated to those of Lacroix *et al.*: there were no correlations between symptom understanding and measures of organic symptom severity and prognosis, hence symptom understanding was unrelated to the severity or complexity of organic damage. In addition there was a significant correlation between organic symptom severity and prognosis such that higher levels of severity were associated with poorer prognosis.

Other findings were, however, inconsistent with those of Lacroix *et al.* (1990). Whilst there was a significant correlation between English proficiency and symptom understanding, this was in the opposite direction to that found by Lacroix *et al.*, indicating that, in the current study, higher levels of symptom understanding was associated with *lower* levels of proficiency in English, not higher levels as found by Lacroix *et al.*. It is not clear what the cause of this relationship might be although it is noteworthy that only 4 out of the 40 participants scored less than 4/4 for English proficiency and hence this result would need replicating with a sample within which there was greater variance in this measure. However, this association was not found when people who had no work to give up pre-pain were excluded from the analysis.

Also in contrast to Lacroix *et al.*'s study, the correlations in the present study between organic symptom severity, prognosis and work status were significant, such that work *was* associated with both fewer organic signs and better prognosis. In addition, age was found to correlate significantly with work status, such that younger people were more likely to have stopped work or be on lighter duties than older people, although this was no longer significant when those people who were not working prior to the pain were excluded from the analysis.

More interesting was the pattern of results found using work involvement rather than work status. Current levels of involvement in work correlated significantly with symptom understanding such that higher levels of involvement were correlated with higher levels of agreement. This relationship held when the 9 participants who had no current work related activity were excluded from the analysis, and symptom understanding approached significance in predicting levels of current work involvement over and about that predicted by age, English proficiency, organic symptom severity and prognosis. This is clearly a promising result but when symptom agreement was put into a path model along with other variables it did not emerge as a significant predictor of work involvement.

The number of subjects in this study was 40 and (depending on the effect size) there may not have been sufficient power in the analysis to adequately test the hypotheses which were being examined. The number used in the current study was broadly equivalent to that used by Lacroix *et al.* (50) but less than the number studied by Schmidz (120).

The type II error rate refers to the probability of accepting the null hypothesis when it is false. This level is conventionally set at 0.20 and hence the power of an analysis is set at 0.80, i.e. there is an 80% chance that the null hypothesis will be rejected when it is false (Howell, 1997). The power of an analysis is a function of a number of things: Type I error rate (the probability of accepting the alternative hypothesis when it is false), the difference between the mean of distribution of the null hypothesis and mean of the distribution of the alternative hypothesis, the sample size (because the variance of the sampling distribution of the mean tends to decrease as N increases) and the particular statistical test being used. However, discussions of power are generally concerned with sample size as this is the easiest to manipulate.

The general equation to determine the power of an analysis is:

Delta = effect size x $\sqrt{N-1}$.

In the case of a bivariate correlation, the effect size is equal to the correlation coefficient. The correlations found between work status and symptom understanding in the present study were under 0.20, (0.14 on the whole sample, and 0.19 excluding those whose work status could not have been affected by the pain) and the correlations between depression and symptom understanding were 0.13 and 0.12 (for the total BDI score and the affective subscale of the BDI respectively). These correlations are considered to constitute a small effect size (Cohen and Cohen, 1983) and differ substantially from the effect size reported by Lacroix *et al.* (1991) in their studies. In their study on 31 patients with chronic respiratory disorders Lacroix *et al.* report a correlation of 0.50 between symptom understanding and a measure of physical, social and psychological adjustment (the Global Assessment Scale), and in their study on people with low back pain (Lacroix *et al.*, 1990) the correlation between symptom understanding and work status was 0.60 in the first sample of 50 patients and 0.54 in the second sample of 50 patients. Such correlations are considered to represent a large effect size. The sample size of 40 used in the present study should have been sufficient to detect a significant difference based on the effect size reported by Lacroix *et al.* The minimum correlation (or effect size) they reported was 0.50. The value for delta (which is looked up in power tables to give a power value for a given level of alpha, set in this case at the conventional level of 0.05), with an effect size of 0.50 and a sample size of 40, works out at 3.12. This converts to a power of 0.87 for a two-tailed test, and confirms that this sample size in the present study was sufficiently large to have an 87% chance of finding a significant association between symptom understanding and adjustment (whether this be work status or depression). However the effect size found in the currently study was very much lower than that reported in the studies done by Lacroix *et al.* and power calculations based on the correlation of 0.19 (found when the 9 subjects whose work status could not be affected were excluded from the analysis),

found that a sample size of 218 people would have been required to obtain a power of 0.80. The issue in the current study is therefore why the effect size found was substantially smaller than found in previous work.

The effect size is equal to the correlation coefficient which in turn can be affected by one of two things: range restrictions and the presence of heterogeneous subsamples (Howell, 1997). In terms of range restrictions the range of scores in symptom understanding in the present study ranged from 2-7 (there were no scores of 1). The range of scores has not been given in the papers by Lacroix *et al.* and without a graph illustraiting the distribution of scores Lacroix *et al.* found between global symptom understanding and work status, it is difficult to assess whether this factor might account for the differences in effect size between the two studies.

There were, however, clear differences in terms of the heterogeneity of the samples studied. Lacroix *et al.* (1990) studied a relatively homogenous group of chronic back pain sufferers, with mechanical back injuries, who had only had pain for between 3 and 6 months, and it is presumed that they all had a job to which they could return. In addition, their participants were assessed on the basis of data collected *before* information about work status was collected, and hence was effectively a prospective study. In contrast, the current study used pain sufferers who had had pain for a significantly longer period of time, with an average pain chronicity of 9 years. In addition, they comprised a more heterogenous group of chronic pain sufferers, having a variety of different diagnoses and pain sites and possibly no job to which they could return, even if they were fit to do so. Hence the greater heterogeneity in the sample studied here may well account for the small effect size found here, due to this difference in the populations studied.

Alternatively, these different results could genuinely reflect different factors which affect work status in the relatively acute phases of pain compared to the longer-

term chronic phases. That is, different factors may play a role in whether people continue work in the long-term *vs.* being able to go back to work in the short-term. For example, the longer pain continues, the more likely it may be that other factors relating to pain may play a role, such as time taken off sick and hence the influence of factors outside of the pain sufferer's control may influence work status more, such as their employer's willingness to continue employing them. However, these reasons are speculative as job availability, and other more specific details related to work status were not assessed in the current study, but may have been important confounding variables.

In summary, the results of the current study suggest that the generalizability of Lacroix *et al.* findings to issues other than return to work in chronic pain sufferers within 3 to 6 months of sustaining a work-related injury, remains to be demonstrated. In addition, the unique contribution of symptom understanding in predicting work status was not demonstrated by Lacroix *et al.* as they did not run regression analyses or partial correlations to see whether symptom agreement emerged as a unique predictor of work status when other important variables were also considered. Further, whilst Lacroix *et al.* considered the role of hypochondriasis and hysteria (measured by the MMPI) in symptom understanding, they did not consider pain intensity. In the present study a weak relationship emerged between pain intensity and symptom understanding. This raises the possibility that pain intensity may play a role in disagreement about symptoms, suggesting that people may have less confidence in the medical account of their symptoms the more intense the pain they are experiencing.

The results of the current study, however, did support Lacroix *et al.*'s findings in so far as they relate to the SAI and the relationship between its various measures, notably the independence of symptom understanding from prognosis and organic symptom severity.

5.7.3 Limitations in the operationalization of Lacroix et al.'s model

The lack of evidence supporting the view that the SAI predicts adjustment could arguably be down to the particular measures used in the current study. None of the measures of adjustment used in the current study were the same as those used by Lacroix *et al.* (1991). The latter used the Global Assessment Scale (Newman, 1983). However, Lacroix *et al.* (1991) state that a high score on this:

> "reflects a patient who is functioning at a superior level in all aspects of life. Such a patient pursues activities of interest, is socially active, and is able to maintain close interpersonal relationships with friends and family members" (p. 270).

Hence the Roles and Goals Questionnaire used in the current study was judged a more appropriate measure to use, as it too records levels of involvement in activities of interest and relationships. However, the measure used by Lacroix *et al.* was rated by the nursing unit manager and was therefore not self-report. It was intended as an objective measure of adjustment rather than a subjective one. The measures of adjustment used in the current study were subjective ratings. Whilst it may be that symptom understanding only correlates with objective measures, this is a possibility which would need to be tested in future research.

5.7.4 Limitations to the concept of 'accuracy' of understanding

Whilst the operationalization of Lacroix *et al.*'s model may have been adequate in the current study, there are clear criticisms which can be directed at the assumptions inherent in the model itself.

Lacroix *et al.* refer to symptom *accuracy* rather than symptom *agreement* because they assume that the doctor has the 'correct' understanding of the symptoms. They also assume that any incorrect understanding can be easily rectified. The understandings people have of their illness may not reflect degree of 'accuracy' which can be corrected through greater education by health care professionals. Different people

often have different, non-medical, understandings of health and illness (Stainton-Rogers, 1991). Indeed, beliefs about the causes of pain have been shown to vary between pain sufferer's and other health care professionals, but this has been interpreted as resulting from a failure to take responsibility for the pain, with a tendency for pain sufferers to blame the pain on other health care professionals' failure to treat them (Eccleston, Williams and Stainton-Rogers, 1997).

It seems plausible to suggest that the extent to which pain sufferers agree with a medical understanding of their symptoms may be 'motivated'. That is, there may be reasons why some pain sufferers will disagree with their doctor's understanding of their symptoms reflecting, for example, an unwillingness to come to terms with the intractability of the pain which in turn may reflect a desire to return to a pre-pain lifestyle. Hence, rather than it being a question of education resolving the discrepancy in understanding, this discrepancy may reflect a more fundamental aspect of being unable or unwilling to adjust to the pain. For example, if the medical understanding implies long term pain, no hope of cure and hence no return to a pre-pain lifestyle, pain-sufferers will be expected to differ in terms of their acceptance of this understanding, depending on how involved they were in their pre-pain activities. Hence symptom understanding may not just predict adjustment, it may be directly influenced by other factors that relate to levels of involvement in pre-pain activities.

However, there was no evidence to support the view that symptom understanding may relate to levels of pre-pain involvement in particular domains of life. Pre-pain levels of involvement in the five life domains did not predict symptom understanding in any of the five path models, nor was this relationship one which is moderated by FGA as the interaction between pre-pain life domain involvement and FGA did not significantly predict symptom understanding in any of the five models.

A further point that should be made relates to the level of representation of

meaning accessed by the SAI. Although a small correlation was found between symptom understanding and depression, the level of representation accessed by the SAI may not necessarily be one associated with the evocation of emotion. Following on from the discussion of levels of meaning and how they might be accessed (Chapters 1 and 4) it may be that, following Teasdale and Barnard's model (see section 1.4.3), beliefs which are judged according to whether they are true or false (i.e. meaning which is represented at a prepositional level) do not access the level at which emotion is represented. As Lazarus states, in considering emotion, the relational meaning of events needs to be considered:

> "relational meaning results from a higher or more synthetic level of analysis. At that level the separate variables are lost in favor of a new relational concept -e.g. feeling demeaned, sensing an uncertain threat, feeling failure to live up to an ego-ideal, feeling attainment of what one wants, sensing enhancement of one's self, or suffering an irrevocable loss." (Lazarus, 1993; p. 13 and 14).

Hence it may be that it is the *implications* of lack of agreement between the patient and the doctors understandings of the patient's symptoms which are vital in understanding depression.

5.7.5 Does FGA moderate the relationship between pre-pain life involvement and depression?

This aspect of the path modelling aimed to extend the findings of Schmitz *et al.* (1996). Schmitz *et al.* (1996) argued for conceptualizing pain as something that, by definition, presents obstacles to the achievement of life goals. They showed that FGA significantly moderated the relationship between pain and depression such that those people scoring higher on flexible goal adjustment were less likely to be depressed in the face of pain. The current study aimed to expand this research by assessing whether there were particular domains of life that, when blocked or disrupted by chronic pain, were more likely to result in depression than others, and to assess the role of FGA in

moderating these links.

In contrast to the study by Schmitz *et al.*, the assumption that chronic pain would act as an obstacle to involvement in different life domains was testable. Levels of involvement in each of the five life domains reduced significantly between pre and post-pain time periods with the exception of the area of relationships, generally providing support for this assumption. Measures of involvement also showed that for pain sufferers the highest scores are given to the areas of relationships, health and independence. This broadly replicates the findings of Lam and Power (1991) who demonstrated that relationships and health emerged with the highest involvement scores in younger and older adults, and that independence emerged as a significant area of concern in older adults. It is assumed that the presence of chronic pain is the main reason for this decrease in involvement scores although age may play a role in this result as well. However this possibility was not tested in the current study, as a second, pain free sample was not used to assess perceived changes in involvement over time.

The hypothesis that FGA would moderate the relationship between pre-pain life domain involvement and depression received little support in the current study, although the sample size was small and this could have been the result of insufficient power in the analysis. The interaction term between FGA and pre-pain levels of involvement in four out of five of the domains of life did not significantly predict depression. The one exception was the domain of health. However, contrary to predictions, FGA did not reduce the likelihood of becoming depressed when pre-pain levels of involvement in health were high, but rather *increased* it. This result is difficult to explain. Notably, there was also a significant and positive relationship between FGA and current levels of involvement in health. This suggests the possibility that current levels of involvement in health might reflect degree of concern about health. Hence a combination of high FGA and high pre-pain involvement in health might reflect high levels of concern about health. The latter might, in turn, relate to depression, particularly as measured by the

BDI as it contains somatic items, some of which reflect concern about physical symptoms. The idea that the relationship between FGA and pre-pain health involvement and depression might reflect general concerns about health receives some support from the fact that dropping somatic items from the BDI and re-running the analysis resulted in this relationship becoming non-significant, suggesting the somatic items play a key role in this result. However, if this were so, then the interaction between pre-pain involvement in health and FGA should also have predicted current levels of involvement in health, but it did not.

This part of the study was novel and hence no other data is available to determine what sample size might have been sufficient to detect a significant moderational effect of FGA on role/goal involvement other than that in the current study. However, if it is assumed that this effect is small then a sample of approximately 300 may be required to adequately test this relationship.

The effect size of the relationship between FGA and depression was 0.45 using the total BDI score and 0.44 using the affective items of the BDI. This is almost identitical to the effect size found by Schmitz *et al.* of 0.46, and indeed a significant association between FGA and depression was found in the present study.

Determining the number of subjects needed for the F test of the significance of R^2 of the addition of the interaction between FGA and pain intensity in predicting depression is given by the equation:

$n = (\lambda/f^2) + w$

where $f^2 = (R^2_{Y.A,B} - R^2_{Y.A}) / 1 - R^2_{Y.A,B}$.

$R^2_{Y.A,B}$ refers to the proportion of variance of Y accounted for by Steps 1 and 2 (or block of variables 'A' and 'B') and $R^2_{Y.A}$ refers to the proportion of variance of Y accounted for solely by Step 1 (or block of variables 'A').

w is used to represent the number of degrees of freedom associated with the source of variance in the dependent variable, which in this case in the number of

independent variables used in the equation, and λ is a value looked up in tables based on the power (as noted earlier, typically set at 0.80) (Cohen, 1988).

Using this equation to determine the number of subjects that would have been required to detect a change in R^2 of 0.02 (that reported by Schmitz *et al.* as the change in R^2 determined by the interaction between pain intensity and FGA.)

$f^2 = (0.30 - 0.28)/1\text{-}0.30)$

$= 0.028$

With power set at 0.80, alpha at 0.05, u (the number of IVs entered in Step 2, in this case 1) and λ equals 7.8, N=279 + w, $\approx$ 280.

No prior published test has been done of the interaction between role/goal involvement and FGA in predicting depression so there is previous data to compare the results of the current study with. However the results of the present study suggest that these effect sizes are small, and a sample of around 300 may be required to adequately test this hypothesis.

5.7.6 Subsidiary results concerning FGA

Flexible Goal Adjustment emerged as a significant moderator in two further cases, in the relationship between pre-pain levels of involvement in work and present pain intensity, and in the relationship between pre-pain levels of involvement in hobby and current levels of hobby involvement.

Higher levels of pre-pain involvement in work correlated with lower levels of pain intensity for those participants low on FGA. Those scoring relatively moderate to high on the FGA scale showed the reverse relationship, whereby higher levels of involvement in pre-pain work were correlated with higher reported levels of present pain intensity. This suggests that there may be some further variable responsible for this pattern of results not measured in the current study. The relationship between low levels

of FGA (or inflexibility) are linked with high levels of involvement in work and low complaint levels of pain may, for example, reflect a character trait, such as stoicism. However, it is noteworthy that this result disappeared when the 9 participants who had no current work activity were excluded from the analysis, suggesting the people not currently working played an important role in the demonstration of this result. Hence this result would need replicating before further exploring the possible causes of it.

FGA significantly moderated the relationship between pre-pain levels of hobby involvement and current levels of hobby involvement. Higher levels of FGA were associated with a positive relationship between pre-pain and current levels of hobby involvement, supporting the view that FGA is an important variable in understanding adjustment to pain. This result suggests that those scoring relatively highly on the FGA scale continue to engage in similarly high levels of involvement with their hobbies as they did before the pain began, compared to those low on FGA, who show a decrease in levels of involvement pre and post-pain.

In summary, whilst there was evidence consistent with the assumption that chronic pain impedes people's ability to be as involved in key domains of life (e.g. work, hobbies, health) as they were prior to the pain, there was no evidence that people are less likely to become depressed in the face of such an impediment if they are high on flexible goal adjustment, although this may have been due to insufficient power in the analysis. However, there are limitations with the measure of coping used in the present study which are discussed in section 5.7.8.

5.7.7 Replication of Schmitz et al..

The results of Schmitz *et al.* that FGA would moderate the relationship between pain intensity and depression were not replicated in the present study. This result does not seem to be something that can be explained by methodological differences between the two studies. The same measures of pain intensity and FGA were used in both

studies. The pain intensity measure was a composite score based on four measures of pain: most, least, typical and current pain intensity. However, a different measure of depression was used. In the current study the BDI was used, in the Schmitz study it was the 'Centre for Epidemiological Studies Depression Scale'. There has been wide-spread discussion of the role of somatic item selection in chronic pain research into mood complaints. Specific studies which have looked at BDI somatic item selection in chronic pain sufferers have reached differing conclusions regarding whether such item selection reflects depression or disability associated with chronic pain. The study by Williams and Richardson (1993) demonstrated a considerable discrepancy between pain sufferers' scores on somatic items and their scores on other questionnaires designed to address negative mood and negative cognitions. However, a subsequent study concluded that, although there was discrepancy between pain sufferers' scores on affective and cognitive items relating to depression and somatic items, all three types of item did relate to a common core of depressive symptomatology (Novy *et al.,* 1995). Given that the latter study concluded that total scores of the BDI could still be understood as a reliable indicator of depression in chronic pain groups (Novy *et al.,* 1995), changing the depression scale should not dramatically alter the pattern of results, resulting in a failure to replicate previous findings. However, to check this, the regression analysis was repeated using only the negative-attitude/suicide factor produced by Novy *et al.* (1995) of the BDI. However, removing the somatic items from the analysis and including only cognitive and affective items in the depression score, failed to alter the pattern of results. FGA emerged as a significant predictor of depression but pain intensity did not significantly predict depression, and neither did the interaction between pain intensity and FGA. It therefore seems reasonable to suggest that the use of a different measure for depression is not the cause of the failure to replicate Schmitz's results.

However, there are two further differences between the present study and the study by Schmitz *et al.* which may account for the failure to replicate the findings of the

latter: the first is the number of participants involved, and the second is the pain sample.

1) The present study involved 40 participants whereas the Schmitz study involved 120 participants. As noted in section 5.7.2 the 2% improvement in variance in depression accounted for by the addition of the interaction term between FGA and pain intensity constitutes a small effect size and the calculations show that the failure to find a significant interaction in the present study may have been due to insufficient power in the analysis due to the small sample size.

2) In the study by Schmitz *et al.* the participants studied were receiving inpatient treatment, whereas those in the present study were receiving outpatient treatment. Secondly and perhaps more importantly, 41% of participants in the Schmitz study were headache sufferers, whilst only 7 (18%) of the participants in the present study reported that they suffered from headaches.

The first difference (inpatient *vs.* outpatient) would only be expected to affect the pattern of results if inpatient status was associated with differences in pain intensity and depression. However, both pain intensity scores and depression scores appear roughly equivalent across the two studies. In the present study the average pain intensity of the participants was 5.48 (SD=1.57); in the Schmitz study it was 5.06 (SD=1.52). In addition, 53% of the participants in the Schmitz study scored above the clinical cut-off for their depression scale, whilst 43% of the participants in the present study scored above the clinical cut-off of 15 for the BDI (Phillips, 1988).

The second difference, that of 50% of their participant group being composed of headache sufferers, is difficult to assess in terms of whether it might affect the pattern of results relating to FGA. There is no a priori reason why *location* of pain would affect the relationship between pain intensity and depression. However, there may be other factors which accompany pain location which are important, particularly when the location refers to the presence of headaches. For example, headaches are typically intermittent rather than continuous in nature. It may be that it is factors that relate to the intermittent

nature of headaches, such as the unpredictability of the pain or feelings of uncontrollability, that play a role in the relationship between pain intensity and depression, and that also create a context in which flexible goal adjustment acts as a moderator in this relationship. That is, flexible goal adjustment may play an important moderating role in the development of depression if the pain being experienced is intermittent and uncontrollable and hence continually demands a change in daily life plans. However, seeing as no measures of these variables were taken either in the Schmitz *et al.* study or the present study, this explanation remains purely speculative.

There was evidence that FGA moderates the relationship between pre-pain levels of involvement in hobby and current levels of involvement in hobby. In addition, FGA was negatively associated with depression such that those scoring on FGA also rated themselves as less depressed and positively associated with current levels of involvement in health, suggesting that it may be a construct worthy of further exploration. Nevertheless there are some reservations about the FGA measure.

5.7.8 Limitations of the questionnaire measures used

Flexible Goal Adjustment Questionnaire

Although accommodative coping, or FGA, appears a useful analytic concept, there are questions to be raised about the overlap of the items of the FGA scale and those of depression. Whilst there are items which appear clearly distinct from depression, such as:

'When I get stuck on something, it's hard for me to find a new approach'

(negatively scored), and

'I adapt quite easily to changes in plans or circumstances'

there are also items which have clear hedonic overtones. For example:

'I find it easy to see something positive even in a serious mishap'

'When everything seems to be going wrong, I can usually find a bright side to a situation'

'In general, I am not upset very long about an opportunity passed up'

'I usually find something positive even about giving up something I cherish'

It seems plausible to suggest that the association between low depression scores and high FGA scores may simply reflect conceptual overlap. In addition, some of the items such as:

"It is very difficult for me to accept a setback or defeat."

are global negative statements. The measurement of the coping process may be confounded with coping outcome, as people who are depressed tend to respond to questions which reflect global negatives or negative content. If this is the case and FGA is tapping the same construct as depression scales it may be adding little to our understanding of factors involved in depression and chronic pain.

Such conceptual overlap would not explain why it has been demonstrated as playing a moderating role in the pain-depression link in previous research and why it emerged as a significant moderator in the relationship between the importance of pre-pain hobby and the levels of hobby involvement post-pain, as interactions are independent of main effects, though it raises questions about what such results might mean.

The Roles and Goals Questionnaire

The Roles and Goals Questionnaire also had some limitations as used in the current study. Clearly it was designed to study depression and not chronic pain and the factors which influence depression in chronic pain sufferers may differ from those involved in the development of depression in the absence of pain. The results of the t-tests suggested that in general chronic pain affects people's abilities to be as involved in the four domains of life work, hobby, health and independence as they were prior to the

pain. The greater reduction appeared to be in the work domain, although this was the domain rated one of the lowest in terms of pre-pain involvement.

The individual questions reflect the fact that the questionnaire measures a combination of both physical and emotional involvement in a given life domain, hence it presupposes that there is an activity within each given domain that people can provide answers about. However, in the case of chronic pain this is not necessarily the case. The options adopted in the current study of either giving a score of '1' for having no work or hobby, or excluding such a group from the analysis were both potentially problematic. A group of people who have had to stop their work and/or their hobby, and have not taken up replacement activities, are clearly a group who need to be included in analyses exploring issues of adjustment to pain. However, giving a score of '1' to this subgroup does not seem satisfactory, because the Roles and Goals Questionnaire is not simply a measure of physical involvement but of emotional involvement as well. People may feel attached to, or involved in, domains of life even though they are unable to actively do them. This difficulty is exemplified in the marked difference between the path models predicting current involvement in work including and excluding those who had no current work-related activity. The difference in the pattern of relationships between these two groups are difficult to interpret, and illustrate the difficulties in generalizing about the factors which may predict involvement in work.

An additional problem with the way the questionnaire was used in the current study was that the pre-pain involvement measures that were taken were, of course, retrospective. For example the link between pre-pain hobby involvement and depression may reflect the fact that people who were depressed were more likely to view their levels of involvement in pre-pain activities as higher than those who were not depressed. Hence, depression might be leading people to look back at their former lives in a distorted manner, rating themselves as more involved in life domains, pre-pain, than those who are not depressed.

However, if this were the case, one would expect there to be a general relationship between pre-pain involvement ratings, regardless of domain, and depression. As there was no evidence for a generalized tendency to rate involvement of all pre-pain roles and goals more highly in those who were scored relatively highly on depression, (i.e. no consistent relationship in the path models between pre-pain life domain involvement), it gives the demonstrated relationship between the importance of pre-pain hobbies and depression more credibility as a potential contributor to the development of depression in chronic pain sufferers. The reasons for such a relationship between pre-pain hobby involvement and depression are unclear. The majority of hobbies that were mentioned were active, sporting hobbies, such as keep-fit, swimming, football, and walking, hence the link between importance of pre-pain hobby and depression could result from any number of associated factors: enjoyment derived from the hobby, spin-off benefits of the hobby in terms of a social network, and/or the positive sense of well-being derived from physical activity. Clearly these are issues which are worthy of further exploration. However any causal role of pre-pain hobby involvement in the development of depression could only be reliably demonstrated by a longitudinal design.

5.8 GENERAL CONCLUSIONS AND SUMMARY

The main aim of this study was to explore pain schema by addressing aspects relating to schema structure and symptom meaning, namely aspects of schema content that may relate to pain-adjustment. Specifically it aimed to explore the role of symptom understanding and losses associated with pain in predicting pain-adjustment. There was little evidence to support the hypothesis that symptom understanding predicted pain-adjustment. There was some evidence that pre-pain life involvement in hobbies and the coping style of flexible goal adjustment are important variables in understanding depression in chronic pain. However, both the results of Lacroix *et al.* and those of

Schmitz *et al.*, which formed the basis of the current study, were not replicated, raising some doubts about the generalizability of the results.

Whilst an attempt was made in the current study to measure variables which related to pain-adjustment, the constructs assessed were done so through the SAI, Roles and Goals, and FGA, and these measures have clear limitations. Notably, none of these measures except the SAI, were designed for use with chronic pain groups, hence the validity of the constructs they measure and their relevance to chronic pain remain unclear. For example, FGA sits within a complex and sophisticated model of developmental processes of adjustment, however the items that make up the scale were theoretically rather than empirically derived and may lack ecological validity within the domain of chronic pain. Further, the concept of loss is problematic. For example, in the field of depression Brown and Harris point out:

> "The worth of a person or role does not necessarily disappear with the loss of the person or role – a widow can continue to have good thoughts about her marriage" (Brown and Harris, 1978; p. 234)

however in the field of chronic pain the situation may be even more problematic. As Williams (1998) illustrates, it is often difficult for chronic pain patients to discuss goals which they are uncertain whether they have definitely given up or are just temporarily on hold.

The next study in this thesis therefore aimed to assess aspects of schema content and pain meanings in an unconstrained way, using Grounded Theory.

Chapter 6

An Investigation into the Experience of Having Chronic Pain Using Grounded Theory

6.1 INTRODUCTION

The fourth study in the thesis aimed to examine meanings surrounding the experience of pain, particularly those associated with an inability to accept or adjust to pain. In this study, a broader, less constrained method was used to explore the meaning pain has for pain sufferers by adopting a symbolic interactionist perspective and developing a grounded theory. The latter method attempts to understand pain from the perspective of the sufferer and allows the exploration of meanings which are not determined by prior theorizing. As a result, it promotes the development of concepts for understanding pain experience and hence allows key aspects of schema content or pain meanings which relate to adjustment to be identitifed.

In Chapter 5 pain-adjustment was explored in relation to accuracy of symptom understanding and flexibility in coping with the losses in roles and goals that often accompany chronic pain. Whilst these represented aspects of schema content which have received scant empirical attention, little exploratory work has been conducted to verify the ecological validity of these concepts in understanding pain-adjustment. The next study therefore aimed to provide some assessment of the usefulness of the concepts studied in Chapter 5 in understanding pain-adjustment.

The role of meaning in pain experience has long been recognized as an important factor in understanding individual differences in reported pain complaint (e.g. Beecher, 1959), and much psychological research has focused on examining cognitive mediators of pain experience such as coping style, thoughts and beliefs in an attempt to understand the gap between organic symptom severity and reported pain intensity, or between reported pain intensity and disability. These cognitive mediators are viewed as

playing a vital role in the appraisal of symptoms and hence in making sense of them, i.e. giving them meaning, and some of these pain-beliefs and their association with adjustment have already been discussed (see Chapter 5). Beliefs have often been studied in a fragmented way, focussing on single aspects of pain experience like feelings of control over pain, or beliefs about its cause. However, the choice as to which aspects of pain are explored is often made by the researcher, such as through the selection of word types used in word list research or the choice of questionnaire measures used, and hence does not necessarily reflect the primary concerns or experiences of those with pain. Relatively little research has focused on understanding chronic pain from the perspective of the sufferer and yet understanding people's experience of illness can aid practitioners through improved doctor-patient communication, increased patient satisfaction, greater treatment compliance and increased reports of health (Charmaz, 1990; Bass, Buck, Turner, Dickie, Pratt and Robinson, 1986; Stewart, Brown and Weston, 1989). Charmaz, for example, has argued that understanding the patient's perspective can aid treatment by enabling physicians to discover and act on patient-defined problems rather than the problems doctors may assume are central.

6.2 PREVIOUS RESEARCH

Recent research has explored both patient perspectives on medical issues surrounding chronic pain and broader perspectives on what it is like to live with pain. For example, recent studies have explored the patient's view of issues surrounding the diagnosis (Rhodes, McPhillips-Tangum, Markham and Klenk, 1999), attributed cause (Eccleston, *et al.*, 1997) and treatment (McPhillips-Tangum, Cherkin, Rhodes and Markham, 1998) of chronic pain. These studies have highlighted the role of legitimation of illness in gaining a medical diagnosis (Rhodes *et al.*, 1999), the role of identity and blame in causal attributions of chronic pain (Eccleston *et al.*, 1997) and the reasons that underlie repeated treatment seeking in chronic back pain sufferers (McPhillips-Tangum

et al., 1998).

Other research has explored more general issues surrounding people's lived experience of chronic pain (Hallberg and Carlsson, 2000; Henriksson, 1995a and 1995b; Johansson, Hamberg, Westman and Lindgren, 1999; Osbourne and Smith, 1998) and chronic illness in general (Charmaz, 1987). Whilst these studies are not always directly comparable because they have different research aims, used different analyses and interviewed different patients samples, a number of similar themes have emerged.

For example, themes relating to the description of pain sensations, and their perceived causes, have often been described. In their 'gendered analysis' of the meaning of pain in 20 women who had been sick listed for at least two months with 'undefined musculoskeletal pain', Johansson *et al.* (1999) offered four themes, two of which related to the pain: 'bodily presentations' and 'explanations'. Under 'bodily presentations', Johansson *et al.* offered descriptions of what the pain felt like both physically (e.g. cramping) and psychologically (e.g. like a 'bizarre invader' or 'alien'). Under 'explanations' were descriptions of people's different understandings of the cause of their pain, such as whether it was thought to have a physical, environmental or psychological cause. In their grounded theory, based on interviews with 22 women with fibromyalgia, Hallberg and Carlsson (2000) describe one of the three primary categories making up the core category as 'subjective pain language', which referred to the characteristics and perceived cause of the pain. Hence some of the emerging themes related to identity and cause dimensions of schema. However, the majority of themes that emerged in these studies relate primarily to the *consequences* of pain, such as the effect pain has had on people's self-perception or identity. For example, in their analysis of 9 women with low back pain, Osborne and Smith (1998) offered four themes. Two related to the pain: 'searching for an explanation' and 'not being believed'; two related to social processes: 'comparing the self with other selves' (including their pre-pain self) and 'withdrawing from others'. They argued that people's accounts of pain emphasized

an inability to establish the legitimacy of the pain either to themselves or to others, and that people's uncertainty surrounding why the pain was there played a key role in the distress associated with their disability. The pain was seen as causing change and uncertainty, lack of positive self-regard and a feeling of 'not being the person they used to be'. The authors also argued that, in comparing themselves with others and with their pre-pain selves, interviewees were both describing and evaluating the change that had happened to their lives as a result of the pain. Further, social withdrawal was seen as the result of not being able to fulfill the demands of their social network and not being able to offer an adequate explanation for this due to the invisible nature of their pain. Osbourne and Smith summarize their findings as showing that the experience of pain is primarily described as one characterized by feelings of stigma, shame and apologism.

Similarly, Henriksson's analysis of the experience of 40 women with fibromyalgia (Henriksson, 1995a, 1995b) focused predominantly the impact of pain rather than factors associated more with the pain *per se*. Henriksson listed themes which were grouped into three main categories: 'encounters', 'consequences' and 'strategies'. *Encounters* referred to people's experience with other people, both those in the health care system and those outside (e.g. family and friends); *consequences* referred to the effect the pain had had on everyday living; *strategies* referred to people's ways of dealing with the consequences of the pain. Henriksson identified the period prior to receiving a medical diagnosis as being the most difficult time to deal with, characterized by anxiety and a feeling of not being believed by professional staff, friends and family. Furthermore, although following this crisis period women tended to adjust their activities in response to their disability, the consequences of fibromyalgia were seen as considerable, and included: "changes in habits and roles, in values and attitudes and in future life perspectives" (p. 85) as well as changes to their identity, as women's inabilities to do things were seen as meaning they could not the be person they used to be. However, despite this more global focus on the consequences of pain under

encounters and consequences, the superordinate theme of strategies described how people coped with the pain *per se* rather than how they coped with the encounters and consequences noted above. Under strategies, Henriksson outlines modes of coping which are similar to those outlined by Cohen and Lazarus (1982), and which include strategies such as information seeking, direct action aimed at changing either the self and/or the environment, inhibition of action, intrapsychic or cognitive strategies such as denial and intellectualization, and turning to others for support.

Johansson *et al.* (1999) also documented two themes which related to the consequences of the pain, alongside those relating to bodily presentations and explanations of pain noted above: 'consequences for daily work' and 'consequences for self perception'. They noted that the women they interviewed frequently complained of the inability to do housework and of difficulty fulfilling family roles such as mother, daughter and wife. In addition, their accounts expressed the concept of social norms which were seen as providing the gold standards that the women felt they were expected to live up to in terms of household and family commitments. However, attempts to attain such standards clashed with being understood as having a genuine illness which meant they could not do paid work. Hence one of the consequences of having pain was a tension between wanting to do fulfill certain roles whilst maintaining their status as 'sick'.

This previous qualitative work on chronic pain has tended to focus on the experience of women and has often focused on those with little or no organic pathology. For example, of the four studies examining pain experience, all, coincidentally, focused on the experience of women, and two interviewed those who had no clear organic explanation for their pain (Johansson *et al.*, 1999; Osbourn and Smith, 1998). As a result it is unclear to what extent the findings reported by these studies might generalize

to a more heterogeneous pain sample, one which includes both men and women, and different diagnostic groups (i.e. both those with identifiable pathology as well as those without). More importantly, all these studies, with the exception of Hallberg and Carlsson (2000), offered what were essentially thematic analyses, i.e. multiple themes were laid out with little attempt to explicitly focus them around one superordinate theme. As a result there is little elaboration of how the themes might interrelate and which themes might be the more important in understanding pain-adjustment.

Two grounded theories which have been conducted are those of Hallberg and Carlsson (2000) and Charmaz (1987). However these have focused respectively on the experience of women with fibromyalgia and people with chronic illness in general and not specifically on chronic pain. In addition, perhaps unsurprisingly given the different patient groups they studied, these studies produced different core categories.

Hallberg and Carlsson's (2000) grounded theory summarized the experience of their interviewees as one dominated by pain. They labelled their core category "preoccupied with their pain" which they argued consisted of the three primary categories, labelled: 'subjective pain language', 'diversified pain coping' and 'pain communication'. *Subjective pain language*, as noted above, referred to the characteristics and perceived cause of the pain; *diversified pain coping* referred to what the women did and thought when in pain; *pain communication* referred to how people communicated their pain. This analysis clearly identified pain as the primary problem. In Charmaz's work, it was the threat posed to identity by chronic illness or 'loss of self' which emerged as the salient problem. The relationship between what people wanted to be and what there were able to be in light of the severity of their illness formed the basis of her core category. The identities they were able to attain through illness were categorized into one of four types:

- The 'supernormal' identity: an identity unaffected by illness and one characterized by 'extraordinary achievement in conventional worlds'.
- The restored self: an identity which reflected a return to pre-illness identities which had been placed on hold during a period of illness or adjustment to illness.
- The contingent personal identity: this was reflected in an expressed desire to return to pre-illness identities which were currently unattainable due to present illness, but which were considered possible in the future depending on the progression of the illness, and
- The salvaged self: an identity which is only partly made up of pre-illness identities, retaining some past identity (based perhaps on a valued activity or attribute still able to do or possess) but one which acknowledges that illness has resulted in physical dependency.

The present study aimed to develop a grounded theory whereby emerging themes are integrated into a theory which delineates what is termed a 'basic social psychological process' i.e. a theory that encapsulates the main 'problem' of people with pain and how they attempt to resolve this 'problem'. This was done in order to provide an integrated set of themes, rather than produce another list of themes (as in previous research), and hence provide a framework for future investigation through the presentation of a set of interrelated theoretical concepts which can form hypotheses to be tested. It also aimed to generate concepts which relate to the concern of chronic pain sufferers and see whether the concepts used in the previous study are ones worth pursuing in chronic pain research. Consistent with this aim, a mixed group of chronic pain sufferers were interviewed. They were not restricted to those with little or no identifiable organic pathology, and both men and women were included. The aim was thus to present an account of pain experience which cuts across gender and pathology to

determine common aspects of pain experience and more generally applicable pain meanings.

6.3 SYMBOLIC INTERACTIONISM

Grounded theory, the analysis used here, is based on the more general approach entitled symbolic interactionism. Symbolic interactionism (SI) draws its name from the emphasis it places both on the symbols people use to convey meaning and on the use of these symbols in action and interaction. It is an approach which is credited to Mead (e.g. 1967) and Blumer (e.g. 1969), who are regarded as two of its founding fathers.

Symbols are defined as things that can stand in for other things and because language is conceived of as a system of symbols, it plays a key role in SI theorizing. The ability to think and the role of language are both seen as central to human action because language offers an abstract mode of representation and the ability to think offers a way of manipulating these symbols. Because people are able to think before acting, they are seen as guiding and constructing what they do, rather than just releasing behaviour in response to external or internal forces which are essentially beyond the individual's control. As a result, people are seen as acting predominantly on the basis of their interpretations of the meaning of their own actions and those of other people. Charmaz (1990), for example, summarizes the symbolic interactionist approach as one which "assumes that human action depends upon the meanings that people ascribe to their situations" (p.1161)

One key proposition of the SI approach is the belief that the meaning of a given act, or a given object, is *not* fixed. Hence the meaning of something, whether it be an act or an object, does not reside within the thing itself (e.g. within pain) or within the person perceiving it (e.g. in whether they are flexible goal adjusters or not), rather the meaning is 'read off' the object by the individual person. Hence the individual plays a role in interpreting the meaning of something. To quote Blumer (1969):

> "The nature of an object ... consists of the meaning that it has for the person for whom it is an object" (p. 350).

Symbolic interactionism therefore focuses on subjective meanings because it recognizes that people are able to modify or alter the meanings of the symbols that they use. The meanings of symbols are therefore regarded not as objective and universal but as to some extent individual and subjective. As Ritzer (1992) puts it:

> "socialization is not simply a one-way process in which the actor receives information, but is a dynamic process in which the actor shapes and adapts the information to his or her own needs" (p. 349).

6.3.1 The work of Herbert Blumer

Herbert Blumer is perhaps the person most closely associated with the foundation of symbolic interactionism, being responsible for coining the term and laying out the way in which this perspective could be carried through to a research methodology. Blumer argues that the meanings of things vary according to the perspective of the person, but also that:

> "The contention that people act on the basis of the meaning of their objects has profound methodological implications. It signifies immediately that if the scholar wishes to understand the action of people it is necessary for him to see their objects as they see them" (p. 50-1).

Hence symbolic interactionism offers both a different way of understanding behaviour and a different way of studying it.

The methodological programme that Blumer lays out not only reflects this different approach to research it also reflects one of his central concerns: the gap between theory and data. As a sociologist his principal concern was that much theorizing was divorced from the empirical social world it was meant to relate to. He argued that:

> "No theorizing, however ingenious, and no observance of scientific protocol, however meticulous, are substitutes for developing a familiarity with what is actually going on in the sphere of life under study" (p. 39).

Hence he proposed that theoretical concepts should be developed through a close association with the social world. Blumer (1969) defines the social world as:

> "the actual group life of human beings, it consists of what they experience and do, individually and collectively, as they engage in their respective forms of living" (p. 35).

He argues that close inspection of this world could be used to generate theoretical concepts, stating that:

> "The research scholar who engages in direct examination should aim at casting his problem in a theoretical form, at unearthing generic relations, at sharpening the connotative reference of his concepts, and at formulating theoretical propositions. Such analysis is the proper aim of empirical science, as distinguished from the preparation of mere descriptive accounts" (p. 43).

Hence symbolic interactionism differs from traditional empirical approaches usually adopted in psychology in that it does not subscribe to a causal mechanical view of human behaviour. It does not seek to predict behaviour, but to understand it. Hence, how people react to things such as illness is not conceptualized as 'caused' by factors in a deterministic manner, such as the level of symptom severity. Rather, people are seen as responding to circumstances, such as chronic illness, according to what that illness means to them in the context of their lives and which emerges through their interaction with other people. Hence within this framework pain would be seen, not as something which by its very definition is aversive, threatening, and/or depressing, but as something that is open to interpretation by the person experiencing it.

However, the understanding of this interaction should be distinguished from the meaning of the term interaction when used in the statistical, quantitative sense. This latter sense still refers to a deterministic account of meaning, stating perhaps for example, that people may only get depressed as a result of having pain if the pain is above a certain level. Rather, the symbolic interactionist perspective puts the emphasis not on objective quantities of something but on personalized meanings. An additional, but equally important point, is that meaning is understood in a very different way by

symbolic interactionists as compared with traditional empiricists. As mentioned above, the account given by hermeneuticists is that meaning is constituted through social action. Action is therefore seen as something which lies at the heart of meaning rather than being something that exists outside of it: meaning is constituted through social action. Hence, because it does not exist outside it, meaning does not play a causal role in determining behaviour, that is the cognitive appraisal of what something means would not be seen as preceding and causally determining the behaviour that followed.

6.4 GROUNDED THEORY

Grounded theory is an approach based on symbolic interactionism and appears to fulfil the kind of programme for research laid out by Blumer and outlined above.

It was developed by Glaser and Strauss (1967) and is a form of qualitative analysis which aims to develop theory from data which is collected through an engagement with the social world, attempting to understand things from other people's perspectives. Whilst both qualitative and quantitative *data* can be used to develop theory, it is a qualitative *analysis*, as it is done without the aid of statistical techniques.

Grounded theory differs from much traditional psychological work in that, although both are empirical, grounded theory attempts to approach the data without any pre-conceived theory. Hence the method of grounded theory differs from experimental psychology because it is inductive. In contrast to experimental psychology, therefore, it does not seek to test hypotheses but to generate them. However, the status of the knowledge that this method produces warrants discussion. Blumer, for example, argues that the aim of such a method, which proposes to inspect and explore data independently of any theory with the aim of developing concepts, should be to lead to as comprehensive and accurate a picture as is possible of the social world. However, such a view, which subscribes to the idea that the observer of data is unbiased, has of course been challenged.

6.4.1 Criticisms of induction

Inductive methodologies have been criticized for their assumption that observations can be theory independent and that the observer can see 'data' in an unbiased theory-neutral way. Instead it has been argued that observations are typically theory driven and that observation necessarily involves prior judgements about 'where to look' (Chalmers, 1982). For example, in exploring what determines the boiling point of water, people already 'know' that factors such as atmospheric pressure are important and that the colour of the beaker containing the water is not. Hence, unless the observations which are made are infinite in number, they must be based on some prior theory.

Grounded theory was initially set up as an inductive method and the belief in bias-free observation was apparently endorsed by the assertion that no existing theory on the topic under investigation should be read prior to doing the research. The practise of developing a grounded theory therefore attempted to guard against a theoretically pre-determined understanding of the data being collected by advising that no substantive theories relating to the particular area under investigation should be read beforehand (e.g. in this instance that would be other theories about pain), thereby attempting to ensure that the data collected is not simply 'read' in the terms of a prior theory.

However the idea that any data interpretation could occur uninfluenced by pre-formed concepts seems unsustainable. In the first instance, it is unlikely that people investigating an area will not have read other theories in that area, and secondly, people from different disciplines will have different broad theoretical concepts in mind as a result of their training which may colour their reading of the data. In a paper on this issue, Charmaz (1990) has argued that the grounded theory method necessarily involves the investigator in an act of data interpretation and that this will be influenced by the investigator's academic background e.g. whether they are a sociologist or a psychologist. Hence the reporting of a grounded theory analysis ought to include a declaration of which academic perspective this theory has effectively been developed

from (e.g. psychological, sociological etc.). In addition she argues that whilst some criticisms of the grounded theory approach stem from misunderstandings, arguing for example that:

> "delaying the literature review decreases the likelihood that the researcher will already be locked into preconceived conceptual blinders upon entering a field and in interpreting the data" (p. 1163).

She concedes that a grounded theory analysis involves the researcher constructing a theory rather than 'discovering' one and states that the process of developing concepts is:

> "dialectical and active, rather than ... given in ... reality and passively observed by any trained observer" (p. 1165).

Hence the theorist is seen as active rather than neutral "whose decisions shape both process and product through research" (p. 1165).

6.4.2 The aim of Grounded Theory

Grounded theory uses data to develop new theoretical concepts and the relationship between those concepts. A grounded theory can be either a substantive or a formal theory, where substantive theory aims to give an account of one area of life (in this case the experience of chronic pain) and formal theory offers an account which extends across various different domains.

The aim of the present study was to develop a substantive theory relating to chronic pain and to develop a theory that encapsulates the main problem of people with pain and how this problem is resolved. It is this process of how people deal with their particular problems which constitutes a basic social psychological process. This basic process, once identified, is what constitutes the 'core category' and the development of this category is the primary aim of grounded theory. As Glaser (1978), and Glaser and Strauss (1967) state, a core category needs to be a:

"relevant theoretical abstraction about what is going on in the area studied" (Glaser and Strauss, 1967; p. 23)

"The goal of grounded theory is to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved." (Glaser 1978; p. 93).

6.4.3 The method of Grounded Theory

Grounded theory is based primarily on the process of induction, whereby data collection both precedes, and forms the basis of, the development of a theory. This theory is the product of two processes:

a) the generation of conceptual categories and their conceptual properties, and

b) the development of hypotheses or generalized relations among the categories and their properties.

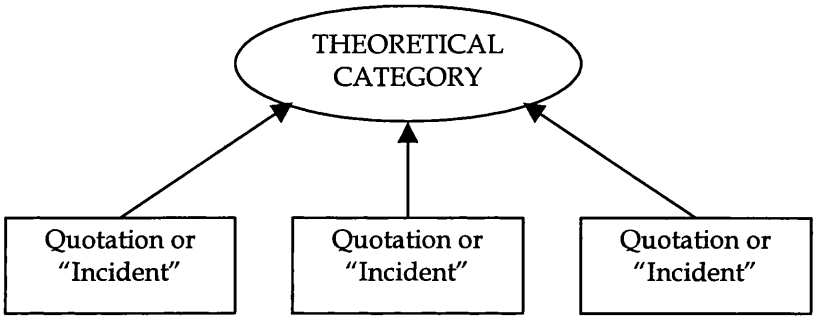
These two processes lead to the development of the 'core category' and the stages involved in developing the core category are: open coding, theoretical sampling and memo writing.

The development of categories

Categories are developed by the method of 'constant comparative analysis'. This method is carried out by comparing incident to incident within and across interviews. Through this process commonalities among incidents will be observed and these are given theoretical codes. This is the initial stage of data analysis and is referred to as '**open coding**'. These theoretical codes reflect the concepts that the data are viewed as indicating. Certain incidents will be seen as indicting a particular concept, such as 'coping efforts', and these will form the basis of a category (see Figure 6.1). As a category emerges in this way, incidents are also compared to the category in order to extend the properties of this category. These properties represent the different meanings people ascribe to the category, e.g. they might be the different coping efforts that people

perceive are necessary in order to cope with pain.

Figure 6.1: A diagrammatic representation of the relationship between what people say and the theoretical category to which these quotations are seen to relate



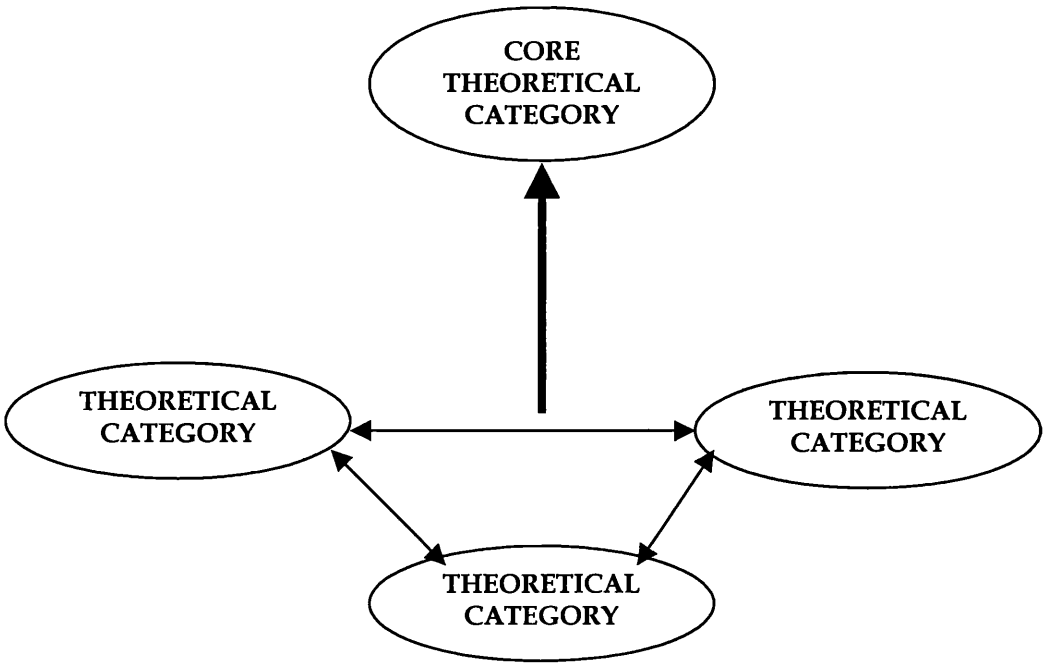
Once categories have become established in this way, the next stage of '**theoretical sampling**' is adopted whereby these categories are actively explored by the researcher in order to make sure that they are fleshed out as much as possible. This stage is considered to be a process of deduction and is used as a means of gaining as diverse a range of meanings as possible. In this stage the already induced categories are used as conceptual guides as to where to go next in order to elaborate and saturate the theoretical concepts, that is, it is used to decide which issues should be explored within subsequent interviews and/ or which groups of people should be interviewed. For example, if it emerged that there was a relationship between age and coping efforts, then people of different age ranges would be sampled in order to fully explore this relationship, and hence saturate the properties of the category relating to coping efforts. Whilst this process is referred to as a deductive process, it is used as way of checking on the emerging conceptual category rather than as a way of verifying pre-conceived hypotheses. Hence theoretical sampling looks for what could be or is the case, not for what logically ought to be the case and hence still leads to results which are grounded in the data. This stage of data collection continues until no new meanings emerge and the

categories are considered to be 'saturated'.

The final process in the development of a grounded theory relates to the comparison of the categories that have been developed in order to find the most abstract category that seems to form the central process being indicated in the data i.e. the core category. This process of developing the core category is primarily achieved through the **'writing of memos'**. These are comments written by the researcher throughout the data collection and analysing process about what the categories seem to refer to and how the categories that are emerging seem to inter-relate. All the categories are compared with each other in order to assess the most abstract level, i.e. the level which all these concepts seem to point when they are considered altogether. It is this final higher level concept which forms the core category (see Figure 6.2).

The grounded theory method therefore involves breaking the data down into small chunks or categories and then building it up and it is this process of breaking down and building up which potentially enables unexpected relations to emerge.

Figure 6.2: A diagrammatic representation of the relationship between categories and the core category



The core category is the one which represents the resolving, solving or processing of the problem within the particular domain. However it may be the case that two potential core categories emerge. If so, then two theories are written up, one around each of the core categories and only those categories which relate to the core cateory are written up as part of the theory.

It should be noted that the terminology and analysis used here to describe the different aspects of grounded theory analysis follows from the original formulation of grounded theory as described by Glaser and Strauss (1967) and Glaser (1992). There is another, altered formulation of grounded theory (Strauss and Corbin, 1998) but the original methodology and terminology is used here because this has been argued to have a more coherent logic underpinning it (Rennie, 1998), centering on the process of induction rather than verification.

6.4.4 Evaluating a Grounded Theory

The differences in approach between grounded theory and traditional empirical psychology are important in terms of understanding how a grounded theory is to be evaluated. Because it uses the method of induction and is a historical-hermeneutic form of analysis, rather than using a hypothetico-deductive method (Habermas, 1988), terms such reliability, validity and generalizability have different meanings. Hence, grounded theory is evaluated in a different way from traditional empirical psychological work.

Reliability

Within the context of hypothesis testing, reliability means that the result of a given study is not just due to chance (i.e. is replicable) and will not change over time (i.e. it is stable). Hence another researcher ought to be able to repeat the study and produce the same result. In contrast, grounded theory seeks to explore the best account of the data collected and involves interpretation by the researcher. However, this interpretation is one which must be grounded in the data, hence given the same data, a

researcher familiar with grounded theory ought to reproduce a similar, though not necessarily identical, theory. The findings of any grounded theory are *not* assumed to be ones that will be stable over time, i.e. ahistorical. The perspective upon which grounded theory is based is a historical one, and assumes that meanings are constantly in flux and are likely to change over time. Hence reliability is not a key issue in this approach, rather, the central issue is whether the theory is sufficiently grounded in the data and hence is a *credible* theory, a notion which will be discussed in more detail shortly.

Generalizability

Generalizability refers to the fact that the sample studied can be taken to be representative of a given population, and hence the results of the study can be generalised from the sample to the population the sample is seen to represent. Grounded theory seeks to attain as much diversity as possible in terms of the meanings people ascribe to a given experience. Hence the issue is not whether the sample can be seen as representative of a population, but whether it adequately demonstrates diversity of meaning. The latter is assessed via alternative criteria discussed below. However, a related issue is the implication these different criteria have for the issue of sample size. Grounded theory seeks to generate abstract conceptual categories, and whilst these are based on empirical facts, they are not reducible to them. Empirical facts are seen as indicators of a category. It is the meaning of these indicators, and the category that they indicate, which is of interest in grounded theory. The purpose of gaining more cases (people) is to discover the variation in the category. Hence, once no new meanings emerge within a given category, that category is considered 'saturated'. So although interviewing a different set of people may, for example, result in different accounts of how the pain had affected them, for example, i.e. produce different indices, the concepts that these accounts indicated would not necessarily change. In addition, if different accounts did lead to different concepts, if the theory is sufficiently grounded in the data, the most that should happen in the face of new facts is that the theory should require

modification. Hence further participants should at most point out modifications to the theory rather than point to a substantially different theory.

In contrast to the criteria of reliability and validity, Glaser (1992) argues that grounded theory needs to meet the alternative criteria of: fit, work, relevance and modifiability, where fit means "will fit the realities under study in the eyes of subjects, practitioners and researchers in the area" and works means "it will explain the major variants in behaviour in the area with respect to the processing of the main concerns of the subjects" (Glaser 1992, p. 15). If these two criteria are met, Glaser argues the theory will also have achieved relevance. In addition, he argues that grounded theories should not be written in stone but modifiable to incorporate new data

> "accurate description and verification are not so crucial when one's purpose is to generate theory. This is especially true because evidence and testing never destroy a theory (of any generality), they only modify it. A theory's only replacement is a better theory" (Glaser and Strauss, 1967; p. 28)

> "The credibility of the theory should be won by its integration, relevance and workability, not by illustration used as if it were proof. The assumption of the reader, he should be advised, is that all concepts are grounded and that this massive grounding effort could not be shown in a writing. Also that as grounded they are not proven; they are only suggested. The theory is an integrated set of hypotheses, not of findings" (Glaser, 1978; p. 134; emphasis in original).

6.5 AIMS

The present study aimed to explore people's experience of having chronic pain and to develop a grounded theory from this.

6.6 METHOD

6.6.1 Participants

Chronic pain was defined as present if it was linked to a benign condition, was ongoing and had persisted for more than 6 months despite medical treatment. The other

inclusion criteria were:

- No visual and/or auditory problems
- An ability to read and write English
- Aged over 18 years.

Twenty-two pain sufferers were recruited from the Outpatient Pain Clinic at Northwick Park Hospital. This number of subjects is comparable with numbers used in previous qualitative work on chronic pain (Hallberg and Carlsson, 2000; Johansson *et al.*, 1999) but more importantly is determined by the issue of saturation whereby data collection ceases once no new meanings emerge. The study was approved by the Institutional ethical committee and all participants gave written, informed consent (see Appendix D).

6.6.2 Design

The current study used interview and questionnaire methodologies. The latter were used primarily to gain participant details, they were not used in the grounded theory analysis.

6.6.3 Materials

Pain measures:

i) Four 101mm Visual Analogue Scales of pain intensity: present pain, average pain over the last week, worse pain over the last week and least pain over the last week. They were anchored 'No pain'/'Worst pain imaginable'. (See Appendix A.)

ii) Details of whether the pain was continuous or intermittent, its chronicity in years, its location and whether they took medication for their pain or for depression.

Depression measure: short form of the Beck Depression Inventory (BDI; Beck *et al.*, 1979). (See Appendix D.)

6.6.4 Procedure

Ideally when developing a grounded theory, the interview would be as open-ended as possible, in order to allow people to discuss any aspect of pain experience they felt was relevant, and hence allow a theory to emerge unforced by a prior agenda. However, due to ethical constraints, participants had to be given information about what the study involved prior to participation. Hence they were informed that the study concerned the effect pain had had on their lives (see Patient Information Sheet, Appendix D). Participants were given the following instructions verbally prior to the start of the interview:

> "This is a study about people's experience of having pain. I'll be asking you to talk about what your experience of having pain has been. Because it's about your experience, there are no right or wrong answers, I just want to know what having pain has been like for you. Also, I'll be expecting you to do most of the talking. There might be things that you say that I'll want you to explain in more detail, if so then I'll ask you to elaborate on that topic. Do you have any questions? OK, so can you tell me about your experience of having pain."

Interview time was limited as participants were seen at the Pain Clinic had to attend their medical appointment in addition to taking part in the study. Hence interviews ranged from 20-60 minutes, with the average being approximately 30 minutes long.

6.7 RESULTS

Demographic details of the participants and their scores on pain and mood measures are shown in Table 6.1. As can be seen from this the majority of participants were women, had pain located in their lower back and/or legs, reported that the pain was always present (continuous) and took medication to try and control the pain.

The interview data was transcribed and it was coded using ATLAS/ti version 4.1. for Windows. It was analysed using the constant comparative method as discussed above in section 6.4.3.

Table 6.1: Characteristics of participants

Age in years Mean (SD)	55.68 (17.42)
Sex (% female)	71%
% using medication for pain relief	82%
Chronicity (years of pain) Mean (SD)	12.23 (16.33)
Primary Pain Site	Head 7% Neck 4% Chest 4% Lower back and legs 39% Legs 25% Multiple sites 21%
Present pain intensity (0-100mm scale)	48.86 (27.64)
% with continuous pain	86%
BDI scores (short form) Mean (SD)	9.79 (5.95)

6.7.1 Analysis

6.7.1.1 Aim of analysis

The objectives of the analysis were explicitly exploratory. As noted above in sections 6.4.3 and 6.4.4 grounded theory is based on symbolic interactionism and hence the focus is on identifying and outlining the *diversity* of understanding that is expressed by participants. That is, it is the range of meanings the pain has, the range of difficulties it might produce, and the range of ways people interpret and deal with it that is of interest. As a result, interviews are conducted with a minimum of prompting or imposition of theoretical concepts by the researcher, and the interview is naturally occurring conversation, only loosely guided by the interviewer. The data is therefore not

the product of the administration of standardised interviews, hence, no claims can be made about the frequency with which particular problems emerge and there is therefore no firm basis from which to state the proportion of the sample understanding a particular aspect of pain in any one way, as people may have discussed different aspects of their experience of pain. The analysis is therefore not a content analysis and no attempt at quantification of responses is made as this could potentially be misleading. The objective of a grounded theory is not to establish *how many* participants understand pain in a particular way or experience certain things as a result of pain, but to demonstrate *the range of meanings* that pain can have.

6.7.1.2 Coding package

The interviews were transcribed in full and coded using the software package for qualitative research, Atlas/ti (version 4.1). This package allows the researcher to create and attach codes to lines of text and to write memos which can either be attached to specific codes or remain 'free', i.e. unattached to particular codes. Text relevant to more than one category can be given multiple codes. All instances of text relating to a particular code within and between interviews can be easily compared, enabling the constant comparative method which forms the basis of grounded theory methodology to be carried out. Different quotes relating to the same topic or concept can be compared for variability between responses and respondents, and in this way, finer distinctions can be drawn and new codes created.

6.7.1.3 Use of individual data (quotes)

All interviews were coded, and all contributed to the list of open codes developed. No participants were excluded from the analysis. Consistent with the aim of grounded theory, quotes are used as illustrations of the different meanings that have been discovered in the analysis. Quotes used within the grounded theory itself (section 6.7.3) are chosen:

i) for their clarity in illustrating the relevant issue which is being outlined (i.e. the clarity with which they convey a certain meaning relating to the experience of pain),

ii) to illustrate the range of different meanings which fell within each of the subcategories, and

iii) to cover the range of participants interviewed.

A selection of individual quotes (covering the full range of participants) and how they relate to the open codes that form the basis of the grounded theory are listed in Appendix E. This is offered to demonstrate the face validity of the open codes. Typically, one to two quotes per code are given to allow the range of participants to be covered. Not every quote relating to a given code is shown and no frequencies of occurrence of the quotes relating to each code are given, for the reason noted in section 6.7.1.1, and should not be read as though it is demonstrating the *frequency* with which certain themes emerged (see section 6.7.1.1).

6.7.2 Development of the grounded theory

6.7.2.1 The development of categories: open coding

The development of a grounded theory began with interviewing participants and coding the interview data using the technique of 'opening coding'. This involves comparing statements both within and across interviews to look for common themes, which are then coded: a method termed constant comparative analysis. The aim is to develop theory from individual accounts of experience and therefore involves developing concepts derived from people's accounts, i.e. developing a set of 'second-order constructs' from people's descriptions of their experiences (termed 'first-order constructs'). The conceptual categories that are developed from open coding seek to describe the basic social psychological problem faced by the participants, and how this

problem is resolved. For example, having to do things more slowly emerged as a concern for some interviewees and was assigned open codes which reflected the particular activity or activities each participant mentioned, e.g. the code 'slower walking' was attached to instances where participants mentioned the pain resulted in this problem. Together, codes can be seen as indicating superordinate constructs, such as 'speed'. The latter in turn signifies higher order concepts. For example, the significance of the change in speed with which people could do things was seen here as indicating a fundamental shift in people's relationship with their environment (which formed the first primary category 'private experience'), and also as indicating the more superordinate construct 'a change to normal life', because doing things more slowly meant they could not take part in activities in the usual way. Hence, even in the initial stages of coding (open coding) the codes being generated are ones which are seen as indicating concepts which can describe the basic problem people are dealing with and how this problem is resolved.

Due to this focus on a single, albeit, abstract problem, not all codes necessarily end up relating to the core category. Whilst the core category is meant to integrate as many codes as possible, sometimes codes emerge that do not relate to the core category, but possibility relate to a different core category. As only one core category should be described in any one grounded theory, codes which do not relate to the core category, are left out. In the present theory the codes which formed the basis of the core category related to the consequences of pain rather than the pain *per se*. Hence whilst there were accounts in interviews of how the pain felt (labelled: 'pain description'), what participants thought was causing their pain ('pain explanation'), what treatments participants were currently taking or had tried in the past ('pain treatment') and how the pain began ('pain trajectory'), these codes are not included in the current theory. This was because, following the first few interviews after which theoretical sampling began, it became apparent that the key problem concerned the constraint imposed by pain rather

than on the pain *per se* and hence these codes did not play a central role in the theory. Such codes may form the basis of a different grounded theory. Indeed the grounded theory offered by Hallberg and Carlsson (2000) centres around themes similar to those listed above. For example, they discuss how the pain feels ('pain description'), what their interviewees believed caused it ('pain explanation') and what treatments people used to cope with it (of which 'pain treatment' may form a part). In the present study whilst codes relating to pain, its explanation and treatment emerged, they did not form a central part of the theory. The relationship between the initial codes and the final categories is shown in Appendix E.

6.7.2.2 Theoretical sampling

Theoretical sampling refers to the process of 'guided' data collection. In grounded theory, data collection and data analysis occur simultaneously. As the analysis develops and codes and categories are produced, theoretical sampling is used to 'saturate' the categories by attaining as wide a range of meanings as possible concerning each category. This involves more directive data collection which can occur either through the deliberate choice of participants who might be expected to give different accounts from those already collected and/or through more focused questioning about particular issues. In the present study theoretical sampling was used in both these ways, firstly by seeking out interviews with a wide range of participants: those with different sites of pain, men and women and people of varying ages. In addition more focused questioning was used around the concepts as they emerged, and both of these strategies were used to develop all four of the primary categories. For example, in the category concerning challenge to identity, it emerged that activity restriction was not always an inevitable consequences of having pain, but was sometimes a strategy which was used to avoid projecting an identity the participant considered to be undesirable. Focused questioning was therefore used to ascertain what types of activities were restricted. Through this, it emerged that activity restriction could sometimes (though not always)

be perceived as affecting one's identity. Theoretical sampling therefore took the form of asking people in subsequent interviews whether a) they saw themselves as different now compared with before the pain, b) whether they felt other people saw themselves as different now compared with before the pain, and in what ways. In addition they were asked whether they ever avoided certain activities, places or people and to give examples of what type of environments and people they might avoid in order to explore the conditions under which such deliberate activity restriction would occur.

6.7.2.3 Theoretical development: from categories to a core category

The core category is meant to relate to a key problem and how it is resolved, and this category is indicated both by the principal categories and the open codes. The coding and development of categories and core categories is an interrelated process with open coding informed by the goal of developing conceptual categories. The way in which the grounded theory developed was as follows, and the full theory is outlined in section 6.7.3.

1) First stage of theory development: activity restriction emerges as a key complaint and the effect of pain on fundamental aspects of action forms the basis of the first category.

An inability to do the things that they wanted to do was a frequent complaint of chronic pain patients, and formed the basis of the first two conceptual categories that were developed. An inability to do things applied to a large number of activities, from housework, to social activities, to simple everyday actions (e.g. lifting cups of tea). The effect of pain on the ability to perform larger scale activities such as work and social activities is well-documented, however in the development of conceptual categories consideration has to be given to what such activity constraint signifies or means to the individual participants. In the interviews conducted here, the complaint that pain affected people's ability to do things which were often described as 'simple', or things

they would not previously have had to think about, was notable. The restrictions in activity caused by pain appeared to indicate fundamental changes in the way people could interact with their environment. A concept was therefore developed to reflect this effect of pain. The category was termed changes in 'private experience' and it was considered to have three properties: the speed with which people could move about and get things done, the access they had to spaces notably where they could socialize, and the ability to act without thinking. These three elements emerged in people's accounts of their experience and more importantly signified their sense of difference from others. This category was therefore seen as indicating the challenge to taken-for-granted or 'normal' aspects of life which became part of the core category.

2) Second stage of theory development: the effect of activity restriction on identity forms the basis of the second primary category.

The implications, or meanings attached to activity restriction (not being able to do certain things, or do them competently) affected people's fundamental relationship with their environment (as documented above) and also affected their identity: how other people saw them and how they saw themselves. This implication of activity restriction was recorded in a memo labelled Activity I.

MEMO: Activity I

> "The principal complaint seems to be that they 'cannot do what they want to do'. Managing this challenge appears to be a key feature of coping with pain. However not being able to 'do' may not literally refer to whether they can do something but whether they can do it 'competently', i.e. it relates to identity and presenting oneself in the way one wishes to."

Hence activity restriction often resulted in challenges to people's identity. The fundamental changes, documented in the first category, also played a role in people's perceptions of changes in identity. That is, not being able to do things without planning

ahead, not being able to do things quickly or spontaneously were viewed by some participants as challenges to who they were as people. Such challenges appeared to be illustrated largely through people's reference to the changes that had happened to them which were 'reflected back' at them, for example, in terms of other people's reactions to them, or their own inability to do things in the way they used to. A concept was therefore developed to describe the effect of pain on identity. The properties of the category were the different modes of reflection: the actions and judgements of others, one's own ability to do things, physical changes that accompanied chronic pain, and one's surrounding environment.

As with the primary category changes to 'private experience', challenge to identity also indicated ways in which pain could lead to a challenge to taken-for-granted or 'normal' aspects of life, in this case taken-for-granted abilities and associated identities.

3) Third stage of theory development: the concept of constraint on leading a normal life is developed as the key problem and therefore part of the core category.

A grounded theory is meant to account for a key problem in the area being studied and how this problem is resolved. As noted earlier, a key problem that emerged for participants in this study was an inability to do the things that they wanted to (activity restriction). Hence initially, activity restriction was viewed as a potential core category as this was a key complaint of the participants, however it did not seem to sufficiently capture the fundamental challenge to the everyday world (the taken-for-granted), and the effect it had on people's ability to 'be' who they wanted to be, that also emerged in people's accounts. Hence the more abstract concept of 'constraint' was developed as this was thought to more adequately encompass all of the above. Furthermore, the focus of this constraint was considered to be more abstract than simply not being able to do certain things. Along with the considerations for the use of the

broader term of constraint rather than simply activity restriction noted above, the *object* of this constraint was similarly broad. Constraint on being able to conduct a normal life was chosen as again it was thought to encompass the central themes which emerged in participants' accounts: these included the challenge to taken-for-granted or 'normal' aspects of life such as dressing and moving, the sense of social isolation and of occupying a different world that was noted, the failure of others to understand their experience, the use of strategies such as activity restriction to maintain a 'normal' appearance and prevent people from attributing their reduced abilities in walking (for example) to their being drunk or old. This constraint was therefore considered to be a constraint on 'normal life'. To reiterate, the concept of constraint on normal life was identitifed as the core problem in the present theory for two main reasons. i) A number of incidents were viewed as indicating the concept of a challenge to normality (noted above). Both the two primary categories outlined earlier, and their individual codes, were seen as indicators of a challenge to things which had previously been taken-for-granted or 'normal', ii) the concept of a constraint on leading a normal life integrated the major themes which emerged in the interviews: including both the challenges presented by pain, and the way people coped with these restrictions, as coping efforts were often aimed explicitly at regaining or maintaining pre-pain ways of life. For example, it was clear that for some people maintaining pre-pain identities or appearing to be without a disability, was an important goal, (this is outlined in more detail in below). Although for others, a new, altered way of life had had to be embraced: that is standards of what was normal for them had had to change. This was recorded in a memo labelled Normality.

MEMO: Normality

"Maintaining normality in i) appearance and/or ii) in daily actions appears to be an important goal. People want to get back to what they were before the pain began or at least some way back to this. For those who cannot get back to doing what they were able to do before there is clearly a process of 'normalization' of their altered activities: accepting that things could no longer be done and accepting new standards of 'normality'. For some the changes were viewed as things that might have happened anyway (regardless of the pain – e.g. as part of growing old which would have happened at some stage).

4) Fourth stage of theory development: the concept of evaluating the impact of pain is developed.

The process of comparing oneself to others and to one's former self was a salient feature of people's accounts of their experience of pain. Whilst there were numerous comparisons that people made, for example, with people they knew and with their pre-pain selves, this process of comparison was seen as indicating how people evaluated the impact the pain had had on what they would normally be doing if it were not for the pain, or what they would like to be doing. Hence although this category indicated the changes that had occurred as a result of the constraint brought about by the pain, and is therefore similar to the two primary categories outlined earlier, the process of drawing comparisons between oneself and others is viewed here as a conscious appraisal of the significance of the changes, and as providing an answer to the question 'has the pain changed what is normal (for me)?'.

5) Fifth stage of theory development: restriction in activities emerges as a way of coping with challenge to identity.

There was variation in the degree to which pain imposed a constraint on normal life, and there was also variation in the way people responded to this constraint. In the present theory, activity restriction formed the basis of the central problem of pain.

However it became apparent that some people deliberately restricted their own activity and that whilst this was sometimes done to manage levels of pain intensity (see stage 6), and keep pain at a minimum, sometimes it was done to manage identity. The conditions under which this type of deliberate activity restriction tended to occur and a number of issues central to this activity restriction as a form of coping emerged. These included the non-acceptance of the limits imposed by the pain, the avoidance of 'disabling' environments, i.e. environments which served to highlight or accentuate people's inabilities to do things, and avoiding activities where the 'audience' witnessing these would be unaware that the person had pain and would therefore be particularly likely to interpret their actions as indicating old age or disability. For example, public environments were often avoided as strangers/ acquaintances would be unlikely to know the 'reason' for their difficulties in doing particular activities. This type of deliberate activity restriction was principally aimed at manage the meanings of their actions to reduce the appearance of disability and thereby reduce the impact of pain on their identity. Hence the main focus of such coping efforts were at coping with the challenge to identity rather than controlling pain intensity *per se*.

MEMO: Activity II

"Activity restriction is not just a consequence of pain. People give up or reduce activities because they do not want to appear disabled or old. The restriction of activity often differs according to the 'audience' who might witness certain actions. Public activities are more likely to be restricted because the pain is invisible and the 'reasons' for the person being unable to do certain things, such as walk, may be attributed to undesirable characteristics such as being old or appearing drunk."

6) Sixth stage of theory development: different ways of coping with the constraint of pain are developed.

A clear line of difference that emerged in people's response to the constraint associated with the pain was the degree to which the constraints were accepted. Some

people accepted the constraints imposed either because the constraints were perceived to be minimal or because pain levels were too severe. In the former case normal standards could be maintained perhaps with some help from other people, whereas in the latter case, normal standards might have to be downgraded or altered in some way, perhaps by substituting activities that could not be done with activities which could be done. The term *Accommodation* was used to reflect this acceptance.

The coping strategy outlined in the previous section reflected a non-acceptance of the constraints associated with pain and was labelled *Subversion* because this form of non-acceptance was non-confrontational. In addition, the focus of coping efforts were directed at trying to reduce the apparent/public impact the pain has had on their public identity. This was done without aggravating levels of pain intensity.

However a further response that emerged was that of *Rebellion* to the constraint of pain. This was characterized by a focus on doing things even though it lead to unpleasant pain flare-ups which people knew they would regret later, in an attempt to continue doing what they used to do.

MEMO: Adjustment

"Adjustment accepted: activity is modified, people do what they can within limits, this often involves an acknowledgement that certain things can no longer be done. People make the best of what they can achieve, and accept help from other people such as family, friends and paid help. Whilst they may not like the life changes that have occurred they realize they have little choice. These changes might be seen as ones where life is basically normal but slightly altered, such as slower than before, or involving different activities, alternatively, for some these changes may be viewed as a fundamental shift: now leading a different life in which news standards of what is normal are developed.

> "Adjustment resisted – pain is seen as an obstacle to living the life they want to live, and doing what they want to do. The pain has made them dependent on others, and has resulted in a loss of freedom, and an inability to engage in voluntary action. The pain affects all domains of life, work, housework, social life, sleep. They may become aware of their reflected self and angry at public misunderstandings e.g. being treated as invalid. Meanings directly challenged, refusal to be stigmatised, maintain personal pride regardless of others. This non-acceptance of problems of pain can involve deliberately doing things even though pain is made worse.

6.7.3 Maintaining 'a normal life' through the constraint of pain. A Grounded Theory.

One of the principal complaints of chronic pain sufferers related not so much to the pain itself as to the fact that it stopped them from doing the things they wanted to do. Whilst the type of activity that pain restricted varied, the inability to do simple, everyday, taken-for-granted activities such as carry shopping bags, put on socks and climb stairs, often caused as much frustration as the restriction of larger scale activities such as ability to work, go out socially and engage in sporting activities. Activities often had to be given up or took longer to do, however, these changes had a number of different implications: they meant that people were unable to fulfil their family or work responsibilities, they resulted in them letting people down, they affected people's perceived status as 'normal', for example, by affecting their ability to walk properly, and they led to feelings of stigma and social isolation. The coping efforts of those in pain were therefore often focused as much on maintaining a normal life as on directly minimising the pain, indeed, minimizing the pain was often seen as the most effective and direct way of getting back to normal. However, whilst efforts directed at managing this broader impact were sometimes consistent with reducing levels of pain, there were times when managing the pain and managing the life impact of the pain came into conflict. The degree to which pain presented a challenge to keeping life working normally and the way that this challenge was interpreted and met formed the core

category of the following theory.

Four principal categories emerged, the first related to changes in their private experience; the second related to their public experience of themselves and how people saw and treated them; the third related to how they evaluated the impact these changes had had on them; and the fourth related to how they dealt with these changes. All four categories related to the core category of maintaining normal lives and all four overlap and interlink with one another, reflecting the broader implications of the pain, the limitations it is perceived as producing and how people make sense and respond to these limitations.

6.7.3.1 Category 1: Private experience.

Chronic pain often affected people's private experience. This in turn affected some people's view of themselves (their private 'sense of self'), their place in the social world around them and their sense of difference from other people. Changes in people's private experience resulted from three principal changes brought about by pain: the speed at which they could do things, the space they were able to move around in and the experience of the mind and body as no longer working in synchrony. Such changes served to challenge some of the more fundamental aspects of life which they had previously taken-for-granted.

Whilst these changes were often the inevitable consequences of having pain, they were interpreted by pain sufferers in a variety of ways. Some took them as an indication that their way of life was fundamentally altered, others interpreted it as indicating a change but one which fell within the realms of normal life progression e.g. that they were getting older, whilst others did not see these changes as impacting on their sense of self in any way.

6.7.3.1.1 Speed at which things could be done

The presence of pain often meant that activities could only be accomplished if they were done more slowly than usual. For example, activities were done more slowly in order to prevent pain from increasing or from flaring up later. This slowing down was often communicated through feelings of occupying a different sort of world, but most commonly by a feeling of getting older.

> "Well I feel like an old woman whereas before I did not. I think it's as simple as that.....Because I creep about sometimes, I can hardly move. If I get out of bed at night and I creep about and I get out in the morning and I'm all stiff and sore and, it feels a struggle to get going. I just feel I've made myself prematurely old I suppose." (S18; 61 year old woman)

One participant communicated both of these senses:

> "I mean I've been active quite a long time and to sort of bring your life down to like a walking pace um (.) you go to do something that you normally wouldn't even think about or hesitate about doing and you end up in pain ..... You just, it's, you do just slow down basically, you know where, it's a bit like going on holiday, you go somewhere down on the coast and the lifestyle is a lot slower. You come back to London and you feel like everything's going past you at 90 miles an hour. So I mean it, it is the same feeling that where I've been going along doing what I would normally do, I've had to come down to sort of being down the coast and go slowly like. It does make you feel sometimes feel old" (S1; 39 year old man).

Such slowing down often meant that people could no longer engage in social and/or family events in the same way as before, with people around them automatically engaging in activities at a pace faster than the person with pain could manage. Hence these changes could contribute to a sense of isolation and exclusion.

> "my children will sort of say oh we can do this and that and I don't keep up with them when they walk. I'm the one lagging behind shouting at them saying what's the point of me coming with you if you're not going to wait" (S8; 52 year old woman).

6.7.3.1.2 The contracting social world.

Chronic pain could also result in greater spatial confinement, in extreme cases effectively committing people to their homes. Travelling of any kind became

problematic, whether it involved walking, or travelling by a form of transport, be it car, bus or train. The social spaces that one could gain easy and unconstrained access to therefore became limited. Keeping in touch with changes in one's surrounding environment became more difficult and everyday activities such as going out shopping and sitting out in the garden became restricted. Hence the opportunities for informal socializing with friends and neighbours often became reduced. All these changes resulted in what was effectively a contracting social world. As such, people reported experiencing a sense of social isolation, boredom and depression. This contracting world might be something that arose from not feeling up to going:

> "I've always been sociable, clubs and all that sort of thing but I didn't want to go when I had that pain..... Cos I always love to mix with people and you know I've got a lovely social life, but when I felt like that I didn't want to go." (S11; 82 year old woman)

Or fear of what might happen or go wrong if they did go out:

> "I go nowhere. I go nowhere only to the local shops, oh no, I go nowhere, nowhere at all, because I wouldn't go on my own. I would be afraid. And I wouldn't go out at night because I can't see, I wouldn't see where I was walking and if I (.) lost my balance at all I would go, so I wouldn't go out at night and I used to like going out at night." (S12; 80 year old woman)

Or actual disability (inability to move)

> "So now, as I explain to people, I live in a box. I can't get out unless somebody comes with a car to take me because I can't walk far enough. I get out of my box three times a day to get my meals. .....You never get any air, you never, I mean I knew such a lot of people round where I live, I never see them anymore" (S13; 84 year old woman).

"I mean lots of things that I would want to do I'm a sixth form tutor and they're going on an adventure weekend now I'm somebody who's done windsurfing parasailing, whatever, they're going to be doing those things over that weekend and when I said to the senior teacher organizing it well I would do something, I would love to go but will my ankle be able to cope with it, well he said bluntly no, so I'm going to be the only sixth form tutor not going on the sixth form weekend which again impacts professionally as well as the sheer frustration of not being able to do the sort of, that sort of thing that I would normally incorporate into most holidays or so sometimes your friends are going away, some friends were doing some paint balling and it was racing around and I can't run on it so I couldn't go with them paint balling .... it was daft things like not, if I fancied a mars bar and not being able to go out and get a mars bar and it was it was like being in prison and my house was actually my prison because I couldn't get out I couldn't even get in the garden you know," (S20; 49 year old woman)

"the way the pain has affected me is depression. The fact of not being able to do. I was always an extremely active person. I worked full-time until I was 68, did a secretarial job and I loved working, but once you stop that and you're children obviously leave home and life becomes terribly boring. At the moment it's infuriating to be honest (laughs) it's just me and my husband and it's the television and the newspaper and that bounds your life. That is one of the main problems" (S17; 79 year old woman).

6.7.3.1.3 The fractionating of mind and body

Pain presented a challenge to the performance of simple everyday activities and opened up a distinction between the mind and the body that for some did not exist before the pain. As one lady put it:

"in here (points inside) I want to do it here I want to do it (points to head) but down here it (points to body) doesn't let you do it anymore and I resent it" (S6; 54 year old woman).

Because action often resulted in pain flare-ups, actions suddenly had to be thought through in advance, as opposed to done first and thought about later. Hence whereas action largely proceeded automatically, i.e. without any conscious detailed planning, before the pain, this automaticity became challenged. This in itself was viewed by some as a fundamental shift in their way of life.

> "whatever I do I have to very be careful how I do it, what I do and how I do it. Sitting down, stand up walking, anything I do I have to think first then act. Like before you act first then think later but now I have to think first, how am I going to do it, then do it. It's like completely, my life is reversed, completely set back like I'm starting to live my life again trying to learn to live again just like I'm on a training programme" (S7; 41 year old woman).

> "I have to train myself with everyday stuff. It was hard at first because the pain started while I was pregnant, then after the baby, I was too busy to even think before I done something, like if I started rushing around, if I was late going somewhere I started rushing about and start, then I'd bend over without bending my knees or something, then I'd hurt it again so I think actually hurt myself helped me train myself better so I know if I rush around and bend down without thinking I'll hurt myself so I have to bend down then pick up something or pick my son up and bend my knees first. That was hard cos sometimes if they cry suddenly you just go and grab them you know and that way you sort of twinge it again so I've had to train myself so sometimes I don't respond as quickly as I could but then I know that I've responded in the best way, so that's one of the ways I train myself." (S22; 26 year old woman)

The very nature of this change in the ability to do things automatically meant that the more mundane activities of life could become ones which had to be concentrated on, such as getting dressed or washing one's hair. This could be seen as contributing to an increased focus on the more mundane and everyday aspects of life which in some instances contributed to a sense of loss of meaning in life and a sense of achieving very little. In addition, this change resulted in a loss of spontaneity which in turn could contribute to feelings of ageing.

This alteration in the relationship between thought and action could also signal an altered relationship between the mind and the body. For some it meant that the body was no longer something that could be taken-for-granted. This again was something that became noticeable for many people, as much through small-scale activities such as reaching out for things, hanging out washing, as for larger-scale things such as playing golf or dancing. However such a disjuncture between the mind and the body was not only experienced through an altered way of acting, with the two no longer working in synchrony and the body being seen as in some sense 'broken'. Sometimes the pain was

also seen as highlighting the distinction between mind and body through aspects of the pain which were seen as the most difficult to cope with. Whilst for some the mind was understood as willing while the body was unable, for others the central problem was the effect that the pain had on their mental state.

> "pain-wise I was able to control it quite well, you know and mentally as far as the pain was concerned I was able to control it very well, but mentally as far as my own self-being was concerned I, it was wrecked I mean I just, I got severely depressed" (S19; 39 year old woman).

6.7.3.2 Category 2: Challenge to identity

The concept of identity is complex and distinctions that have been made between different aspects of a person's identity are numerous (see Deschamps and Devos, 1998). Typically psychological researchers draw a distinction between social identity and personal identity because identity is thought to be based partly on similarity to a group or category (social identity) and partly on dissimilarity or idiosyncratic characteristics which are considered more unique and personal (personal identity). In this section of the grounded theory, identity is not considered explicitly along these dimensions. Instead the focus is on the perceived challenge to identity which here is seen to operate principally through the process outlined below: one which is termed the reflected self.

Following Mead (1967) it is assumed that people have multiple identities and that their identity may change according to the particular aspect of their lives being considered. Hence people may have different identities according to whether they are being thought of as a friend, a mother, a daughter, or a colleague, and so on.

Identities are also considered things that are flexible rather than fixed, and hence entities which are constantly being shaped. As Erikson (1956) (quoted by Strauss, 1997; p. 111) says, identity

> "is never gained nor maintained once and for all. Like a good conscience, it is constantly lost and regained".

Hence, in this chapter, identity is viewed as part of an ongoing process. Following Strauss (1997) identity is also understood as being something which is connected to appraisals of oneself, both those done by oneself and those that are perceived as done by others. The idea of mirrors and masks that Strauss puts forward as metaphors for understanding identity is a useful one for understanding the responses of chronic pain sufferers presented here. Strauss argues that people see themselves in the mirror of others' judgements. In response to this, people may chose to project a certain image, or, to wear a particular 'mask'. As Strauss argues:

> "The masks he then and thereafter presents to the world and its citizens are fashioned upon his anticipations of their judgements" (p. 11).

Hence a dynamic relationship exists between the image one attempts to project, one's sense of identity as reflected back in the judgements of others, or 'mirrors', and the efforts one makes to continue projecting the image or deciding to project a different image or 'mask'.

The term 'reflected self' is used here to refer to anything which is perceived by chronic pain sufferers as indicting their identity or sense of self, that is anything which is perceived as reflecting back who they are as people. The different properties of this category were the different ways in which identity or sense of self could be reflected back.

6.7.3.2.1 Modes of reflection

The identity of chronic pain sufferers could be reflected back in a diverse number of ways: in the actions and judgements of others, in their own ability to do things, in the physical changes that often accompanied chronic pain, such as weight gain, and in their surrounding environment. For example, the inability to do housework may be reflected back in the standard of cleanliness of the house pain sufferers live in. Examples of identity being reflected back in the reactions of others included people's comments on the pain sufferer's appearance:

"he goes what's the matter Mum you look really upset but I don't feel upset it's just the way I must look, it must alter my appearances which I know it (the pain) has done" (S6; 54 year old woman).

or through comments on their actions:

"I mean few weeks ago, isn't it, come round I was supposed to clean all the biological filters and all that, and I'd been sitting there gearing meself up, oh I'll go out in a minute and it was cold as well like. I'll go out in a minute. He turns up he says ain't you done it yet?" (S1; 39 year old man).

Or through comments on a change in their mood:

"Well I got so quick tempered so bad tempered I used to just lash out and my husband used to say now look calm down, calm down. But it was annoying me because I couldn't do what I wanted to do.... I got very quick tempered and if I couldn't bend or do anything I used to just lash out. You know I used to break things (laughs)." (S3; 79 year old woman)

and even through offers of help:

"I suppose I feel it's got a bit of a, not a shameful stigma but it's obviously got a stigma to it ... It does put a different image on people and it, perhaps it looks like you need help when you don't want help. .... you see even in my job, we come across some disabled children who are in the normal system. And we say to the able children don't do too much for them they don't like it. Because they don't and I feel that's the category they're going over themselves to help you you, you don't want it and you don't ever want to be in that category" (S8; 52 year old woman).

Or offers of companionship

"I don't like to meet up with them because I don't want to think that they're walking to walk with me when they're, maybe they're in a hurry and I can't walk. ... I do say to them, you walk on because I can't, I can't keep up you when you want to on, you get on." (S12; 80 year old woman)

A principal mode of reflection that emerged was people's perception of what they could do. For some, the ability to do things was seen as fundamental to their identity, whilst for others it was not. However, doing can refer both to the simple carrying out of an action or alternatively, something more akin to 'performing', that is not just doing something but doing it *competently.* The notion of performative action also refers to action which is perhaps more likely to be linked to one's identity as it

often relates to expected standards of competence, i.e. what is considered 'normal'. However what is considered normal relates to person specific factors such as how well individuals used to do these things before the pain,

> "now I wouldn't say I was houseproud but I did keep a very clean and tidy home .... but, take it I would do my housework thoroughly three times a week but even when I was at work dust, polish, hoover, change the nets clean the windows etc., now I haven't done my dusting since the 19th of December, ... that isn't me at all" (S6; 54 year old woman).

> "When you walk round shops and things like that you take it for granted but when you can't do it, it's hard work.... I can't do nothing, I can't do nothing. I can't even put my shoes on some days. I have to get me put on for me, and me socks." (S9; 65 year old man)

> "I mean I've got quite high standards at home of tidiness, cleanliness, order, and that's all, that doesn't help you see that is another aspect, perhaps I should mention, living in a clutter and not keeping my standards up in the house or the garden is, does affect one's, I think gets you down a bit, subconsciously, do you understand that? ... I mean I used to look out of the train window and see people's ramshakled gardens and think why on earth can't they tidy it, it's not very hard or do some order to their garden or make it look pretty and now I understand. As people's houses get older the paint peels and all that, I can see how it's happening, standards have had to drop." (S18; 61 year old woman)

Also more generic factors such as how well a person of that age is expected to be able to do those things:

> "if it is damp and I'm sitting in the car, I find it embarrassing getting out, because I'm very stiff, mainly on my right side and I feel as if I must look 70, not sort of in my early 50s, and I've got a young child there and I'm sort of hobbling along" (S8; 52 year old woman).

Hence the failure to keep up to date with house cleaning is seen by some as an indicator that they are not their usual self as typical standards of cleanliness have not been met. However expectations of failure to maintain standards may not only be a consequence of inactivity but a *cause* of it:

> "I mean I love to swim but I just cannot get, it's my head, I just cannot get my head into motivation to go swimming, you know, a) because I've put on so much weight cos I've put on what 4 stone,.... and that really does blow your mind you know for going from a size 10 to a I was up to a size 20.... I still feel physically in myself I, um, **I know it's not me** but at the same time you know you want to go swimming and so therefore you know it's the vanity side and also it's the case that knowing that I used to be I used to compete a lot, I used to you know do competitions and all the rest of it you know..... I don't know what it is, maybe because **I feel I'm going to let myself down** that I don't feel I'm going to be able to do what I want to do.... it was one of my areas where I knew I was good, I knew I was respected for what I, you know for what I did, and I obviously used to train other people and all the rest of it, and to have to go back to the beginning is I think the hardest point for me is to know that I've actually got to bring myself down to such a low level and to actually pick myself back up again and do it" (S19; 39 year old woman. Emphasis added).

Changes in identity were also reflected back in physical changes that sometimes accompanied pain:

> "Well the pain and the immobility caused me to put on weight this is why I say it's tangendental, and it has affected my image in that I feel fat, you know and I've put on two dress sizes and I have a whole range in silk suits and things like that that I have tailor made with short skirts and I feel suddenly self-conscious and I will only wear long skirts or trousers and I usually don't wear trousers because it makes me look fatter than ever," (S20; 49 year old woman)

> "I know I'm fat I know I'm big .... I'm not as mobile as I was before so all this I feel might contribute to my weight, all this is bothering me, I don't want it to be like this to be honest, but I can't help it because anything I do I feel the pain," (S10; 50 year old woman)

Whilst some of the things that reflect back identity may be relatively fixed, such as bodily changes like weight gain or weight loss, some only emerge in particular environments. For example certain environments may serve as reminders of what cannot do:

> "I'd like to go away for a week or so. ... There's no point. ... I just can't do what I want to do and I'd rather say let's not do it .. so we don't bother we haven't been away (.) I think we went away a couple of Christmases ago is the last time but it, it is silly because all I do is go from a bedroom to the lounge to dining room and back again you know. I just couldn't go out. Couldn't go for a walk along the front where we were and (.) so rather than be frustrated there I'd rather not go and not be frustrated" (S5; 64 year old man).

Hence certain environments serve to accentuate one's disability. So called 'disabling environments' (Yardley, 1997) may be a regular feature of everyday life. An example of such may be shopping centres.

> "I would like to join my wife say in a simple shopping spree which I can't unless I'm prepared to take a walking stick and sit down every 10 or 15 minutes, ... I have to, when I go to a shop, or when I go shopping I have to make sure that I can park nearby or park come down in a lift if it's say (inaudible) do my shopping or sit on some benches until I feel better again go back inside the shop, you'd be surprised at how many shops haven't got a chair. You'd be surprised at how many places just don't just don't cater for anybody that might want to sit down" (S5; 64 year old man).

> "If I'm standing indoors, like I get a bit wobbly or sometimes bang I might be out the back I'll sort of stumble, hit me head on the wall, or something like that. If I fall .... If I'm near something strong I can pull myself up, but not always, sometimes if I'm in the middle of a wide pavement and I've gone down there's nothing to get hold of. People look at you as if you're drunk or something and there's nowhere to hide, you know what I mean. A lot of people know I'm like this but strangers they think I've been drinking or something." (S9; 65 year old man)

6.7.3.3 Category 3: Evaluating the impact of pain

The two categories outlined above reflect the perceived impact the pain has had on people's lives. However perceiving changes to one's sense of self and one's public identity formed part of a larger process of making sense of the pain and the impact it had had on their lives in general.

Chronic pain sufferers spent time evaluating the impact the pain had had and whether it had made a fundamental difference to who they were as people and how they could lead their lives. This was done principally through a process of social comparison.

Chronic pain sufferers frequently made sense of the limitations imposed by the pain and the general impact the pain had had on their lives by comparing themselves with others who were either more or less fortunate than themselves. Typically the negative aspects of their lives were emphasised by comparing themselves with those better off:

> "I also get very, not um bad tempered, very irritable and this is where the resentment starts because I think why can't I be like the others cos I see my sister in law who's 67 she's digging her garden she's coming round taking me shopping, she's running here she's running there.... and I think she's able to do that why aren't I able to do that" (S6; 54 year old woman),

and the positive aspects by comparing themselves to people worse off:

> "Well I see three people, very elderly, well I say very elderly about my age, going about in wheelchairs, people got them in wheelchairs or they've got their own wheelchairs and getting them about. And I think oh well perhaps they're worse off than me cos they've got one of them chairs. And there's two or three blind people I see trying to get across the road and I think oh God it must be awful not to be able to see. I can read, I can see the television. I can see the garden" (S13; 84 year old woman).

> "Well I've seen them turn into wineos through that, you know. People that are the same, same thing as myself they don't go and they don't see (inaudible) and they get disheartened and they get, you fall into a category don't you, going to the park, things like that. And I have seen some of the people I've worked with and they don't ever come back from that stage you know. So, you can sit down and let something like that happen or you can get up and go for it you know" (S14; 39 year old man).

> "I think maybe because where I work is a rehab unit we have a lot of very very bad, very damaged people and I tend to think well compared to them it's nothing, cos they really are very bad they're in wheelchairs you know and can't eat, incontinent and I think well compared to them. I've got nothing to complain about have I." (S21; 54 year old woman)

In addition, people also compared themselves to broader standards of normality, such as behaviour changes that might be expected with age, such as one man when asked about how he had felt about the affect pain had had on his social life answered:

> "If I was 30 I'd be shattered, but at this age I would accept it" (S5; 64 year old man).

And another woman volunteered:

> "I suppose another thing is I can't really play sport any more but perhaps since I've got older it doesn't bother me so much if I was younger it would. (S21; 54 year old woman)

However whether people accepted certain changes as age-appropriate depended to some extent more on how youthful they perceived themselves to be, rather than on their actual age. Hence another reflected:

> "Well it's affected my life, let's go back to 1995 I was very happy, outgoing, sociable, dancing singing, entertaining, everything, not like a 50 year old at all much younger sort of person .... Whereas I would be standing up at the bar (laughs) or standing along wherever, you know and it feels awful that people have to squash along to make way for me (laughs). You're treated like this old infirm person and you don't wanna be an old infirm person, before the time's, before I think the time's ready for it.... Oh I'd love to feel young again" (S6; 54 year old woman).

Hence an important mode of understanding what had happened to them occurred through a process of comparing themselves to how they were before the pain and hence their own standards of 'normality':

> "I cannot do a lot of the things I used to do 'cos I used to be a very, well I used to like all the DIY at home or whatever and I can't do 90% of it, I do little bits and pieces to keep myself occupied, but the strenuous things I can't do anymore. So that also gets me down knowing things I used to do I can't do. Knowing what an active person I used to be. .....I used to play tennis, I used to play squash, a lot of, a lot of DIY, decorating, painting, er, in my job I used to say, I was very active I used to do the street markets, so there was a lot of meeting a lot of people, getting up at, well I used to start early and come home late so a very active life, but that's completely changed." (S4; 52 year old man)

> "from being someone that was so active to have to do things and sit down at a desk it is, it is just soul destroying you know because my whole personality revolves round sport, with being physical, that is what makes me shine if you like. I'm not the kind of person that sits behind a desk" (S19; 39 year old woman).

> "I mean especially sort of old school friends and that that even I was friends with after I left work and that I just don't want them seeing me like this, because I'm just not, yeah I'm older, I'm wiser, I dare say I am a lot more astute, I certainly think about things a lot more now but at the same time I sort of think to myself well with the extra weight that I've put on you know with the things that I have to, you know especially when I'm limping, you know I can walk into a room and I'll be fine and then you know you get up and you're just like an old woman, you know, you're just a cripple and when you perceive yourself like that it's very hard to sort of catch up with people that you haven't seen for years and try and explain why you're like that" (S19; 39 year old woman).

The 'conclusions' of this process of evaluation of the impact of the pain were reflected in the final category presented here, in the extent to which people accepted or accommodated to the pain.

6.7.3.4 Category 4: Accommodating to the pain

People's perception of the changes brought about by pain and the degree of impact it had had on their lives varied widely. The coping efforts of chronic pain sufferers were typically aimed both at dealing with the pain itself and at dealing with the restriction the pain had imposed on their lives. However these two aims did not necessarily coincide. Activities were often given up, reduced, or avoided, but activity patterns reflected different hierarchies of concern: for some activity was maximized within the limits of the pain, for others remaining as normal as possible took priority and attempts were made to do things regardless of the pain. For some, the pain was perceived as not particularly restrictive, resulting in only minor changes in daily activities and hence no fundamental change in way of life. Hence little to no accommodation is required. For others, the pain was seen as demanding more radical life changes with some pain sufferers viewing this change as requiring a downgrading of standards and hence a shift in what they now consider to be 'normal'. For others some change in activity pattern is required. However, this change is conceptualized as part of a normal process such as one of problem-solving and finding ways round the obstacles presented by pain. Whilst the latter two reflected degrees of acceptance of the pain, for

some the life changes apparently demanded by the pain were not accepted.

The three principle modes of response to the limitations imposed by the pain emerged in the present study were therefore: accommodation, subversion and confrontation. However rather than being fixed coping styles, whereby individuals reported using one of the three, people reported engaging in one or the other at different times.

6.7.3.4.1 Accommodation

Activities that people chose often represented a form of negotiation with the pain. What was considered best for both the pain and achieving as much activity as possible were kept in concert through careful pacing to get the maximum cost benefit ratio possible. If activity led to pain or pain flare ups these were restricted. Activity was worked in with the pain, hence the limits imposed by the pain were accepted and people made the best of working within those limits. People who adopted this mode of working with the pain also reflected an acceptance of the pain. This may represent a downgrading of aspirations and an acknowledgement that certain things could no longer be done:

> "Whereas I've learnt not to do those sort of things you know you can't do it I mean it's like taking her shopping, um, lifting carry bags of dog food and the like, she has to do it or we have to get the kids in to do it like" (S1; 39 year old man).

> "Well I'm just thinking that I can't do it anymore and that's it, we've missed out, feel frustrated when you see the athletics and running was my sport and you can't do it, well you feel a little bit sad I'd say, too late now, it's passed us by..... (I) accept it, accept it, there's nothing else you can do you've got to accept it, (.) I'm not happy about it but what can you do." (S16; 52 year old man)

Such a downgrading was normalized by some and seen as part of an ageing process that would have occurred/was occurring anyway:

> "But it's life isn't it. You have to expect that things go wrong as, in particular as you get older, I don't think there is a person who hasn't got anything wrong as you get older, or very very few" (S15; 77 year old woman).

Whilst for others a change in activity was viewed more as a slight shift in activities which was less about giving things up, than findings ways round those activities and doing similar types of activity. Hence:

> "Same as going on holidays isn't it you just have to, instead of going to the mountains you have to go the valley don't you. You know it's the same thing. Even though you enjoy going for a walk you just have to do it on the level don't you, it's (inaudible) pace isn't it. And take the mobile just in case you can't get back. (laughs)" (S14; 39 year old man).

> "I think if you have a whole lot of things happen and had eye surgery when I was 7 so I had no sight for a year and I effectively started my education at 8 so there's been a lot of things, a lot of hoops that I've had to jump through so nowadays if somebody presents a hoop to me I just think right, I accept it as a challenge, how can I jump through it, so mine is down to life experience and if somebody says you can't possibly do that then that is the gauntlet has been laid down and you can assume with great confidence that I will do it, not out of bloody mindedness but you know if they say oh no you can't possibly manage to do that and it's something that's sensible then I just think of ways around it and manage to do it so I say that's a life experience thing (laughs)." (S20; 49 year old woman)

> "I can't do anything really active like sports or something or, you know stuff like that. I'm not supposed to do energetic sports I'm supposed to do, I can go swimming I'm not a real swimmer so I just go there for a bit of exercise rather than fun. But I could do like, I used to enjoy aerobics and stuff so now I have to go for the gentler ones. I can't run. I can't go for a jog round the park or anything, ... I can't lift the washing basket but I can kick it along or push it along or bend my knees and just lift it if it's light or, stuff like that. I can hang the clothes up but I hold the pegs in my hand so I don't have to keep bending down and you know I sort of train myself like that so I still do stuff I just do it differently." (S22; 26 year old woman)

However, as with identity, adaptation was viewed as a process. For some it was more of an ongoing daily battle:

> "Well I get angry and then it subsides because I have to doctor my movements and my activities in that parameter, ... but not angry to making me be morose and ill, it's angry and I sit and talk to myself and say you've got to just work within those lines hopefully something can be done," (S5; 64 year old man),

whilst for others accommodating to the pain only came after several years experience:

> "But you do, you know, you just you do adapt it's it's I suppose second nature really. I mean you go on holiday you slow down on holiday it might take you three or four days to sort of come down to that pace, um I've had four years to sort of slow the whole system down and sort of think about it whereas someone's that's probably going through the first stage of what I've been through would be finding it very hard to to adapt and tearing out there lifting things and ending up in pain." (S1; 39 year old man).

Hence for some the impact of the pain was often attenuated by re-arranging the way they did things or by using people's help to assist them in doing the things they could no longer do.

6.7.3.4.2 Subversion

Subverting the limits imposed by the pain principally reflected a non-acceptance of these limits and an attempt to find a non-confrontational way around them, keeping the appearance of life as normal as possible whilst actually altering activities to a significant degree. People engaged in this form of coping dealt with the restrictions of pain by managing the meanings of the pain. Hence frequently accompanying this type of response was a desire to return to a pre-pain life, with original standards of what normal life is remaining. This was achieved through covert efforts such as avoidance strategies, whereby activities were prioritised in order to maintain their pre-pain identities. Hence whilst the intended consequence of this style of coping was to appear to be the same person as before as much as possible, and to return to a pre-pain life, an unintended consequence was that the pain actually caused greater disability than it need have done. In addition, this style of coping was frequently accompanied by a refusal to accept help.

Hence people were unwilling to use visible props to help the pain, such as cushions to sit on, or receive help from other people, but were willing to use tablets for example, in order to help dull the pain, so that they could carry out activities as normally as possible. In addition, particular environments and people were avoided who might highlight identity changes, such as environments that highlighted disabilities and people who they had not seen for a while and who would be more likely to notice the changes that had occurred as a result of the pain.

The consequences of perceiving restricted activity as reflecting identity was therefore often associated with coping efforts that were specifically directed at managing the meanings surrounding the consequences of restrictions. Hence, those who perceived their identity as adversely affected by the effects of pain, e.g. felt stigmatized or felt old, attempted to avoiding environments in which they appeared something one did not wish to appear to be: that is they managed the reflected self.

A central aspect of the experience of having pain is that the pain is invisible. A frequent consequence of this invisibility is that the reasons for a pain sufferer's inability to do certain things remains hidden along with the pain. This is the case unless the pain sufferer or someone who knows about the pain, decides to make that information public. If this information is *not* made public then simple actions can be misinterpreted.

As noted earlier, identity can also be reflected back through actions and reactions of other people, hence people may avoid seeing people they have not seen for a while and avoid environments in which there are people who are unfamiliar with reasons for their behaviour, and who are therefore likely to misunderstand it and attribute it to 'old' age or 'disability'.

"Well because I used to make dinners, and like I say, I'm houseproud I suppose I must be houseproud because I would clean my house from top to bottom cos I'm really proud of where I live and how we live and I and I would like them to see the house, come into a lovely environment and, you know, and I think oh **if anyone comes I've got to clean this house I'm not just able to say oh come and visit me for me, I think, no I've got to be Doris, how I've been all these years the house is sparkling the dinner's on the table, running about, doing this doing that** and I really resent that cos like we used to do it together Harry used to help me an awful lot with the running about and helping..... but I still don't want the people there because I don't want them to see me limping and struggling that's the worst part of it if anything, that's what I hate, is when I have to limp and struggle out of chairs and I don't want them, that's the bit I don't want them to see, you know, that's the bit I hate most of it all. I think oh, you know, **look at her how she's gone down**" (S6; 54 year old woman. Emphasis added).

"It completely changes your lifestyle **because you're looking to ways to avoid it, where you're not going to be noticed** ... It hasn't actually lost my confidence because I try to avoid places which will show that I'm not confident.... at the moment I've given up swimming. And things like that, because I think I've gone less active and I've put on weight with it, um, (.) as I say anywhere where there's a lot of activity, walking, or even if I take my young one to the playground and there are other parents there, I sort of take a very backward role now and I've got to point of saying to him, do you know do you think you've outgrown things like that let's go round here you know (laughs) (.) It's just so it's not exposed and I suppose I'm with a lot of the younger mothers as we'll you know having only a seven year old, because it can show you up" (S8; 52 year old woman. Emphasis added).

Hence, the way some people deal with activity restriction caused by the pain was to further restrict the activities they engaged in. This was so that they could manage the meanings of their actions and restrict the opportunities people had to make attributions that the person in pain wanted to resist. In effect this was a form of identity management, avoiding situations where the self that was being reflected back was not one the person identified or felt comfortable with:

> "there's a film exhibition on in town somewhere that one of my daughters went to see last week and she knows that I'd love it, and her friend said well why doesn't your dad come and she says he can't walk and I can't walk round an exhibition and I'm not going to be wheel, I'm not going to go in a wheelchair.I really am not, not yet. (I feel) angry and realizing my age because part of its probably age and I do not like to feel I'm getting older this is what bugs me .... I still run a very successful little business and I still work as many hours as I want to work. And I want to continue, but it makes me feel as if old age is coming in too fast, not gracefully" (S5; 64 year old man).

Restricting activities in this way play a central role in the day-to-day life of some pain sufferers. In particular the activities that tended to get restricted were ones where the meanings of their actions were unknown, which often included public activities and particularly social activities. Hence people tried to reduce any perceived stigma by choosing their environments and audiences carefully.

However, not all those who were aware of the potential impact of the pain on their identity attempted the type of meaning management outlined above, instead they either attempted to ignore it and continued in their day to day activities as much as possible, or attempted to confront it.

> "you know I often heard people saying you know, hear them on the documentaries and everything else, people that are ill saying people talk about you as if you weren't there. But it's true. You know, poor Pat this and poor Pat that like, you know, you just get browned off with the whole lot of it don't you. That is one of the, that is one thing you can get very bitter about you know, but I just tell them I'm here, you know (laughs) I'm not gone yet. They haven't put the lid on the coffin yet like you know. You just have to, you just have to tell them like you know. But it's funny how they treat you, they just put you in a category here, you know somebody who has to be, somebody that has to go for a sleep in the afternoon ..... I think they're going to label you one way or another so you may as well stand up in the beginning and say you know really I don't want to be labelled. I don't want anyone turning around and saying well poor Pat this and poor Pat that you know. I won't let it be done" (S14; 39 year old man).

> "I felt a bit frustrated that I couldn't sit on the sofa without a pillow you know, and I felt a bit embarrassed like if somebody came I'd take the pillow away so they wouldn't know that I've had to put a pillow behind my back, I know it sounds silly but cos you know like, so but now they all know I sit with a pillow cos in that way because everyone knows about my back, before everyone didn't know I didn't tell everybody for some reason for a little while, you know I was just sort of coping with it, and I didn't tell everyone I had a torn disc at first, just didn't tell them, I don't know why I didn't tell them but I just didn't want them to know for some reason I don't know why, so in a way I had to hide it as well like it's a bit weird, I know it sounds weird but I didn't want them to know that I needed special treatment or something like that, I wanted to be treated like normal, so." (S22; 26 year old woman)

Hence although the invisibility of the pain is something which leads to the non pain sufferers' failure to understand the suffering of the person with pain, this very hidden-ness also allows some people to avoid 'disabled' labels, because the disability is hidden. Were the disability visible, this may lead to higher levels of stigma (see Goffman, 1964). However, paradoxically, people often experience higher levels of activity restriction due to pain partly through attempts to avoid being labelled.

6.7.3.4.3 Confrontation/Rebellion

Rebelling against the restrictions imposed by pain was an 'in vivo' concept (i.e. one used by a participant). In this category the restrictions associated with the pain are challenged head-on and flouted, hence activities are deliberately done, even though the pain will become aggravated. Once again this represents a form of non-acceptance of the pain.

> "I mean like I love amusement rides and stuff like that you know I used to, I am one crazy hell of a person I really am , I love the excitement I love the danger I get so much adrenalin from it and what stops me is that adrenalin because I know once you get that adrenalin rush you know that I'd then let myself go and I've done it a couple of times you know when I've gone on rides you know and I've started to run and you know you start, you just get so excited especially when you've got the kids beside you. You know and by the end of the day you know, you know you've done too much, you know that you shouldn't have done it and you get up the following morning and you get really angry with yourself, you know, and then you get rebellious because you think to yourself hey fuck it you know I've done this you know I mean I don't give a shit if I done it and you get very very rebellious" (S19; 39 year old woman).

> "I'll do my normal chores I have to do and I'll stick to that which I've been sticking to all my life, regardless of the pain like I'll do my prayers for about 20, 25 minutes which I must sit down and do it to get up after I've sat down it's worse because now the pain in the legs is worse as well but I'll still do it, I'll still do it the same position as I used to do because changing the pattern is only giving in, to me it's giving in so I will not change" (S2; 55 year old woman)

Hence whilst both rebellion and subversion are characterized by the rejection of limits imposed by pain on activity/identity, in contrast to the coping strategy of subversion, rebellion involves deliberately engaging in activities which will make the pain worse.

6.8 DISCUSSION

The difficulties associated with chronic pain often extend far beyond dealing with the pain itself. Pain can affect large and small-scale activities alike, but whilst the interference pain may cause in small-scale activities may seem trivial in comparison to some of the larger scale activities, in many ways these small changes often indicated a more fundamental challenge to people's everyday reality through challenging the taken-for-granted aspects of their world. The idea of 'taken-for-grantedness' is central to the idea of a normal life and a normal self. In her grounded theory about carers of Alzheimer sufferers, for example, Orona (1997) comments that:

> "events are anticipated in a potential future, many of which are taken-for-granted. In this taken-for-granted world, a person remains "as before", forever performing the little idiosyncrasies that come to make the person as he/she has come to be known. However, as seen in the case of Alzheimer's disease, the person does not remain "as before"" (p. 184; emphasis in original).

Hence challenging the normal or everyday can challenge some of the most profound aspects of life, most notably identity and sense of self.

In the present study, four principle categories emerged which all related to the challenge to normality that pain presents and the ways people made sense and responded to this challenge. Pain could lead to a change in people's private experience and hence their sense of self through an altered relationship between mind and body, a slowing down of the speed at which things could be done and a contracting social world brought about by restricted movement. It could lead to changes in people's more public sense of identity, a change which some deliberately set about trying to manage by avoiding environments and people who reflected back an identity they did not wish to project. People also tended to try and make sense of the impact pain had had on them through comparing themselves with those around them and with themselves pre-pain, and, finally, they expressed different ways of accommodating to the pain, some of which reflected an acceptance and willingness to work within the limits set by the pain, some a disguising of the limits imposed by the pain, and others which expressed a non-accepting rebellion against these limits.

All these represented different ways in which people perceived and interpreted their pain. However, people did not necessarily fall into only one of each of the categories. People reported both comparing themselves to people worse off than themselves and better off than themselves; they reported accommodating the pain to their life and at times rebelling against it. Whilst pain could be perceived as affecting people's sense of self and their sense of public identity, some people perceived change to one, both or neither of these aspects. Hence a sense of having aged may occur without any feeling that one's public identity had altered, whereas for others a sense of ageing

was linked with a sense that they were perceived as 'old' by those around them.

Having pain can result in restricted activity in a variety of ways. Sometimes restricted activity is the direct and unavoidable consequence of having pain, such as in the case of severe pain like sciatica. However, restrictions in activity often reflect ways of coping with the pain and hence represent choices. Whilst deliberate activity restriction may be a way of preventing pain flare ups later, whereby pain and activity are weighed up in a cost-benefit analysis, it may also be a way of avoiding activities where pain sufferers may feel stigmatized.

Efforts directed at maintaining a normal life in spite of pain may involve maintaining normal appearances in actions such as walking, and in daily living conditions such as having a clean and tidy house. Difficulties in maintaining normality may result in feelings of stigma or marginalization. Whilst other people may play a role in 'mopping up' activities that the person in pain can no longer do, thereby lessening the impact the pain has had, for some, offers of help are perceived as unwelcome evidence of their disability.

There are a number of relatively recent qualitative studies which have examined the experience of chronic pain from the perspective of the sufferer noted in section 6.2. These differ in important ways from the present study, both in their aims and the type of analyses used, hence it should be noted that the results of these studies and those of the current study are not directly comparable. Consistent with grounded theory methodology, the present study was conducted with no preconceived theoretical agenda and the aim was to explore people's experience of having pain, hence the study began with open-ended interviews, following up on topics raised by participants in subsequent interviews (theoretical sampling). In contrast, some of the studies mentioned above had very explicit study aims from the outset, which meant certain topics were prescribed in advance of the interview. For example, the study conducted by Rhodes *et al.* (1999)

aimed to explore a theme which emerged from a related study, namely '*the meaning of diagnostic tests to people with chronic back pain*' (p. 1189). Clearly different aims (and in some cases, associated differences in the patient groups interviewed) can lead to the development of themes which may not emerge in open-ended interviews, as certain issues are explicitly asked about, an obvious example in the study by Rhodes *et al.*, being the meaning of diagnostic tests.

A further difference between these studies and the current one is that all the studies noted above offered thematic analyses rather than a grounded theory, with the exception of the study by Hallberg and Carlsson (2000). As a result, they do not develop a core category and thereby identify a single 'basic problem' and how this problem is resolved in the chronic pain groups they interviewed. The core category is a level of abstraction higher than the themes explicitly offered in research using thematic analysis rather than grounded theory, and as a result is more comparable to the summaries offered by researchers rather than the themes themselves.

The conceptual categories generated in the present study will therefore be compared both with the themes and the summaries of other research. However, it should be borne in mind that the presence or absence of particular themes within the present theory in comparison to other qualitative work on chronic pain does not provide a measure of the theory's 'accuracy', as the aim of a grounded theory is to generate rather than test hypotheses. In addition, in grounded theory, only those themes relevant to the core category are documented, in contrast to a thematic analysis which can list all the prominent themes that emerge.

6.8.1 Principal Concepts

In the current study, the basic 'problem' for chronic pain sufferers that emerged was of constraint, both in terms of a constraint on what people could do and what they could be. Furthermore, the key focus of this constraint was conceptualised as being on

people's 'normal' everyday lives and the way this challenge to normality was perceived and met formed the core category in the grounded theory. Previous research on pain has focused on activity restrictions accompanying pain and some qualitative work has also noted the effect on identity that may result. However, few have conceptualised constraint as being the focus of people's coping efforts.

6.8.1.1 The concept of constraint

In the present study, the inability to do things, or do them in the same way as before, underpinned the two first primary categories: private experience and challenge to identity. The idea that pain affects people's identity or sense of self has been noted in qualitative work on chronic pain and chronic illness in general. However the impact of pain documented under the category 'private experience' have rarely been discussed in chronic pain research, a notable exception being the work of Henriksson (1995a; 1995b).

The idea that pain causes interference in terms of a range of activites is widely reflected in the chronic pain literature. Numerous studies have documented the impact pain has had on people's activities such as work, recreational and social activities (e.g. Kerns *et al.*, 1985). In addition, activity restriction has been noted as a key motivator for seeking treatment in pain sufferers (McPhillips-Tangum *et al.*, 1998). In a two-stage study with patients attending medical care for mechanical back pain, McPhillips-Tangum *et al.* (1998) used open-ended interviews to elicit participants' reasons for seeking medical care, and then sent them a questionnaire to measure the perceived importance of these reasons in their decisions to seek treatment. They found that the joint most important reasons for seeking medical treatment given were difficulties in performing normal activities, and a desire to know the cause of the pain. Both of these reasons were cited by 97% of the people surveyed and this was rated as more important that pain intensity. The authors state:

> "Nearly all participants cited difficulty in performaning normal activities as a reason for seeking medical care. In fact, participants cited activity limitation more often than increased pain." (McPhillips-Tangum *et al., 1998*; p. 291).

In a further study exploring a sub-group of these participants, Rhodes *et al.* (1999) stated that:

> "Virtually all of our respondents said that they were driven by difficulties in performing their daily activities to seek the cause of their pain." (Rhodes *et al.*, 1999; p.1190),

linking the limitations in activity with a desire to know its cause.

Limitations to activity have also been documented in the qualitative work conducted on chronic pain noted in section 6.2. Henriksson's account of the experience of women with fibromyalgia illustrated that different aspects of life such as work, family and leisure become disrupted. Johansson *et al.* (1999) analysis suggested that the inability to do housework and fulfill family roles was a central issue for their interviewees, and 'consequences for activities' was one of their themes, and Osbourne and Smith (1998), whilst not having activity restriction as an explicit theme, state that the experience of pain is characterized by loss, as numerous activities can no longer be done.

6.8.1.2 Challenge to identity

The fact that chronic pain can lead to a challenge to identity is a recurring theme in different qualitative studies on the experience of chronic pain and chronic illness, however its place in the analyses offered by different research varies. In her work on chronic illness using grounded theory, (see section 6.2), the effect of chronic illness on identity formed the core category, although the sample interviewed did not include those with chronic pain. The effect on identity was also noted in the work of Johanssen *et al.*, and Osbourne and Smith, and Henriksson, although was only listed as an explicit theme in one. In their grounded theory of chronic pain Hallberg and Carlsson (2000) the impact of pain on identity is not discussed.

In their thematic analysis of the meaning of pain for Swedish women, Johansson *et al.* (1999) list 'consequences for her self perception' as one of their four superordinate themes. This category contained three subordinate themes: 'risking her good name', 'womanliness' and 'sexuality'. The first theme referred to women's reputations being challenged by the reduced ability to do work and yet having an illness which could not be diagnosed and which women perceived as eliciting doubt and mistrust in the eyes of other people. Womanliness referred to feeling insufficiently womanly as a result of pain, although the only example given in this category was one interviewee's suitability for adoption being questioned as a result of her illness, and sexuality referred to problems the women reported in their sex lives arising from the pain.

Osbourn and Smith's (1998) summarized their research as indicating that their interviewees lacked positive self-regard and a feeling of not being the person they used to be. Whilst impact to identity was not listed as an explicit theme, it formed a key part of the theme 'comparing this self with other selves'. Social comparisons, were seen by the authors as describing and evaluating the changes that had occurred because of the pain, and that such comparisons:

> "revealed their sense of loss and threat, and the debilitating impact of their experience on their self-concept" (Osbourne and Smith, 1998; p. 76)

For Osbourne and Smith the distinction between sense of self and public identity is used to illustrate that it is the former which becomes altered by the pain whilst the invisible nature of pain left public identity largely unchanged:

> "For the participants in this study the invisibility and day-to-day variability of their chronic pain left their apparent public-social identity, to some extent, unchanged whereas the restrictions and intense unpleasantness of their body had eroded radically their personal sense of self. As a consequence, overt and visible distress and disability was often the only currency available to them to establish the legitimacy and 'reality' of their pain to others, but this only compounded the erosion of their self-regard." (p. 78)

In contrast to the work of Osbourne and Smith, both people's view of

themselves and their public identity were both seen as affected by the pain in the present study. Henricksson also documented for some people not being able to do what they wanted to do meant they could not the be person they used to be under the theme 'loss of abilities', although again, this did not constitute a major theme.

The place of challenge to identity in the current theory clearly differs from these previous studies. For example, they differed from the themes generated by Johansson *et al.* as they were not gendered themes. In addition, the mechanism by which identity was evaluated differed from that outlined by Osbourne and Smith. As noted above, the latter proposed that comparisons with others served to highlight identity change. In the current theory, changes in abilities and other people's reactions were seen as reflecting identity change, whilst comparisons with others were conceptualised in the current theory as part of evaluating the extent to which normal life had been altered by the pain and this is discussed in more detail in section 6.8.1.4.

Further, in contrast to the work of Charmaz, challenge to identity does not form the core category in the current study. Instead it is a primary category which indicates the key concept of 'constraint'.

6.8.1.3 Private experience

In contrast to the impact on identity, the impact of pain on 'private experience', or people's fundamental relationship with their environment, has received little attention in previous qualitative work on pain. For example, it is not documented in Charmaz's theory or the work of Johansson *et al.* and Osbourne and Smith (1998). However, Henriksson (1995a) has noted the effect of pain on 'limitation in motor performance', and this appears under the main theme of 'consequences'. Henriksson notes that people with fibromyalgia could still do certain things except at a slower pace, although does not mention the other two themes noted in the present study of reduced social space and the changed relationship between mind and body. The need to organize things, or plan in

advance emerges, but is listed as a coping strategy, i.e. as a means of gaining control in Henriksson's study (Henriksson, 1995b). There is little doubt that factors such as reducing the speed at which one does things and thinking before acting enable people to reduce pain and hence it seems plausible to suggest that it could operate as a means of gaining control. However, in the present study coping was conceptualised as acting at a more abstract level and how people cope with pain *per se* was not the topic of the present study.

6.8.1.4 The disruption of normality

The core category in the present study of maintaining normality is consistent with other research findings. The idea that chronic pain causes a problem to normal life is implicit in the desire to return to doing what one used to, or being what one used to be, issues which are central to the categories outlined above. These issues are also documented in previous research into chronic pain, although the desire to return to a normal life appears in the summaries of these research findings rather than as explicit themes. For example, Johanssen *et al.* (1999) found that the pain resulted in women being unable to do housework and in having difficulties in fulfilling family roles (such as mother, daughter, wife). They argued that social norms provided 'gold standards' that the women they interviewed felt they were expected to live up to, in terms of household and family commitments. However, attempts to live up to such expectations clashed with being understood as having a genuine illness which meant they could not do paid work. Hence conceptions of normal standards (social norms) emerged as important criteria against which the women in their study measured themselves. Similarly, Osbourne and Smith (1998) summarize their interviews as showing:

> "the participants endeavoured to continue to live in their social world of healthy people, often appearing and trying to appear healthy themselves, but failing habitually to live up to the expectations and responsibilities implicit in that world" (p. 77)

suggesting again that chronic pain sufferers compare themselves to normal

standards, although the social norms they refer to are general ones, relating to the world of 'healthy' people, rather than the more specific gendered roles outlined by Johansson *et al.* (1999)

Henriksson (1995a) also notes that the women he/she interviewed: "want to be able to do more and live the life that they used to have (p. 75). Whilst in Hallberg and Carlsson's (2000) grounded theory the concept of wanting a normal life is implicit in their description of pain as taking over people's lives.

However, whilst themes relating to normal standards and normal lives emerged in previous research, the role such themes played differs from the role they were considered to play in the current study. Previous qualitiative work on chronic pain has tended to focus on the discrepancy between people's inability to do things whilst appearing to be healthy and able on the outside. This tension between reality (the presence of pain) and appearance (the appearance of being pain-free) is seen as heightened when there is no medical evidence to support the fact that the pain is 'real'. The work of Johansson *et al.* (1999) and Osbourne and Smith (1998) in particular, focus on this discrepancy.

In the present study, the focus was somewhat different as the aim was not to study just those pain patients who had *no* identifiable organic pathology. Hence what emerged in the present study was the suggestion that the challenge to leading a normal life that pain presents is central not only because it not only describes one of the key problems of pain, it also forms part of how this problem is resolved. More specifically, it is proposed that how normal standards are altered or maintained form a central part in differentiating the different coping responses to having chronic pain which are discussed in section 6.8.1.6.

Most similar to the formulation offered here is the grounded theory of Charmaz (1987). She found her participants articulated a similar goal, as the aim of the people interviewed which was of returning to pre-pain abilities and identities. i.e. one of

wanting to be normal rather than 'sick'. For example, she states that

> "chronically ill people resoundingly reject identities founded in invalidism. They do not wish to be patients first and persons second" (p. 286)

In Charmaz's grounded theory of chronic illness the focus of her research was on the challenge to identity, and how this challenge was dealt with in terms of whether or not people accepted that their pre-illness identity had to be relinquished. The patterns of response to the challenge to identity she documents has some similarities to the response to the challenge of constraint outlined in the present theory. Charmaz's work, though not on chronic pain, reveals similar responses to chronic illness, from non-acceptance to acceptance. However, unlike the work of Charmaz, which was focused solely on identity and which was longitudinal and hence explored identity change over time, the present study was cross sectional and documented people's response to the constraints of pain rather than just their response to the challenge it posed to identity.

6.8.1.5 Evaluating the impact of pain

The evaluation of whether normal life has been affected by the pain is hypothesized here as occurring principally through a process of social comparison. There are various comparisons that can be made in addition to upward and downward comparisons such as social comparisons (with others) temporal comparisons (with self at different times) and it has been argued that in chronic illness temporal comparisons are more common than comparisons with others (Tennen and Affleck, 1997).

The first two principle categories, private experience and challenge to identity indicate the impact the pain has had. However it is suggested here that social comparisons revealed the extent to which normal life had become altered because of the pain.

There is a considerable body of theory and empirical research concerning social comparisons and their function. For example, Buunk, Gibbons and Reis-Bergan (1997) argue that social comparison theory as originated by Festinger (1954) is no longer a

single theory but rather a "broad perspective on human behaviour" (p.19). Whilst some researchers view social comparisons as playing a role in one's attitude to oneself (e.g. Festinger; 1954), Mettee and Smith (1977), for example, define social comparison theory as being about:

> "our quest to know ourselves, about the search for self-relevant information and how people gain self-knowledge and discover reality about themselves" (Mettee and Smith, 1977: p.69-70)

others argue that comparisons with others are used as coping strategies (e.g. Wills, 1981; Jensen *et al.,* 1991). Wills (1981), for example, argued that when people are in situations which lead to a decrease in subjective well-being they often compare themselves with other people who are worse off than them in an effort to enhance their subjective wellbeing. He also argued that such downward comparisons were particularly likely to occur when there was no opportunity for people to change the situation responsible for the initial decrease in subjective well-being. Following on from Lazarus and Folkman's distinction between problem-focused and emotion-focused coping made at a later date (1984), (and outlined in Chapter 5), downward social comparisons are therefore seen by some researchers as an emotion-focused coping strategy. In contrast, Tennen and Affleck (1997) argue that it has not been established that social comparisons are coping strategies, because research has not measured whether such comparisons are effortful, they argue that they might be more accurately understood as beliefs or cognitions rather than coping strategies.

Whilst all four qualitative studies on chronic pain discussed in this chapter raised the issue of social comparisons, only Osbourne and Smith (1998) and Hallberg and Carlsson (2000) speculated on what their particular function might be.

For example Henriksson (1995a) states simply that:

> "The women relate their present ability to perform different activities with how it used to be, and with other women their own age. They are not satisfied with their accomplishments and want to be able to do more and live the life that they used to have." (p.75)

and Johansson *et al.* (1999) state:

> "The women described how the pain had consequences for their everyday capacities. They evaluated their responses in relation to former capabilities and present expectations" (p.1796)

Hence these researchers imply that the function of social comparisons are to describe and evaluate respectively.

In Hallberg and Carlsson's study (2000), comparisons with others in a worse situation was only briefly discussed and they were categorized as passive behavioural-cognitive coping strategies and summarized as similar to emotion-focused coping strategies. Osbourne and Smith (1998), however, are more explicit. 'Comparing this self with other selves' was listed as a theme in their research, and they argue that social comparisons helped reveal the personal meaning of the pain held by the individual sufferer. They further argued that social comparisons were used to describe and make sense of their situation, rather than as coping strategies. For example, Osbourn and Smith (1998) suggest that downward comparisons did not appear to be associated with improvements in subjective well-being:

> "their comparisons served almost inevitably as an index of their sense of threat and loss. Attempts to buttress self-esteem by comparison with those more unfortunate often proved counterproductive and served only to remind participants of their own gloomy prognosis." (p. 72).

And in summary, they point to the complex function that social comparisons might play:

> "To be understood, each comparison needed to be seen in its personal context and it was in their complex network of comparisons that the individuals' sense of their situation was revealed. Overall, comparison was an equivocal coping strategy and served best as an index of the participants' attempts to manage their distress and uncertainty and helped to reveal the personal meaning of their chronic pain." (p.77)

In the present study, a similar conclusion was independently reached about the nature of social comparisons in that multiple comparisons were made, not just downward and upward ones, but comparisons with pre-pain selves and with generalized others, such as people who are older or younger. These comparisons were viewed as illustrating the impact the pain had had on an individual's life and in particular as demonstrating their appraisal of that impact and served to make sense of their response to the pain (documented in section 6.8.1.6). Hence, in the present study social comparisons were not viewed as a coping strategies, however, it is not suggested here that social comparisons do not ever serve as coping strategies. The present study was not testing hypotheses but generating them and hence no test was made in the present study of the function that social comparisons served. It seems likely that, as Tennen and Affleck (1997) have argued, social comparisons may serve multiple functions sometimes acting as coping strategies sometimes as what they term 'comparison conclusions' or beliefs.

6.8.1.6 Response to constraint

The present study differs from other qualitative work on chronic pain largely through this final category. Previous work on pain has tended to focus mainly on describing the experience of living with pain, involving descriptions of the pain *per se* and its consequences, however when they come to discuss coping strategies they tend to focus on strategies which are used to cope with the pain *per se* rather than the consequences of the pain on daily life. Coping strategies have been documented in the work of Hallberg and Carlsson (2000) and Henriksson (1995b) although both suggest that their sections on coping reproducing well-established distinctions in the coping

literature, with Hallberg and Carlsson (2000) drawing similarities between their findings and the distinction between active and passive coping, and Henriksson (1995) drawing similarities with the strategies outlined by Cohen and Lazarus (1982).

In the present study, the key consequence of having chronic pain was identified as a constraint on normal life. This constraint was seen as responded to in one of three ways, which reflected the degree to which people balanced pain severity and the constraints they experienced:

i) accommodation, referred to the response whereby people accepted the constraints associated with pain and kept pain to a minimum whilst maximizing the activities they could do. Normal standards of living were either altered to accommodate the change, perhaps by giving up certain activities or maintaining them, perhaps with the help of others whereby tasks were redistributed,

ii) subversion, referred to the response whereby the constraints imposed by pain were resisted and pre-pain standards of normal life still aspired to. However effort was put principally into maintaining normal identities, rather than maximising the activities that could be done, indeed activity restriction was often a consequence of attempts to limit the impact of pain on identity. Hence normal standards of life were largely defined in terms of attempting to retain pre-pain identities, and

iii) rebellion, referred to the response whereby constraints were resisted and normal standards aspired to. However this was characterized by deliberate confrontation with pain, notably an unwillingness to pace activities to keep pain levels manageable. Hence activities were often done deliberately despite the impact on pain levels due to an unwillingness to accept the limitations on activity imposed by the pain.

These methods of coping are seen as representing people's response to balancing pain severity with constraints to activity and identity. In contrast to the majority of the coping literature on pain, the coping responses documented here are not focused exclusively on how people cope with the pain *per se*. This is because in the grounded theory presented in this chapter the key problem, or 'stressor' identified in the theory was 'not being able to do the things one wanted or would normally do'. This is in contrast to the grounded theory of women with fibromyalgia produced by Hallberg and Carlsson (2000) in which pain *was* identified as the central problem. As a result, under their category entitled 'diversified pain coping' they, as the title suggests, list pain-specific coping strategies. These were: 'self-initiated activity' (e.g. attempts to manage or reduce the pain by engaging in activities such as walking and swimming, or cognitive strategies such as distracting oneself from pain through reading, and relaxation), 'professional treatments' (e.g. the use of traditional or alternative therapies such as physiotherapy and homeopathy to relieve the pain), 'passivity' (e.g. bed-rest, comparison oneself with others in a worse situation, avoiding interactions with others) 'escape behaviours' (e.g. taking pain medication, drinking alcohol and taking sick leave) and 'resignation' (which they liken to catastrophizing, as it is characterized by feelings of hopelessness and lack of control).

As noted earlier, they summarize these themes as reflecting the passive-active distinction in the coping literature, with 'self-initiated activity' and 'professional treatments' categorized as 'active' or 'problem-focused' strategies, and the remainder categorized as 'passive' or 'emotion-focused' strategies. These strategies bear little similarity with the ones documented in the present study, although given the different key problems identified, this is not surprising. However, Hallberg and Carlsson identified a passive strategy 'avoiding interactions with others', which they thought was used by pain sufferers "probably because of an implicit conception that 'when I am in pain, the body damage gets worse through activity' (Hallberg and Carlsson, 2000: p.

33). In the present study, avoidance of others was seen as a way of coping with the challenge to identity resulting from the pain, and hence would be viewed as a deliberate and active coping strategy. These differing interpretations do not mean that only one of these explanations is valid but point to the fact that strategies can be used for different purposes.

Henriksson's analysis also included a typology of coping strategies however the analysis was not a grounded theory and hence did not involve identifying one key problem or stressor. Instead, a number of different consequences of having fibromyalgia were listed, not just pain, but tiredness and cognitive difficulties, such as difficulty concentrating. The strategies listed were therefore response to one or all of the possible difficulties that may be associated with fibromyalgia and were categorized as: 'routines', 'performance of everyday activities', 'adjustment to changed abilities', 'change of life situation', and 'attitudes to limitations'. Henriksson argues that these strategies reflect the modes of coping outlined by Cohen and Lazarus (1982): information seeking, direct action aimed at self or environment, inhibition of action, intrapsychic or cognitive processes, e.g. denial intellectualization, and turning to others for support. However Henriksson does not elaborate on the similarities and differences between his/her analysis and Cohen and Lazarus's.

In terms of similarity with the present study, 'attitudes to limitations' is the most comparable. Under this category Henriksson lists three responses: 'acceptance of limitations', 'resistance to change' and 'developments of new talents and interests'. The former refers to an acknowledgement "that there are limitations that have to be taken into consideration" (p. 83) and clearly resembles the category 'accommodation' in the present study. Under resistance to change Henriksson states "some of the women show resistance and avoidance" (p. 84) and outlines the sort of responses which are included in the present study under the two categories 'subversion' and 'rebellion' respectively. For example, Henriksson noted how some women reported covering up and pretending

their problems do not exist because they do not want to show a weakness, and some reported doing as much as they can regardless of the levels of pain.

6.8.2 Limitations of study

Grounded theory seeks to describe one core category. As a result it clearly does not offer an exhaustive list of the problems associated with chronic pain. It is clear that some of the themes documented in previous research were not outlined in the current study. The core category that emerged here focused on the consequences of having pain, rather than issues surrounding the pain *per se*. As noted earlier, any omissions do not invalidate the theory but instead indicate the limits of its scope. For example, the concept of the legitimacy of the pain was not emphasized in the grounded theory presented in this chapter, and yet has emerged in previous research, notably that of Osbourne and Smith. This could be because all the participants in Osbourn and Smith's study were a relatively homogenous group with little medical explanation for their pain, and those in the current study formed a mixed sample of people, some of whom knew the organic cause of their pain and some of whom were given a less clear-cut explanation such as that it was due to 'wear and tear'. However issues associated with the invisibility of pain (which form part of the issue of legitimacy) were documented in the present theory, for example, through the provision of a space for the misunterpretation as actions being due to ageing or due to drunkenness, which emerged as important to the category 'challenge to identity'.

6.8.3 Constructs measured in Study 3

One of the aims of the present study was to provide some assessment of the grounding of the concepts used in Study 3. There was evidence for the ecological validity of the concepts explored in the previous chapter although reservations about them remain.

Coming to terms with life restrictions caused by pain bore many similarities to coming to terms with the restrictions brought about by the ageing process. Hence this provides some support for the adoption of concepts developed in the ageing literature to the study of pain, as occurred in the case of Flexible Goal Adjustment used in the previous chapter. Indeed the concepts of both Flexible Goal Adjustment and Tenacious Goal Pursuit were ones that emerged in the current study. Coping concepts that emerged related both to downgrading aspirations (FGA) and to finding ways round obstacles imposed by the pain (TGP) such as finding ways of being able to go on holiday. However, both seemed to reflect a degree of acceptance to the pain, the first by acknowledging that there was little they could do to combat the pain and aiming to make the most of what they could do (downgrading) and the latter as maximising the things that they could do and thereby minimizing the *perceived* impact the pain had on their lifestyle. However, a fine line seems to exist between finding ways round the pain in order to maximise what can be done and finding ways round the pain in order to retain one's pre-pain identity. Whilst the former may relate to a degree of adjustment to the pain, the latter may reflect non-acceptance. In addition, there is a difference between people who attempt to pursue obstacles and do so paying the price of increased pain and those who manage to find ways to pursue obstacles which do not lead to increased pain. Again the latter may be associated with positive adjustment to pain whereas the former may not. Hence the questionnaire developed by Brandtstädter and Renner may need refining in order to detect the subtle differences between different responses to the pain.

The roles and goals questionnaire aimed to measure the extent to which people were involved in the roles/goals and hence the extent to which they formed a key part of people's sense of identity. In the present study identity did indeed emerge as a key concept, however challenge to identity was based on numerous abilities, not all of which can be described as coming under the terms of roles and goals. For example, for some

people not being able to move around quickly was a significant challenge to identity, as was muscle loss/weight gain. Furthermore, roles and goals were assessed because of the key role they play in theories of depression. However such theories have frequently centred on loss, yet the central issue that emerged in the current study was not the theme of loss but rather the slightly different theme of constraint.

Constraint, or not being able to do certain things, implies that the status of the things that cannot be done is potentially questionable. Not only does constraint signify the possibility that activities can be done but at a price, whether that be intolerable levels of pain or presenting an identity one does not wish to present, it also indicates that the issue of whether certain activities can be done in the future is open to question. Hence pain does not necessarily involve unequivocal loss. The significance of this is that different people may have different understandings of the extent to which things can no longer be done and this difference is arguably reflected in people's response to constraint. Williams (1998) has made a similar point. For example, she has said:

> "The pain sufferer suffers a range of losses, temporary or permanent, as well as considerable uncertainty, not least concerning the permanence of such losses." (Williams, 1998; p. 67)

Agreement about symptom understanding (cf. Lacroix *et al.*) did not emerge strongly in the present study. Knowing the cause of the pain and having the pain legitimated by the medical profession are themes which have emerged in other work, most notably that of Rhodes *et al.* (1999) and their work on the meaning of diagnostic tests. However this issue is different from being in agreement about what the cause of the pain is and how long it is going to last for, and problems with the concept of accuracy have already been discussed (Chapter 5; section 5.7.4). Issues clearly exist around the extent to which doctors, patients, family, friends and other people have a shared understanding of the pain and what it does and does not signify, such as understanding that pain is present (rather than absent and resulting in the mis-attribution

that difficulty walking is due to age). It is, however, important to note that these concepts are not being in any way refuted by the grounded theory presented in the present chapter, as the grounded theory simply suggests possible hypotheses, it does not test them. Hence it is suggested that agreement about symptom understanding did not emerge as a salient issue in the interviews conducted in the presents study, but this does not mean this is not a construct which may relate to pain-adjustment.

6.8.4 Possible mediators of the pain-disability link

Whilst a grounded theory principally represents a hermeneutic project, contributing to an understanding of the experience of having pain, it can also be translated into testable hypotheses.

A variety of concepts emerged in the current study, but one of the potentially more useful in understanding the variation in pain-adjustment, particularly levels of disability or activity restriction, is the concept of identity management. Ironically those deliberately avoiding activities in an attempt to conceal their disabilities may appear on measures as more disabled than their physical limitations might suggest. Hence a possible mediator of the pain-disability link may include levels of concern about identity presentation.

6.9 GENERAL CONCLUSIONS AND SUMMARY

A grounded theory was developed from interviews with 22 chronic pain patients attending an outpatient clinic for routine medical management for their pain. The experience of chronic pain was conceptualized principally as one of constraint, both in terms of what people could do and what they could be. People's ability to accept the constraint formed the basis of their coping efforts and future research on coping with pain may benefit from examining the different ways in which people cope with this constraint as well as how people cope with the pain *per se*. The degree to which people

were able to accept the constraints imposed by pain may be linked to the extent to which identity is thought to be put at risk through the inability to perform certain activities. If constraints are viewed as going against who one is, people may be more likely to fight the constraints and tolerate increased pain and/or cut down on certain activities.

Some participants mentioned deliberately restricting particular activities in an attempt to minimize the disabling and stigmatizing effects of chronic pain. Hence a possible mediator in the relationship between pain and disability which could be studied in future research might be concern about self-presentation, or more specifically awareness of and concern about hiding the stigmatizing effects of pain.

Chapter 7

Summary and conclusions

The aim of this thesis was to study the role of schema and meaning in chronic pain. Four studies were conducted which used a range of different methods to assess pain schema and pain meanings, and which considered two aspects of pain schema: schema function and schema content. The first two studies in the thesis addressed schema and meaning within the context of *how* pain meanings might dominate information processing in chronic pain sufferers, and hence focused on schema *function* in chronic pain; and the second two studies addressed schema and meaning within the context of *what types* of pain meanings appear to be associated with poor adjustment to chronic pain, and hence focused on schema *content.* The conclusions of the thesis therefore relate both to the specific findings of the individual studies and the broader, theoretical implications these studies have for: i) information processing biases in emotion and pain (schema function), and ii) theories of adjustment (schema content). This chapter will therefore summarize the specific findings of Studies 1 and 2 as they relate to schema function, along with the studies' limitations, and then discuss the broader implications of these as they relate to information processing biases in pain. It will then summarize the specific findings of Studies 3 and 4 as they relate to schema content, along with the studies' limitations, and then discuss the broader implications these have for understanding individual differences in adjustment to chronic pain. The chapter will then conclude with a brief discussion of the clinical implications of the research presented in the thesis and will conclude with a discussion of the trajectory of the studies in the thesis and the strengths and weaknesses of the methods used.

7.1. SCHEMA FUNCTION AND INFORMATION PROCESSING BIASES IN CHRONIC PAIN

Studies 1 and 2 examined aspects of schema function to explore mechanisms involved in, and potentially responsible for, information processing biases in chronic pain patients. Leventhal and Everhart's model formed the starting point of this research. This model proposes that the repeated experience of pain leads to the development of complex pain schema which can then play a role in elaborately interpreting sensory input and contribute to the continuation of pain in the absence of continuing peripheral input.

Previous research has demonstrated that people with chronic pain preferentially recall pain-related material in comparison with other material, and compared with non-pain sufferers. This evidence has been interpreted as consistent with the presence of a more complex pain-related schema in chronic pain sufferers in comparison to pain free controls. Hence this research has offered some support for the view that extended pain experience may lead to the development of a more complex pain schema, thought to contribute to the continuation of pain through such processes as the biased perception and biased labelling of ambiguous stimuli as 'painful', and the experience of pain through the activation of pain memories rather than through nociceptive activity.

7.1.1 Study 1

Study 1 aimed to build on previous research into pain schema by exploring whether the pain-related recall bias was the result of processes specific to retrieval: it aimed to see whether retrieval inhibition played a role in schema selection in chronic pain. However the results of this study provided no evidence of a recall bias towards pain-related material in chronic pain sufferers meaning that no inferences about the role of retrieval inhibition in the recall bias could be made. A recall bias was demonstrated in all participants, although this was towards the categorized neutral word group. The

finding of a general recall bias among all participants towards recalling the gardening words suggests that the recall bias previously demonstrated in chronic pain sufferers becomes easily over-ridden by other factors which enhance recall performance, such as tighter categorization and/or the possibility that these words are more concrete and imageable. Given that previous studies which have demonstrated a pain-related recall bias have typically not used a categorized neutral group of words (e.g. Edwards *et al.*, 1992; Pincus *et al.*, 1993), this raised the possibility that categorization processes may play a role in this recall bias because a) the effect of categorization processes on recall have arguably not been fully explored/controlled for in previous research, and b) group status may affect perceived word meaning, with pain sufferers possibly viewing a larger number of words as pain-related than non-pain controls.

7.1.2 Limitations of Study1

The key limitations of the study revolve around the failure to replicate a pain-related recall bias in chronic pain sufferers and the failure of the directed forgetting effect. The latter could have been due to a lack of power in the analysis, however a recall bias was demonstrated towards gardening-related words and hence the failure to demonstrate a pain-related recall bias appears not to be due to a Type II error. It seems more probable that the reason related to the materials used and the inclusion of a categorized neutral word group.

Methodological adjustments could have been made to improve the chances of demonstrating a pain-related recall bias by using a self-referential encoding manipulation, and by using an uncategorized neutral word group as used in studies which have successfully demonstrated pain-related recall biases (e.g. Edwards *et al.*, 1992). However, self-referential encoding is thought to be a deeper form of encoding and increased depth of encoding affects the possibility of demonstrating retrieval inhibition, it seems likely that, even if this manipulation had been used, it would have

compromised the directed forgetting effect. Hence, whilst retrieval inhibition and depth of encoding may be conceptually distinct, they are not necessarily empirically distinguishable, as depth of encoding seems to lead to a diminution of the directed forgetting effect, as discussed in Chapter 2. Given that altering the encoding manipulation in order to improve the chances of demonstrating a recall bias may only serve to further weaken the directed forgetting effect, an alternative way of replicating the pain-related recall bias might have been to use the same words as in previous studies, and hence use an uncategorized neutral word group.

However, the use of the same words as used in previous research would not solve a further problem with the design of Study 1. Floor effects in the levels of recall from each of the three word categories occurred and indeed similar problems were identified by Myers *et al.* (1998) in using a three word type design in directed forgetting in 'repressive copers'. Myers *et al.* solved this problem by changing from three word types to two, thereby raising the level of recall per word category. However, reducing the number of word categories to two types in chronic pain research would have meant using a design which has not been used in previous studies on chronic pain and recall. Hence before such a two word category design was used it would be sensible to start by demonstrating that a recall bias occurs when only two word types are used, one pain, one neutral.

A potential confounding variable in the study of retrieval inhibition when semantically related words are used was identified in Study 1 and this was directly tested in Study 2.

7.1.3 Study 2

Study 2 explored the relationship between perceived word meaning and personal interest, and demonstrated that chronic pain sufferers perceived more words as pain-

related than pain-free controls. It provided evidence consistent with the view that the pain-related recall bias may relate to categorization processes whereby pain sufferers perceive a larger pain category compared with non-pain controls and that this may be a factor involved in enhanced recall of pain words in this participant group. Whilst there is no direct evidence in this thesis that this is the 'cause' of the recall bias (most notably because these same words were used in Study 1 and did not lead to a pain-related recall bias in chronic pain sufferers) there is no doubt that categorization effects have not been fully considered in previous work. Further, as discussed more fully in Chapter 3, these differences in perceived word meaning make inferences about both self-referential encoding and retrieval inhibition problematic. For example, categorization effects question the adequacy of the control group in retrieval inhibition studies. Whilst all pain sufferers may be perceiving a larger number of pain words, categorization effects are not adequately controlled for across the forget/remember manipulation. Those receiving the 'forget' instruction effectively see 2 word lists whereas those receiving the 'remember' instruction effectively see 1 word list. Hence impoverished recall following a 'forget' instruction may reflect differences in word category size. Categorization processes are therefore not adequately controlled for in this design and such effects could, at the very least, confound the interpretation of results from these studies.

Whilst the categorization processes that occur in a recall task may differ significantly from those used in the card sorting task, the results of Study 2 demonstrate that the role of categorization processes in the pain-related recall bias in chronic pain sufferers requires further exploration.

7.1.4 Limitations of Study2

The main limitation of this study concerns the nature of the categorization task. An unconstrained card sort design was used so people were free to categorize words however they chose. However, this meant that some of the category labels people

produced were idiosyncratic and unrelated to either pain, negative emotion or gardening. Although this is arguably a process that occurs when people are presented words for recall, the instruction to categorize *all* the words meant that words could not remain ambiguous or have dual meaning (such as the word splitting referring to both pain and gardening) but had to be placed in one category or another.

However there is no clear solution to these two issues. Providing people with category labels (pain, negative emotion and gardening) would have set up prior expectations about word meaning which are not set up in the recall tasks typically used in recall bias studies. Further, allowing word meaning to remain ambiguous would have complicated the results of the study in terms of category sizes across groups, because those perceiving word ambiguity would effectively be acting as though they had seen more words in total.

7.1.5 Implications for previous findings into, and theories of, information processing biases and pain.

Information processing biases in emotion and pain have typically been interpreted in terms of schema theory such as that of Leventhal and Everhart, Beck or Williams *et al.*. As discussed in Chapter 4, these theories differ in terms of the nature of the schematic representation they propose, hence the theoretical implications of the findings in this thesis depend to some extent on the particular theory being considered. However, in general, the results of Study 1 and Study 2 suggest that the role of word categorization in information processing biases in emotion and chronic pain needs to be considered. Self/other encoding manipulations and forget/remember instructions may affect categorization processes and hence the results of such experimental manipulations do not necessarily reflect the operation of self-schema or the role of retrieval inhibition as previously inferred. The self-referent encoding manipulation can arguably be seen as the product of relational and distinctiveness encoding rather than supporting the

presence of a self-schema. In addition, as noted in section 7.1.3, impoverished recall following a forget instruction may partly be the product of receiving two short word lists as compared with receiving one long word list (i.e. the remember instruction) resulting in different category sizes between forget and remember instructed participants as well as differences between participant groups. However, at present these alternative explanations of self-referential encoding and directed forgetting remain hypotheses which require testing, as the results of Study 1 and Study 2 suggest only that categorization processes enhance recall (Study 1) and that word meaning and hence category size may differ systematically between participant groups (Study 2).

Both of these alternative explanations of these encoding manipulations (self/other) and directed forgetting assume the occurrence of biases in perceived word meaning which differ according to group status. As a result, these alternative explanations can be seen as still involving an information processing bias, more specifically an interpretative bias towards thematically related concerns, such as a bias towards interpreting material as pain-related in chronic pain sufferers. Hence the theoretical significance of this needs to be considered within the context of Leventhal and Everhart's theory and Williams *et al.*'s Integrated model.

The tendency to perceive more words as pain-related is an effect consistent with other findings in chronic pain research of a pain-related interpretative bias in chronic pain sufferers in comparison with pain-free controls (e.g. Pincus, Pearce, McClelland and Farley, 1994; Pincus *et al.*, 1996). Hence the pain-related recall bias can arguably be seen as the result of an interpretative bias which affects categorization processes but which is still schema driven. Thus this would suggest that encoding processes play a key role in the pain-related recall bias.

There is no clear evidence that biased categorization effects may be the specific reserve of emotion and pain as a parallel effect was demonstrated in amateur gardeners as they perceived more words as related to the theme of gardening than to any other

theme. Hence this effect could be seen as reflecting enhanced 'knowledge' or levels of 'interest' rather than schema. However, if the term schema is understood as referring to a complex knowledge structure relating to a single topic then this effect is indeed compatible with the presence of such a schema. The particular theory that was adopted in this section of the thesis was that of Leventhal and Everhart and their notion of schema reflects not simply a knowledge base but a level of representation that embodies emotional and pain responses i.e. a 'hot' level of representation.

Leventhal and Everhart's theory provides a richly detailed description of how pain experience becomes mentally represented and can influence pain perception and experience. However, whilst the pain-related recall bias can be seen as consistent with the role of a complex knowledge structure which aids the encoding and retrieval of material, the evidence that this is consistent with the role of the type of schematic level of representation proposed by Leventhal and Everhart is less convincing. As discussed in Chapter 1 (section 1.4.1) and Chapter 4, the schematic level of Leventhal and Everhart's model represents an analogue of past pain experiences. As there is no link between the strength of pain-related recall bias and levels of pain intensity this raises questions about whether the schematic level is being tapped by word list methods and memory tasks. Whilst it could be argued that interpretative biases and recall biases are consistent with conceptual activation of the schematic level, such an interpretation arguably seems unnecessarily elaborate as this result can be explained by appealing to complex knowledge representations at a conceptual level without appealing to schematic involvement.

The significance of an interpretative bias in terms of the Integrated model of Williams *et al.* is less clear. In their book on cognitive psychology and emotional disorders Williams *et al.* report on a body of work which predominantly uses word lists and they largely assume that word meaning is invariant across participant groups. Whilst they acknowledge certain limitations with using word lists they claim that they offer

increased amounts of experimental control. This assumption seems questionable, given that interpretative biases have been demonstrated in anxiety sufferers and such results have been interpreted in line with their theory. In addition, they acknowledge that such interpretative biases can occur not just for words which are actually considered different in meaning but which sound the same (i.e. negative and neutral ambiguous homophones) but for material which is ostensibly neutral. For example, in their discussion of the processes underlying the anxiety-related interpretative bias they state that:

> "negative items may appear to come into consciousness of their own accord due to the operation of previously primed items acting to disambiguate otherwise neutral stimuli in a negative way." (p. 281).

Williams *et al.* argue that interpretative biases can arise from either strategic, active memory processes or passive ones. The former involves active conscious memory search and the latter involves passive memory processes, such as things coming to mind without any conscious effort to retrieve them. They argue that the biased interpretations of ambiguous homophones towards negative meanings in anxious participants (e.g. writing down 'weak' rather than 'week') could be the result of priming brought about by mood state, or by frequent rumination on threatening themes. As a result such people have "relatively frequently activated representations which bias towards threat on these interpretative tasks" (Williams *et al.;* p. 283). Hence whilst interpretative biases are consistent with their theory, they can be seen as arising from strategic and/or passive processes and it is unclear which process may lie behind the interpretative bias demonstrated in chronic pain sufferers in Chapter 3. Because information processing biases in chronic pain have been summarized as supporting the role of processes of elaboration (a strategic process) rather than priming (a passive process) (Pincus, 1993), it would be more in keeping with such findings to suggest that the interpretative bias towards perceiving word meanings as pain-related in chronic pain sufferers is the product of conscious strategic processes. This means the process of elaboration is

involved. Elaboration refers to the deployment of mnemonic cues which can occur either at encoding or retrieval of a target word and which become associated with it, thereby aiding its retrieval. The results of Study 1 could therefore be interpreted as showing that such elaboration involves the use of category labels such as 'pain' more often in chronic pain sufferers than non-pain controls, e.g. that pain sufferers make more use of a higher order grouping/categorization strategy than non-pain controls. However, there is no direct evidence that it is the result of a strategic process, and the interpretative bias could be one which precedes conscious labelling and reflects the automatic process of priming.

Although the result of Study 2 can be interpreted as an information processing bias, as mentioned earlier, it remains to be demonstrated whether this is a feature of enhanced knowledge about a given area of life, or whether it indeed relates to something 'emotive'. In Teasdale and Barnard's Interacting Cognitive Subsystems model they propose that the recall bias in depressive participants is the product of material being processed at the Implicational or 'emotionally hot' level of representation. However, as noted earlier, the interpretative bias demonstrated in Study 2 in chronic pain sufferers was also demonstrated in a participant group who had an interest in a portion of the words (amateur gardeners) and hence does not appear to be an effect which is the specific reserve of emotional and pain 'disorders'.

The results of Study 1 and 2 together suggest that categorization effects should be more carefully considered in work on information processing biases in pain and emotion. To date, a pain-related recall bias has typically been demonstrated when 3 different word types have been used, sensory-pain, affective-pain and neutral words. However the neutral words have tended to be uncategorized. Whilst Study 2 examined how people categorized words and whether this differed according to group status, the neutral word group used was a gardening category, hence the words were different to those used in previously published work on recall biases in chronic pain sufferers.

Hence future research exploring the role of categorization processes in information processing biases could begin by repeating Study 2 but using the same words used in the Edwards *et al.* (1992) and Pincus *et al.* (1993) studies. Studies could also be conducted to explore whether the processes underlying this biased interpretation appear to be automatic or strategic ones by for example exploring the effect of pre-conscious priming of category labels on subsequent recall.

In summary, Study 1 aimed to explore a mechanism (retrieval inhibition) involved in the preferential selection of pain schema which then dominates information processing. However, it is argued in this thesis that when semantically related words are used (and hence when there are identifiable categories of words), the directed forgetting paradigm may not be able to clearly tease apart the process (retrieval inhibition) from the effect it aims to explain. This is because perceived word meaning (resulting from the dominance of pain schema in information processing which in turn cause an interpretative bias) could potentially cause an apparent lack of retrieval inhibition. More specifically, it is argued that category size (caused by an interpretative bias) may vary along with the directed forgetting manipulation (the instruction either to 'forget' or 'remember' the first list of words that has been seen). Hence, the retrieval inhibition paradigm may not be able to study why pain schema might dominate consciousness, independently from the domination of pain schema. As a result, the retrieval inhibition paradigm is somewhat limited in its ability to provide a clear answer to the initial research question which concerned a potential mechanism for the dominance of pain schema in the processing of information and the selection of pain schema. The remaining two studies in the thesis therefore aimed to explore pain meanings associated with poor adjustment to pain. Further, they aimed to use methods which were arguably better able to tap pain meanings than those used in Studies 1 and 2. In the latter studies, pain meanings or schema content were assessed using word lists. This method infers

schema content from material which is preferentially recalled or interpreted. However, in Chapter 4 it was argued that to gain access to more individualized pain meanings, individual pain descriptors needed to be used along with an understanding of the hypotheses about those descriptors.

7.2 SCHEMA CONTENT AND PREDICTORS OF ADJUSTMENT IN CHRONIC PAIN

Studies 3 and 4 explored aspects of schema content that are associated with poor adjustment to pain, and focused on issues surrounding understandings and acceptance of the limitations imposed by pain on everyday life.

7.2.1 Study 3

In Study 3 a method was used which was specifically designed to assess symptom representation at a conceptual level: Lacroix *et al.*'s method for measuring symptom understanding. Lacroix *et al.* demonstrated the utility of this measure in predicting return to work in back pain sufferers following a work-related injury, whereby higher levels of agreement were associated with a greater likelihood of returning to work, and also demonstrated its more general use in predicting disability in people suffering from chronic respiratory disorders.

Study 3 aimed to explore Lacroix *et al.*'s claim that this method tapped into a crucial predictor of pain-adjustment by offering a measure of schema distortion/accuracy. However the results of Study 3 did not support the view that symptom understanding predicted pain-adjustment when measures of current involvement in different life domains and depression were used as measures of adjustment. Reasons for these results were discussed in Chapter 5 and may relate to a Type II error or sample differences between this study and that of Lacroix *et al.* which lead to a reduced effect size.

The effect of role/goal loss and coping were also assessed to explore the relationship between acceptance of the limitations imposed by pain on pain-adjustment, although again no clear results were found. Pre-pain levels of involvement in hobbies were associated significantly with current levels of depression suggesting that disruption to this life domain might be important in understanding adjustment. The coping style of flexible goal adjustment did not emerge as a significant moderator of the relationship between role/goal 'losses' and current adjustment, although again, this may have been due to reduced power in the analysis. However there are clear limitations with this study which relate to the measures used.

7.2.2 Limitations of Study 3

The key limitations of this study revolve less around the design of the study and more around its theoretical basis. As a method of tapping sensory schema it has been argued that Lacroix *et al.*'s method represents an improvement on word list methods as it uses the patients' own pain symptoms. In this way it may therefore address schema content more accurately and more directly by questioning people about their symptoms, rather than using the indirect method of memory tasks to assess schema content. In addition it addresses their hypotheses about their symptoms and hence arguably assesses aspects of the meaning of the pain symptoms which word list methods and memory tasks arguably do not. Furthermore, whilst this aspect of pain schema was addressed within the broader context of the impact the pain had had, by measuring pre-pain life involvement in different life domains, the method is still limited. The primary limitation is the assumption that the doctor's assessment constituted the 'correct' view of the pain symptoms and hence that a measure of agreement between doctor and patient was a measure of the degree of 'distortion' of the pain patient's sensory pain schema. This assumption can clearly be challenged. Doctors can vary in the diagnoses and explanations they give to patients regarding the pain and in some instances the patient

may have a more complete understanding of their symptoms, particularly if there are multiple problems and etiologies involved. Furthermore, this schematic distortion could either be under-elaborate or over-elaborate and this method would not be able to distinguish between the two. However, the latter distinction might be more valuable in predicting pain adjustment, as degree of elaboration might relate to factors such as degree of rumination about the pain problem.

Furthermore it is not necessarily agreement about symptom understanding that is the central issue in relation to adjustment. For example, there may be agreement in symptom understanding but that agreement may reflect the fact that no cause has actually been identified. Hence having a diagnosis may be more important than being in agreement with one's doctor that there is no diagnosis. Lacroix *et al.* argue that there are various aspects of schema namely, symptom cause, their consequences, their time-line and possibilities for their cure. Whilst symptom cause and to some extent their consequences were addressed in Study 3, it may be the symptoms consequences and possibilities for their cure which are crucial when considering pain adjustment. Understanding the symptoms is clearly a vital first step in being offered treatment and perhaps more importantly in signifying the possibility of a cure. A method which examines cause but not cure may therefore be too partial an account of pain symptoms to be of predictive value. Hence, although Lacroix *et al.*'s method involved asking patients about the possibility of a cure for their pain, the same question was not asked of the doctor and it may be agreement about the possibility of a cure which predicts adjustment better than symptom understanding. For example, Osbourne and Smith (1998) argue that biomedical explanations fail to be of help in understanding chronic condition such as pain, and go so far as to argue that:

> "The participants' frustrations highlighted the dominance and essential weakness of the application of a purely biomedical model in their attempts to conceptualise their situation. Such medicalization of our understanding of our bodies is referred to extensively in the medical sociology literature... and is shown in this study to be a major impediment to the participant's endeavours to understand and accommodate to their pain." (p. 75).

There were also problems with the measures used to assess role/goal loss and coping style and these were discussed in section 5.7.8. A particular problem concerned the potential confounding of the measurement of coping with the measurement of adjustment, and this was discussed in Chapter 5 (section 5.7.8).

7.2.3 Study 4

Study 4 aimed to directly address the meaning of the pain to individual pain sufferers by using open-ended interviews and analysing them using grounded theory. Four key categories emerged which all related to how people perceived and responded to the impact the pain had had. Pain was seen as potentially affecting both people's private sense of themselves and their more public sense of identity. The impact the pain had on people's lives was evaluated through a process of social comparison whereby people compared themselves both with other people around them and with their pre-pain selves. This impact was then dealt with in a number of different ways, with some people accommodating their lives to fit around the pain and accepting certain life changes, whilst others continued to challenge the limits the pain imposed by, for example, doing things known to aggravate the pain.

In general, much of peoples' lives were geared towards maintaining normality, hence the over-arching theme of this theory was the way in which people attempted to lead normal lives through the constraint of having pain. This meant not only trying to regain 'global' standards of normality, such as being able to walk like a typical person of that age, but for some people, in regaining or maintaining more personal standards as well, such as appearing younger than their chronological age. However, for others, the

possibility for maintaining pre-pain standards of normality had to be relinquished and changes in what they considered 'normal' had to be made.

The four categories that emerged, and which related to this central theme, did not relate to each other in any straightforward way. That is, there was no obvious, inevitable link between the size of the life impact which was perceived and people's response to it. Quite often, small life changes were perceived as having a huge impact. Hence the severity of people's disability did not always relate to adjustment. Whilst for some, pain severity clearly resulted in severe disability (e.g. in the case of sciatic pain), for others the level of pain complaint was relatively mild but still had considerable negative consequences.

7.2.4 Limitations of Study 4

A grounded theory can only address one substantive issue, in this case the personal experience of having pain, with an emphasis on how it had affected their lives and how this impact had been dealt with. Hence the theory presented did not address issues surrounding symptom understanding and treatment seeking, although these emerged as issues in people's interviews and could be the topic of a grounded theory in their own right. However this is not considered a limitation of the grounded theory presented in the thesis or the grounded theory method in general. This focusing on one substantive issue is considered essential in order to produce a coherent theory and serves to stress that no grounded theory is an exhaustive theory of a given area such as chronic pain.

Perhaps the most important limitation of this study relates to the sample studied and the fact that it included only patients attending a pain clinic. The theory presented arguably represents a select and perhaps biased sample of chronic pain sufferers which may limit its generality and scope. However, the theory which was presented related to perceived life impact and, as noted in Chapter 6, people's reasons for attending clinics is

often to minimise the impact the pain is having. Sampling from the wider community may therefore serve to produce accounts from people for whom the pain poses little of no life impact and hence may not offer information which extends the meanings of the categories presented in Chapter 6. Although this remains an empirical question, it is not one that diminishes the value of the theory presented in Chapter 6, but rather one that questions its scope.

7.2.5 Implications for theories of depression and adjustment in chronic pain

The studies conducted in this thesis have implications for theories of depression in chronic pain and also implications for theories of activity avoidance and chronic pain.

Study 3 examined predictors of depression, looking at both the role of symptom understanding and role/goal losses and coping. These predictors focused on accurate understanding of the limitations associated with pain, and the actual limitations imposed by pain in terms of role/goal loss (more specifically, reduction in role/goal involvement). Whilst little could be concluded about the role of these in predicting adjustment based on the findings of Study 3 due to the lack of significant relationships found, the results of Study 3 did suggest that levels of pre-pain involvement in personal interests and hobbies may play a particular role in the development of depression in chronic pain sufferers. However, this result would need to be replicated in a longitudinal design to check that it was not the product of a retrospective positive bias whereby those who were currently depressed over-estimated their level of pre-pain involvement in an activity that they had previously considered pleasurable. Such a study could be a topic for future research. In addition, whether this relationship reflects the reduction of enjoyable activities in everyday life or the loss of activities arguably more central to one's sense of identity remains to be explored.

The results of Study 4, however, do have implications for theories of depression

and activity avoidance. A great deal of work in the chronic pain literature focuses on understanding depression in chronic pain. As noted in Chapter 5, theories of depression often focus on the notion of loss. The idea that there are numerous losses that accompany the experience of chronic pain receives support from the findings of Study 4. However Study 4 suggests the a key concept in understanding the problems associated with chronic pain is that of constraint, and this differs somewhat from the concept of loss. Constraint, or not being able to do certain things, implies that the status of the things that cannot be done is potentially questionable and hence that they are not necessarily losses. The concept of constraint indicates the possibility that activities can be done but at a price, whether that be intolerable levels of pain or presenting an identity one does not wish to present. It also indicates that the issue of whether certain activities can be done in the future is open to question. The significance of this is that different people may have different understandings of the extent to which things can no longer be done and this difference is arguably reflected in people's response to constraint, which is documented in Study 4. Williams (1998) has made a similar point, arguing that whilst chronic pain may be associated with a range of losses, the status of such losses is uncertain. This suggests that theories of depression in pain may need to be reconsidered and/or that one of the dominant emotions accompanying pain is not depression arising from loss, but frustration arising from constraint.

In brief, the findings of Study 4 also have implications for understanding activity avoidance in chronic pain. Much previous research into activity avoidance centres on the role of fear and anxiety in the avoidance of physical and social activities (e.g. Asmundson, Norton and Norton, 1999) however the results of Study 4 suggest that avoidance behaviours may be the result of attempting to maintain pre-pain identities and not solely concerns surrounding the pain itself.

Finally, the results of Study 4 suggest relatively new concepts for understanding adjustment in chronic pain. The grounded theory method allowed people's experience of pain to be explored without adopting any prior theoretical commitments, to see what categories emerged and hence how theory development in understanding people's adjustment to chronic pain might proceed. One clear finding that did emerge was that adjustment to pain may mirror adjustment to the ageing process. The experience of chronic pain was likened to that of 'premature ageing' both explicitly by some participants through their expression of feeling that the constraints brought on by the pain have happened too rapidly and reflect an experience analgous to not being able to be allowed to grow old gracefully, and implicitly through its effect on factors such as speed of movement, loss of spontaneity, restricted movement and its effect on dependency. This parallel could be explored more fully in future research.

7.3 CLINICAL IMPLICATIONS

The clinical implications of the studies reported in this thesis fall broadly into those relating to the treatment of pain intensity and those relating to adjustment to pain.

In this thesis the argument has been forwarded that the pain-related recall bias demonstrated in chronic pain sufferers may not tap the schematic level of Leventhal and Everhart (1979). In addition, and as noted in Chapter 1, there is evidence that efforts to alter people's conscious beliefs and thoughts about pain through cognitive-behavioural therapy often do not result in reductions in pain intensity. Together this suggests that methods addressing the verbal level of representation, as posited by Leventhal and Everhart, have little impact on pain intensity but do have an impact on pain adjustment. This suggests that other methods might be more appropriate for targeting changes in pain intensity. Theoretically it seems that in order to tap the type of schematic level of representation put forward by Leventhal and Everhart, sensory pain input would need to be manipulated along with conceptual level input. In the area of depression, Teasdale

and Barnard argue that emotion can be triggered by verbal material if it addresses the 'implicational' level of representation, which in their model is the level of representation which is 'emotive'. This level is equivalent to the 'schematic' level in Leventhal and Everhart's model. Recent theorizing about cognitive approaches within clinical psychology, most notably Brewin (1989), have suggested that in order to change emotional experiences such emotive levels of representation need to be tapped, i.e. they cannot be changed by addressing conscious beliefs alone.

The results of Study 3 suggest that levels of pre-pain involvement in personal hobbies/interests play more of a role in depression than pre-pain involvement in work, relationships, health and independence, and could therefore be a focus for psychological therapy. However the results of Study 4 suggest that the impact pain has had on people's identity should be explored and hence the focus of any therapy should arguably be broader, particularly for those who restrict their activity in order to project as 'normal' an image as possible. In addition, there were clear parallels between experiencing chronic pain and growing older. Hence psychological therapy could also focus on developmental and life span issues and their role in adjusting to pain.

7.4 TRAJECTORY OF THE STUDIES IN THE THESIS

Study 1 aimed to explore a possible contributor (lack of retrieval inhibition) to the pain-related recall bias previously demonstrated in chronic pain sufferers. However a possible alternative contributor to the demonstration of recall biases in chronic pain emerged in Study 2, that of superior categorization of pain-related words in chronic pain sufferers in comparison with pain free controls. Hence one line of research that could be pursued is a closer examination of categorization processes in the demonstration of recall biases in chronic pain sufferers. For example, the words used in previous research could have been used in order to see the effect of pain-status on categorization when an uncategorized rather than categorized neutral word group was used. However, the

results of Study 2 also suggest that those processes involved in the recall bias research may be the product of 'normal' categorization processes which occur as a result of personal interest and do not just relate to 'pathology' as amateur gardeners demonstrated a similar response to gardening words as did pain sufferers to pain words. Hence the emphasis of this line of work would be to explore issues central to 'normal' memory rather than exploring issues more specific to chronic pain experience.

The final study in the thesis involved the use of grounded theory to develop concepts from open-ended interviews. Whilst the interviews were conducted without any pre-conceived theoretical concepts, the themes which were explored included the perceived impact of pain and people's adjustment to it, rather than themes which related to issues surrounding pain diagnosis and treatment. This was principally because the themes of perceived impact were more frequent in people's accounts than those relating to treatment. Hence the aspect of Study 3 which was explored in Study 4 related to the relationship between pain and adjustment and the processes involved in coping with pain.

Had Study 4 been the initial study in the thesis, then the relationship between adjustment to chronic pain and adjustment to the ageing process and the ageing literature in general could have been explored and developed more fully. In addition, the specific hypotheses that emerged from this final study could have been directly tested. Explicit hypotheses which could have been trested include the possible moderating role of concern about identity presentation in the link between pain intensity and pain-related disability or activity restriction that emerged. Those concerned about how they may look to others reported deliberately restricting activities, particularly public or social activities, in order to 'manage' the identity that they projected. In addition, the analogy between having chronic pain and 'premature ageing', suggests that the role of acceptance of factors associated with the ageing process, including such things as the importance of the loss of spontaneity in life, the reduction in the speed that things can be

done, and the development of dependency on people, may play a key role in predicting adjustment to chronic pain.

Alternatively, the results of Study 4 could have been further developed either by extending a grounded theory analysis to other groups who, like chronic pain sufferers, are attempting to maintain normal lives through the face of certain constraints. Such groups might include other people with disabilities whereby the disability forms the constraint, or any people caring for dependants whether these be young children or older adults.

7.4.1 Strengths and weaknesses of different methodologies

There are different approaches that can be taken to study phenomenon in the social sciences. Traditional empirical methods in psychology search for universal causal laws which govern behaviour, whilst historical-hermeneutic approaches serve to discover the meanings people perceive. The latter are subject to change and hence vary between people and across cultures. However, no one approach to research is considered superior, but particular approaches are more suited to addressing particular questions than others. Hence the choice of methods in the thesis has largely reflected the nature of the issue being addressed.

The meaning that symptoms have is thought to be a key factor in understanding pain experience and the use of some methods for exploring pain schema appear to be better than others. In studies on recall biases for example, the meaning of schema content is not explored so much as the general ways in which schema operate to aid the encoding and retrieval of pain-related information. Hence chronic pain sufferers are all grouped together and individual differences left unexplored. In contrast, whilst the grounded theory method can be seen as plotting the range of individual meanings that the pain has for different people, it often gets criticized for potentially being the product of subjective interpretation of the researcher and hence prone to experimenter bias.

However, the results of a grounded theory analysis can be seen as a preliminary stage in what is otherwise a traditional empirical project and hence can lead to testable hypotheses providing some validation of the findings of the grounded theory. Whilst a grounded theory can be conceptualized as generating hypotheses which can later be tested, it can also be seen as a piece of research which documents the range of meanings pain has for people, which constitutes an end in itself.

In summary the studies in this thesis have offered contributions to the understanding of information processing biases in chronic pain and factors involved in adjustment to chronic pain. The work on memory and perceived word meaning in Studies 1 and 2 has contributed hypotheses as to the possible mechanisms underlying the pain-related recall bias (i.e. categorization processes) and how the interpretative bias demonstrated in Study 2 might be understood within Leventhal and Everhart's theory and the integrated model of Williams *et al.*. Study 3 explored evidence for theoretical concepts in the literature on chronic pain and adjustment through a test of Lacroix *et al.*'s assertion that symptom understanding is a significant predictor of pain- adjustment and through a test of Schmitz *et al.*'s claim that chronic pain adjustment is moderated by the flexible adjustment coping style. And finally Study 4 illustrated that people's private experience of themselves and their sense of identity may be crucial in understanding adjustment to chronic pain, proposing that possible moderators of the link between pain severity and adaptive functioning may include concern about the identity people project. Furthermore the results of this study suggest that the analogy between having pain and the ageing process may be one worth exploring in order to understand how and why certain people adjust to pain and certain people do not.

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APPENDIX A

CONFIDENTIAL

PATIENT INFORMATION SHEET

Volunteers are invited to take part in a study investigating memory and long term pain.

It will involve about 45 minutes of your time. You will be asked to do a straightforward test of memory and complete some short questionnaires. These questionnaires will relate to how you are currently feeling. All completed questionnaires, and other information gathered as part of this study, will be referred to by serial numbers only. At no time will any individual participant be mentioned by name or otherwise identified, so the information you put down will be annonymous and confidential. However, some of the questions in the questionnaires you will be asked to complete may be considered to be of a personal nature so please consider this before you give your consent.

Please feel free to discuss details of this study with the researcher present.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason.

You will find a consent form attached, please fill this is if you are happy to participate in this study, and retain this information sheet for your own reference.

CONFIDENTIAL

HEALTHY VOLUNTEER INFORMATION SHEET

Volunteers are invited to take part in a study investigating memory and long term pain.

It will involve about 45 minutes of your time for which you will be paid £3. You will be asked to do a straightforward test of memory and complete some short questionnaires. These questionnaires will relate to how you are currently feeling. All completed questionnaires, and other information gathered as part of this study, will be referred to by serial numbers only. At no time will any individual participant be mentioned by name or otherwise identified, so the information you put down will be annonymous and confidential. However, some of the questions in the questionnaires you will be asked to complete may be considered to be of a personal nature so please consider this before you give your consent.

Please feel free to discuss details of this study with the researcher present.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason.

You will find a consent form attached, please fill this is if you are happy to participate in this study, and retain this information sheet for your own reference.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research.

CONFIDENTIAL

PATIENT CONSENT FORM

Have you read the information sheet about this study?	YES/NO
Have you had an opportunity to ask questions and discuss this study?	YES/NO
Have you received satisfactory answers to all your questions?	YES/NO
Have you received enough information about this study?	YES/NO
Which researcher have you spoken to about this study?	ANNE MILES / VAL CURRAN

Do you understand that you are free to withdraw from this study:

at any time	YES/NO
without giving a reason for withdrawing	YES/NO
without affecting your future medical care	YES/NO

Do you agree to take part in this study? YES/NO

SIGNED..... DATE:.....

PRINT NAME.....

INVESTIGATOR.....

CONFIDENTIAL

HEALTHY VOLUNTEER CONSENT FORM

Have you read the information sheet about this study?	YES/NO
Have you had an opportunity to ask questions and discuss this study?	YES/NO
Have you received satisfactory answers to all your questions?	YES/NO
Have you received enough information about this study?	YES/NO
Which researcher have you spoken to about this study?	ANNE MILES / VAL CURRAN

Do you understand that you are free to withdraw from this study:

at any time	YES/NO
without giving a reason for withdrawing	YES/NO

Do you agree to take part in this study? YES/NO

SIGNED..... DATE:.....

PRINT NAME.....

INVESTIGATOR.....

CONFIDENTIAL **SUBNO.....**

DATA SHEET

Please indicate how hard you feel you tried in this study:

0	1	2	3	4	5	6	7	8	9	10
I didn't try at all										I tried my hardest

Did you notice anything unusual about any of the words?

.....

.....

Did you use any particular strategy to help you remember the words?

.....

.....

CONFIDENTIAL SUBNO_____

NATIONAL ADULT READING TEST (NART)

CHORD	SUPERFLUOUS
ACHE	SIMILE
DEPOT	BANAL
AISLE	QUADRUPED
BOUQUET	CELLIST
PSALM	FAÇADE
CAPON	ZEALOT
DENY	DRACHM
NAUSEA	AEON
DEBT	PLACEBO
COURTEOUS	ABSTEMIOUS
RAREFY	DETENTE
EQUIVOCAL	IDYLL
NAÏVE	PUERPERAL
CATACOMB	AVER
GAOLED	GAUCHE
THYME	TOPIARY
HEIR	LEVIATHAN
RADIX	BEATIFY
ASSIGNATE	PRELATE
HIATUS	SIDEREAL
SUBTLE	DEMESNE
PROCREATE	SYNCOPE
GIST	LABILE
GOUGE	CAMPANILE

CONFIDENTIAL **SUBNO_____**

VISUAL ANALOGUE SCALES

Please place draw a line across the scales like this: _____ to indicate your answer to the questions below.

1) Please rate the level of your pain as it is *right at this moment*

_____|_____|_____

0 **100**

No pain **Worst pain imaginable**

2) Please rate the level of your pain as it has been *on average* over this last week including today

_____|_____|_____

0 **100**

No pain **Worst pain imaginable**

3) Please rate the level of your pain as it was *at its worst* over this last week including today

_____|_____|_____

0 **100**

No pain **Worst pain imaginable**

4) Please rate the level of your pain as it was *at its least* over this past week including today

_____|_____|_____

0 **100**

No pain **Worst pain imaginable**

MOOD RATING SCALE

1) Please rate the way you feel in terms of the dimensions given below

2) Regard the line as representing the full range of each dimensions

3)Rate your feelings as they are AT THE MOMENT

4)Mark clearly and perpendicularly across each line

ALERT	————————————	**DROWSY**
CALM	————————————	**EXCITED**
STRONG	————————————	**FEEBLE**
MUZZY	————————————	**CLEAR-HEADED**
WELL-COORDINATED	————————————	**CLUMSY**
LETHARGIC	————————————	**ENERGETIC**
CONTENTED	————————————	**DISCONTENTED**
TROUBLED	————————————	**TRANQUIL**
MENTALLY SLOW	————————————	**QUICK WITTED**
TENSE	————————————	**RELAXED**
ATTENTIVE	————————————	**DREAMY**
INCOMPETENT	————————————	**PROFICIENT**
HAPPY	————————————	**SAD**
ANTAGONISTIC	————————————	**AMICABLE**
INTERESTED	————————————	**BORED**

CONFIDENTIAL **SUBNO_____**

SELF-EVALUATION QUESTIONNAIRE (SPEILBERGER)

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement, and then circle the appropriate number to the right of the statement to indicate how you *feel* right now, that is, *at this moment.* There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

NOT AT ALL	SOMEWHAT	MODERATELY	VERY MUCH
1	2	3	4

1) I feel calm	1	2	3	4
2) I feel secure	1	2	3	4
3) I am tense	1	2	3	4
4) I am regretful	1	2	3	4
5) I feel at ease	1	2	3	4
6) I feel upset	1	2	3	4
7) I am presently worrying over possible misfortunes	1	2	3	4
8) I feel rested	1	2	3	4
9) I feel anxious	1	2	3	4
10) I feel comfortable	1	2	3	4
11) I feel self-confident	1	2	3	4
12) I feel nervous	1	2	3	4
13) I am jittery	1	2	3	4
14) I feel "high strung"	1	2	3	4
15) I am relaxed	1	2	3	4
16) I feel content	1	2	3	4
17) I am worried	1	2	3	4
18) I feel over-excited and "rattled"	1	2	3	4
19) I feel joyful	1	2	3	4
20) I feel pleasant	1	2	3	4

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you have been feeling *generally* in the *past few weeks*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your general feelings over the past week best.

NOT AT ALL	**SOMEWHAT**	**MODERATELY**	**VERY MUCH**
1	**2**	**3**	**4**

21) I feel pleasant	1	2	3	4
22) I tire quickly	1	2	3	4
23) I feel like crying	1	2	3	4
24) I wish I could be as happy as others seem to be	1	2	3	4
25) I am losing out on things because I can't make up my mind soon enough	1	2	3	4
26) I feel rested	1	2	3	4
27) I am "calm, cool and collected"	1	2	3	4
28) I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
29) I worry too much over something that really doesn't matter	1	2	3	4
30) I am happy	1	2	3	4
31) I am inclined to take things hard	1	2	3	4
32) I lack self-confidence	1	2	3	4
33) I feel secure	1	2	3	4
34) I try to avoid facing a crisis or difficulty	1	2	3	4
35) I feel blue	1	2	3	4
36) I am content	1	2	3	4
37) Some unimportant things runs through my mind and bothers me	1	2	3	4
38) I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
39) I am a steady person	1	2	3	4
40) I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

CONFIDENTIAL **SUBNO_____**

BECK DEPRESSION INVENTORY (BDI)

This questionnaire consists of 21 groups of statements (indicated by numbers 1 to 21). After reading each group of statements carefully, circle the number (0, 1, 2 or 3) next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally well, circle each one. **Be sure to read all the statements in each group before making your choice.**

1.
0 I do not feel sad
1 I feel sad
2 I am sad all the time and I can't snap out of it
3 I am so sad or unhappy that I can't stand it

2.
0 I am not particularly discouraged about the future
1 I feel discouraged about the future
2 I feel that I have nothing to look forward to
3 I feel that the future is hopeless and that things cannot improve

3.
0 I do not feel like a failure
1 I feel I have failed more than the average person
2 As I look back on my life all I can see is a lot of failures
3 I feel I am a complete failure as a person

4.
0 I get as much satisfaction out of things as I used to
1 I don't enjoy things the way I used to
2 I don't get real satisfaction out of anything anymore
3 I am dissatisfied or bored with everything

5.
0 I don't feel particularly guilty
1 I feel guilty a good part of the time
2 I feel quite guilty most of the time
3 I feel guilty all of the time

6.
0 I don't feel I am being punished
1 I feel I may be punished
2 I expect to be punished
3 I feel I am being punished

7.
0 I don't feel disappointed in myself
1 I am disappointed in myself
2 I am disgusted with myself
3 I hate myself

8.
0 I don't feel I am any worse than anybody else
1 I am critical of myself for my weaknesses or mistakes
2 I blame myself all the time for my faults
3 I blame myself for everything bad that happens

9.
0 I don't have any thoughts of killing myself
1 I have thoughts of killing myself but I would not carry them out
2 I would like to kill myself
3 I would kill myself if I had the chance

10.
0 don't cry any more than usual
1 I cry more now than I used to
2 I cry all the time now
3 I used to be able to cry but now I can't cry even though I want to

11.
0 I am no more irritated now than I ever am
1 I get annoyed or irritated more easily than I used to
2 I feel irritated all the time now
3 I don't get irritated at all by the things that used to irritate me

12.
0 I have not lost interest in other people
1 I am less interested in other people than I used to be
2 I have lost most of my interest in other people
3 I have lost all of my interest in other people

13.
0 I make decisions about as well as I ever could
1 I put off making decisions more than I used to
2 I have greater difficulty in making decisions than before
3 I can't make decisions at all anymore

14.
0 I don't feel I look any worse than I used to
1 I am worried that I am looking old or unattractive
2 I feel that there are permanent changes to my appearance that make me look unattractive
3 I believe that I look ugly

15.
0 I can work about as well as before
1 It takes an extra effort to get started at doing something
2 I have to push myself very hard to do anything
3 I can't do any work at all

16.
0 I can sleep as well as usual
1 I don't sleep as well as I used to
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
3 I wake up several hours earlier than I used to and cannot get back to sleep

17.
0 I don't get more tired than usual
1 I get tired more easily than I used to
2 I get tired from doing almost anything
3 I am too tired to do anything

18.
0 My appetite is no worse than usual
1 My appetite is not as good as it used to be
2 My appetite is much worse now
3 I have no appetite at all anymore

19.
0 I haven't lost much weight, if any, lately
l I have lost more than 5 pounds (2 kilos)
2 I have lost more than 10 pounds (4 kilos)
3 I have lost more than 15 pounds (7 kilos)

I am purposely trying to lose weight by eating less:

YES____ NO____

20.
0 I am no more worried about my health than usual
1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation
2 I am very worried about physical problems and it's hard to think of much else
3 I am so worried about my physical problems that I cannot think about anything else

21.
0 I have not noticed any recent changes in my interest in sex
1 I am less interested in sex than I used to be
2 I am much less interested in sex now
3 I have lost interest in sex completely

CONFIDENTIAL **subno_____**

Age.....

Sex.....

Do you have a painful condition at the moment? **YES/NO**

How long have you had this pain for?.....

Has the pain lasted for more than 6 months? **YES/NO**

Where is your pain located?.....

What is your diagnosis (if known)?.....

Are you currently on any medication? **YES/NO**

If so, please could you list the tablets you are currently taking

.....

.....

What is your present occupation?.....

If you are not currently working, what was your previous occupation?

.....

CONFIDENTIAL **SUBNO_____**

GARDENING MEASURES

Do you pursue gardening as a hobby? **YES/NO**

How much do you enjoy gardening?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very much

How often do you garden?

0	1	2	3	4	5	6	7	8	9	10
Never										Very often

APPENDIX B

CONFIDENTIAL

PATIENT INFORMATION SHEET

Volunteers are invited to take part in a study looking at long-term pain and word meaning. The aim of the study is to find out which words people think are similar to each other in meaning and which words people think are different.

It will involve approximately half an hour of your time. You will be asked to sort 44 words into different piles according to their meaning and to complete some short questionnaires. These questionnaires will relate to how you are currently feeling. All the information gathered as part of this study will be totally confidential (it will be referred to by serial number only). However, some of the questions in the questionnaires you will be asked to complete may be considered to be of a personal nature so please consider this before you give your consent.

Please feel free to discuss details of this study with the researcher present.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. Your decision to take part or not will not affect your care and management in any way.

You will find a consent form attached, please fill this is if you are happy to participate in this study, and retain this information sheet for your own reference.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research.

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HEALTHY VOLUNTEER INFORMATION SHEET

Volunteers are invited to take part in a study looking at long-term pain and word meaning. The aim of the study is to find out which words people think are similar to each other in meaning and which words people think are different.

It will involve approximately half an hour of your time for which you will be paid £4. You will be asked to sort 44 words into different piles according to their meaning and to complete some short questionnaires. These questionnaires will relate to how you are currently feeling. All the information gathered as part of this study will be totally confidential (it will be referred to by serial number only). However, some of the questions in the questionnaires you will be asked to complete may be considered to be of a personal nature so please consider this before you give your consent.

Please feel free to discuss details of this study with the researcher present.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason.

You will find a consent form attached, please fill this is if you are happy to participate in this study, and retain this information sheet for your own reference.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research.

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PATIENT CONSENT FORM

Have you read the information sheet about this study?	YES/NO
Have you had an opportunity to ask questions and discuss this study?	YES/NO
Have you received satisfactory answers to all your questions?	YES/NO
Have you received enough information about this study?	YES/NO
Which researcher have you spoken to about this study?	ANNE MILES / VAL CURRAN
Do you understand that you are free to withdraw from this study:	
at any time	YES/NO
without giving a reason for withdrawing	YES/NO
without affecting your future medical care	YES/NO
Do you agree to take part in this study?	YES/NO

SIGNED..... DATE:.....

PRINT NAME.....

INVESTIGATOR.....

CONFIDENTIAL

HEALTHY VOLUNTEER CONSENT FORM

Have you read the information sheet about this study?	YES/NO
Have you had an opportunity to ask questions and discuss this study?	YES/NO
Have you received satisfactory answers to all your questions?	YES/NO
Have you received enough information about this study?	YES/NO
Which researcher have you spoken to about this study?	ANNE MILES / VAL CURRAN

Do you understand that you are free to withdraw from this study:

at any time	YES/NO
without giving a reason for withdrawing	YES/NO

Do you agree to take part in this study? YES/NO

SIGNED..... DATE:.....

PRINT NAME.....

INVESTIGATOR.....

APPENDIX C

CONFIDENTIAL

PATIENT INFORMATION SHEET

Please read this information sheet carefully. Take as much time as you feel you need to decide whether or not you would like to take part.

This study has been reviewed and given ethical approval by the Harrow Research Ethics Committee.

Volunteers are invited to take part in a study looking at how chronic pain sufferers think about their symptoms. The study aims to look at the explanations chronic pain sufferers use to understand their symptoms. It also aims to look at how this understanding fits into a broader context. For example, how their understanding relates to the impact the pain has had on their lifestyle. It is hoped that this study will contribute to our understanding of the experience of chronic pain.
If you decide to take part in this study you will be asked to provide medical and personal information.

Taking part in the study will involve doing two things.

1) Discussing the main symptoms that you suffer from, how they relate to each other, and what you think their cause might be.
2) Completing some questionnaires. These questionnaires will cover a wide range of topics and relate to questions about pain specifically, questions about what activities you've had to change because of the pain and more general questions about mood.

The discussions involved in stage 1 will be tape-recorded so that they can be referred back to later. These recordings will only be heard by the principal investigator.

This study also involves gaining a medical perspective on your symptoms. A doctor will be asked to group the symptoms you have listed in part 1) from a purely medical point of view. You therefore need to consent to having the symptoms that you listed in part 1) given to a doctor. Please note that the doctor will at no time be told how you grouped your symptoms.

All information gathered as part of this study will be totally confidential (it will be referred to by serial numbers only). All information gathered as part of this study will be kept secure. Only the principal investigator (Anne Miles) will have access to it.

This study is expected to take approximately 45 minutes.

Please ask if you do not understand or would like more information.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. If you withdraw at any time this will not affect your subsequent medical treatment or your relationship with your doctor in any way.

Your decision to take part or not will not affect your subsequent medical treatment or your relationship with your doctor in any way.

If you are happy to take part, please complete the separate consent form. Please retain this information sheet for your own reference.

T & HARROW HEALTH AUTHORITY

Patient Identification Label

RCH PROJECT CONSENT FORM

F PROJECT A PILOT STUDY INTO THE UNDERSTANDING OF SYMPTOMS AND THEIR IMPLICATIONS FOR CHRONIC PAIN SUFFERERS

COMMITTEE (E.C.) NO: 2231 PRINCIPAL INVESTIGATOR: ANNE MILES

- TO BE COMPLETED BY INVESTIGATOR

that I have explained this study both orally and in writing to the patient who I am satisfied is now in a position to make an informed decision about participation.

ve not [delete as necessary] completed the checklist overleaf.

Date

lock letters (INVESTIGATOR)

- TO BE COMPLETED BY PATIENT AND/OR PARENT OR GUARDIAN

u read the Patient Information Sheet? YES ☐ NO ☐

u had an opportunity to ask questions and discuss this study? YES ☐ NO ☐

u received and understood answers to all your questions? YES ☐ NO ☐

need further information about the study? YES ☐ NO ☐

u spoken to the person named in Part A of this form? YES ☐ NO ☐

understand that you are free to take part in the study ar to withdraw from It:

y time

ut having to give a reason for withdrawal

ut your medical care being affected? YES ☐ NO ☐

agree to take part in this study? YES ☐ NO ☐

Date

lock letters PATIENT AND/OR PARENT OR GUARDIAN)

TO BE COMPLETED BY REGISTERED NURSE OF RELEVANT GRADE

nt while this study was explained by the investigator to the patient who was given the opportunity to ask any question (s) he wished.

Date

ock letters (NURSE)

FOR STAFF:

- THIS FORM SHOULD BE USED ONLY IN STUDIES INVOLVING PATIENTS AND NOT HEALTHY VOLUNTEERS
- ALL PARTS OF THIS SIDE OF THE FORM MUST BE COMPLETED. COMPLETION OF CHECKLIST OVERLEAF IS OPTIONAL
- ON COMPLETION, THIS FORM (ORIGINAL) MUST BE INSERTED INTO THE PATIENT'S CASE NOTES. A COPY MUST ALSO BE SENT TO THE PATIENT'S GENERAL PRACTITIONER AND A COPY HANDED TO THE PATIENT TO KEEP
- PATIENT CONSENT MUST BE RECORDED IN THE NURSING RECORDS

RM

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SCHEMA ASSESSMENT INSTRUMENT (SAI)

Part 1: Patient form

Please tell me the symptoms you usually suffer from that relate to your pain (these can be physical and/or psychological).

.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....

Please put these symptoms into groups according to which ones you think go together

For each group of symptoms can you tell me:

why you feel they go together

what their causes are

what their physiological basis might be

Cluster 1

..... why do you feel these go together?.....

....

....

....

..... what do you think their cause is?.....

....

....

..... what do you think their physiological basis is?.....

....

....

how long do you think these symptoms are going to last for?

.....

what do you think the cure for these symptoms is?

.....

Cluster 2

..... why do you feel these go together?.....

....

....

....

..... what do you think their cause is?.....

....

....

..... what do you think their physiological basis is?.....

....

....

how long do you think these symptoms are going to last for?

.....

what do you think the cure for these symptoms is?

.....

Cluster 3

..... why do you feel these go together?.....

....

....

....

..... what do you think their cause is?.....

....

....

..... what do you think their physiological basis is?.....

....

....

how long do you think these symptoms are going to last for?

.....

what do you think the cure for these symptoms is?

.....

Cluster 4

..... why do you feel these go together?.....

....

....

....

..... what do you think their cause is?.....

....

....

..... what do you think their physiological basis is?.....

....

....

how long do you think these symptoms are going to last for?

.....

what do you think the cure for these symptoms is?

.....

Cluster 5

..... why do you feel these go together?.....

....

....

....

..... what do you think their cause is?.....

....

....

..... what do you think their physiological basis is?.....

....

....

how long do you think these symptoms are going to last for?

.....

what do you think the cure for these symptoms is?

.....

Cluster 6

..... why do you feel these go together?.....

....

....

....

..... what do you think their cause is?.....

....

....

..... what do you think their physiological basis is?.....

....

....

how long do you think these symptoms are going to last for?

.....

what do you think the cure for these symptoms is?

.....

SCHEMA ASSESSMENT INSTRUMENT (SAI)

Part 2: Medical form

NAME OF PATIENT:..... DATE SEEN:.....

Severity of medical condition

On strictly organic criteria, how severe is the patient's medical condition?

1	2	3	4	5	6	7
Extreme	Very severe	Severe	Moderate	Minor	Very minor	No condition

e.g. for back injury this would be:
1=numerous major physical findings, in excess of those listed in point 2

2=very advanced, multilevel degenerative disc disease (DDD), 2 or more discs protruding

3=advanced DDD, acute/chronic nerve irritation, herniated disc

4=some DDD, moderate mechanical pain, facet pain

5=major soft tissue injury, bad sprain/strain

6=minor soft tissue injury, pulled muscle

7=some spasm, tender points

Functional prognosis

On the basis of physical findings only, what is the prognosis for the patient's condition

1	2	3	4	5	6	7
Extreme	Very poor	Poor	Moderate	Good	Very good	Excellent

1=unable to work, receives permanent disability pension

2=sedentary, part-time work, receives permanent partial (PP) disability pension

3=permanent modified work, numerous restrictions, receives PP disability pension

4=permanent modified work, few restrictions, PP disability pension

5=should eventually resume regular work after temporary modified work

6=discharged to regular activities, little difficulty expected

7=discharged to regular activities, no difficulty expected

Symptom list given by patient:

1._____

2._____

3._____

4._____

5._____

6._____

7._____

8._____

9._____

10._____

11._____

12._____

Specify the way in which the patient should have clustered the above symptoms according to the available medical/psychological information. These clusters should represent the way in which the patient should have ideally organized their symptoms were they to possess a thorough understanding of which symptoms belonged to which medical condition:

Cluster 1

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

what is the cause of these symptoms?.....

.....

.....

what is their physiological basis?.....

.....

.....

Cluster 2

.....
.....
.....
.....
..... what is the cause of these symptoms?.....
....
....
..... what is their physiological basis?.....
....
....

Cluster 3

.....
.....
.....
.....
..... what is the cause of these symptoms?.....
....
....
..... what is their physiological basis?.....
....
....

Cluster 4

.....
.....
.....
.....
..... what is the cause of these symptoms?.....
....
....
..... what is their physiological basis?.....
....
....

Cluster 5

.....

.....

.....

.....

..... what is the cause of these symptoms?.....

....

....

..... what is their physiological basis?.....

....

....

Cluster 6

.....

.....

.....

.....

..... what is the cause of these symptom?.....

....

....

..... what is their physiological basis?.....

....

....

SCHEMA ASSESSMENT INSTRUMENT (SAI)

Part 3: Schedule for comparing patient and doctor understanding

In comparing the assessed and expected clusters, to what extent does the patient's differentiation of symptoms into clusters concur with the expected clusters (i.e. those given by the doctor).

Cluster Differentiation

1	2	3	4	5	6	7
No differentiation at all/ Purely arbitrary						Perfect differentiation/ fully in keeping with the medical/psychological evidence

Cluster Content

In comparing the assessed and expected clusters, to what extent do the symptoms in each assessed cluster concur with the medical/psychological evidence? In terms of percent agreement

1	2	3	4	5	6	7
<14%	14-28%	28-42%	42-56%	56-72%	72-86%	>86%
None	Very poor	Poor	Moderate	Good	Very good	Perfect

Cluster 1

1	2	3	4	5	6	7

Cluster 2

1	2	3	4	5	6	7

Cluster 3

1	2	3	4	5	6	7

Cluster 4

1	2	3	4	5	6	7

Cluster 5

1	2	3	4	5	6	7

Cluster 6

1	2	3	4	5	6	7

Symptom Etiology

With respect to each assessed cluster, to what extent does the patient's understanding of the causes of the symptoms grouped together in each cluster accurately represent the medical/psychological evidence?

1	2	3	4	5	6	7
None	Very poor	Poor	Moderate	Good	Very good	Perfect
Not at all, no Understanding of Medical/psychological Conceptions whatsoever			Some approximation of understanding for some symptoms (half) but very poor for others			

Cluster 1

1	2	3	4	5	6	7

Cluster 2

1	2	3	4	5	6	7

Cluster 3

1	2	3	4	5	6	7

Cluster 4

1	2	3	4	5	6	7

Cluster 5

1	2	3	4	5	6	7

Cluster 6

1	2	3	4	5	6	7

Global Rating

Overall, taking into consideration the number of clusters, the composition of each cluster, the putative etiology for each cluster, and the importance of the various clusters to the patient's presenting symptomatology, how appropriate is the patient's understanding of his/her condition?

1	2	3	4	5	6	7
Completely Inappropriate; Purely arbitrary			Moderate			Perfect

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Roles and Goals Questionnaire

(The same questions are asked about work, most important hobby or interest, most important relationship, health and independence. An example is shown using the domain of work)

Prior to the pain: (Pre-pain involvement score)

	Very little	Moderate amount	Quite a lot	A great deal
a) How much did work make you feel good as a person?	1	2	3	4
b) How much energy and effort did you put into work?	1	2	3	4
c) How successful did you think you were going to be at work?	1	2	3	4
d) To what extent did being successful in other areas of your life depend on your being successful at work?	1	2	3	4
e) To what extent did you think life would feel meaningless or unhappy without work?	1	2	3	4

Present time: (Current involvement score)

a) How much does work make you feel good as a person?	1	2	3	4
b) How much energy and effort do you put into work?	1	2	3	4
c) How successful do you think you are going to be at work?	1	2	3	4
d) To what extent does being successful in other areas of your life depend on your being successful at work?	1	2	3	4
e) To what extent do you think life would feel meaningless or unhappy without your work?	1	2	3	4

Tenacious Goal Pursuit and Flexible Goal Adjustment

(The items in bold are the ones which form the FGA scale. Items 1, 13, 26 and 30 are negatively scored)

This is a questionnaire about how people approach their goals. Below you will find a series of statements which relate to how people approach their goals. Please circle one number next to each statement to indicate whether this statement applies to how you approach your goals. There are no right or wrong answers.

0=strongly disagree 1=disagree; 2=neutral; 3=agree; 4=strongly agree

	Strongly disagree				Strongly agree
1. When I get stuck on something, it's hard for me to find a new approach.	0	1	2	3	4
2. The harder a goal is to achieve, the more appeal it has for me	0	1	2	3	4
3. I can be very obstinate in pursuing my goals.	0	1	2	3	4
4. I find it easy to see something positive even in a serious mishap.	0	1	2	3	4
5. When faced with obstacles, I usually double my efforts.	0	1	2	3	4
6. To avoid disappointments, I don't set my goals too high.	0	1	2	3	4
7. Even when things seem hopeless, I keep on fighting to reach my goals.	0	1	2	3	4
8. When everything seems to be going wrong, I can usually find a bright side to a situation.	0	1	2	3	4
9. I tend to loose interest in matters where I cannot keep up with others.	0	1	2	3	4
10. I find it easy to give up a wish if it seems difficult to fulfil it.	0	1	2	3	4
11. When I run up against insurmountable obstacles, I prefer to look for a new goal.	0	1	2	3	4
12. Life is much more pleasurable when I do not expect too much from it.	0	1	2	3	4
13. I create many problems for myself because of my high demands.	0	1	2	3	4
14. When I have tried hard but can not solve a problem, I find it easy just to leave it unsolved.	0	1	2	3	4
15. In general, I am not upset very long about an opportunity passed up.	0	1	2	3	4

0=strongly disagree 1=disagree; 2=neutral; 3=agree; 4=strongly agree

	Strongly disagree				Strongly agree
16. I adapt quite easily to changes in plans or circumstances.	0	1	2	3	4
17. I usually find something positive even about giving up something I cherish	0	1	2	3	4
18. I avoid grappling with problems for which I have no solution.	0	1	2	3	4
19. I usually have no difficulties in recognizing where my limits are.	0	1	2	3	4
20. If I find I can not reach a goal, I'd prefer to change my goal than to keep struggling.	0	1	2	3	4
21. After a serious drawback, I soon turn to new tasks.	0	1	2	3	4
22. Faced with a serious problem, I sometimes simply pay no attention to it.	0	1	2	3	4
23. If I don't get something I want, I take it with patience.	0	1	2	3	4
24. Faced with a disappointment, I usually remind myself that other things in life are just as important.	0	1	2	3	4
25. I find that even life's troubles have their bright side.	0	1	2	3	4
26. It is very difficult for me to accept a setback or defeat.	0	1	2	3	4
27. Even when a situation seems hopeless, I still try to master it.	0	1	2	3	4
28. I stick to my goals and projects even in face of great difficulties.	0	1	2	3	4
29. When I get into serious trouble, I immediately look how to make the best out of the situation.	0	1	2	3	4
30. I'm never really satisfied unless things come up to my wishes exactly.	0	1	2	3	4

APPENDIX D

CONFIDENTIAL

PATIENT INFORMATION SHEET

Please read this information sheet carefully. Take as much time as you feel you need to decide whether or not you would like to take part.

This study has been reviewed and given ethical approval by the Harrow Research Ethics Committee.

Volunteers are invited to take part in a study looking at what aspects of having chronic pain are viewed as most difficult to deal with by chronic pain sufferers.
The study aims to look at the difficulties associated with having chronic pain and how it has affected people's lives.
It is hoped that this study will contribute to our understanding of the experience of chronic pain.
If you decide to take part in this study you will be asked to provide medical and personal information.

Taking part in the study will involve doing two things:

1) Discussing how chronic pain has affected your lifestyle, and
2) Completing some questionnaires. These questionnaires will relate to questions about pain specifically, and more general questions about mood.

The discussions involved in stage 1 will be tape-recorded so that they can be referred back to later. These recordings will only be heard by the principal investigator.

All information gathered as part of this study will be totally confidential (it will be referred to by serial numbers only). All information gathered as part of this study will be kept secure. Only the principal investigator (Anne Miles) will have access to it.

This study is expected to take approximately 45 minutes.

Please ask if you do not understand or would like more information.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. If you withdraw at any time this will not affect your subsequent medical treatment or your relationship with your doctor in any way.
Your decision to take part or not will not affect your subsequent medical treatment or your relationship with your doctor in any way.

If you are happy to take part, please complete the separate consent form. Please retain this information sheet for your own reference.

NT & HARROW HEALTH AUTHORITY

ARCH PROJECT CONSENT FORM

Patient Identification Label

OF PROJECT AN EXPLORATION OF THE DIFFICULTIES ASSOCIATED WITH HAVING CHRONIC PAIN

S COMMITTEE (E.C.) NO: PRINCIPAL INVESTIGATOR: ANNE MILES

A - TO BE COMPLETED BY INVESTIGATOR

m that I have explained this study both orally and in writing to the patient who I am satisfied is now in a position to make an informed decision about participation.

ave not [delete as necessary] completed the checklist overleaf.

re Date

block letters (INVESTIGATOR)

B - TO BE COMPLETED BY PATIENT AND/OR PARENT OR GUARDIAN

you read the Patient Information Sheet? YES ☐ NO ☐

you had an opportunity to ask questions and discuss this study? YES ☐ NO ☐

you received and understood answers to all your questions? YES ☐ NO ☐

u need further information about the study? YES ☐ NO ☐

you spoken to the person named in Part A of this form? YES ☐ NO ☐

u understand that you are free to take part in the study ar to withdraw from It:

ny time

hout having to give a reason for withdrawal

hout your medical care being affected? YES ☐ NO ☐

u agree to take part in this study? YES ☐ NO ☐

re Date

block letters PATIENT AND/OR PARENT OR GUARDIAN)

C - TO BE COMPLETED BY REGISTERED NURSE OF RELEVANT GRADE

esent while this study was explained by the investigator to the patient who was given the opportunity to ask any question (s) he wished.

re Date

block letters (NURSE)

ES FOR STAFF:

- THIS FORM SHOULD BE USED ONLY IN STUDIES INVOLVING PATIENTS AND NOT HEALTHY VOLUNTEERS
- ALL PARTS OF THIS SIDE OF THE FORM MUST BE COMPLETED. COMPLETION OF CHECKLIST OVERLEAF IS OPTIONAL
- ON COMPLETION, THIS FORM (ORIGINAL) MUST BE INSERTED INTO THE PATIENT'S CASE NOTES. A COPY MUST ALSO BE SENT TO THE PATIENT'S GENERAL PRACTITIONER AND A COPY HANDED TO THE PATIENT TO KEEP
- PATIENT CONSENT MUST BE RECORDED IN THE NURSING RECORDS

FORM

CONFIDENTIAL **SUBNO_____**

BECK DEPRESSION INVENTORY: SHORT FORM

This questionnaire consists of **13** groups of statements. After reading each group of statements carefully, circle the number (0, 1, 2 or 3) next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.

1.
0 I do not feel sad
1 I feel sad
2 I am sad all the time and I can't snap out of it
3 I am so sad or unhappy that I can't stand it

2.
0 I am not particularly discouraged about the future
1 I feel discouraged about the future
2 I feel that I have nothing to look forward to
3 I feel that the future is hopeless and that things cannot improve

3.
0 I do not feel like a failure
1 I feel I have failed more than the average person
2 As I look back on my life all I can see is a lot of failures
3 I feel I am a complete failure as a person

4.
0 I get as much satisfaction out of things as I used to
1 I don't enjoy things the way I used to
2 I don't get real satisfaction out of anything anymore
3 I am dissatisfied or bored with everything

5.
0 I don't feel particularly guilty
1 I feel guilty a good part of the time
2 I feel quite guilty most of the time
3 I feel guilty all of the time

7.
0 I don't feel disappointed in myself
1 I am disappointed in myself
2 I am disgusted with myself
3 I hate myself

9.
0 I don't have any thoughts of killing myself
1 I have thoughts of killing myself but I would not carry them out
2 I would like to kill myself
3 I would kill myself if I had the chance

12.
0 I have not lost interest in other people
1 I am less interested in other people than I used to be
2 I have lost most of my interest in other people
3 I have lost all of my interest in other people

13.
0 I make decisions about as well as I ever could
1 I put off making decisions more than I used to
2 I have greater difficulty in making decisions than before
3 I can't make decisions at all anymore

14.
0 I don't feel I look any worse than I used to
1 I am worried that I am looking old or unattractive
2 I feel that there are permanent changes to my appearance that make me look unattractive
3 I believe that I look ugly

15.
0 I can work about as well as before
1 It takes an extra effort to get started at doing something
2 I have to push myself very hard to do anything
3 I can't do any work at all

17.
0 I don't get more tired than usual
1 I get tired more easily than I used to
2 I get tired from doing almost anything
3 I am too tired to do anything

18.
0 My appetite is no worse than usual
1 My appetite is not as good as it used to be
2 My appetite is much worse now
3 I have no appetite at all anymore

APPENDIX E

The relationship between the open codes (indicated by letters - a, b, c, etc.) and the principle categories 1-4 is shown below. Quotes covering the range of participants are shown to illustrate the open codes.

Category 1: Private experience

Sub-category i): Speed at which things could be done

a) Slower dressing/self-care
S9: One or two things I can do it's hard work, I can't do it quick, I take time. It's like shaving, although my hands aint busted or nothing it still takes me longer to shave than it used to, you know what I mean, I've got to stand in front of a mirror and sometimes I lean on it or lean on the side.

S12: Takes me a long time to get myself dressed.

b) Can't move fast
S8: you suddenly realize you can't move very fast

S18: I creep about sometimes, I can hardly move. If I get out of bed at night and I creep about and I get out in the morning and I'm all stiff and sore and, it feels a struggle to get going.

c) Slower walking
S13: I mean at present it's took me all my time to get from the front entrance to the lift, whereas a few years ago I'd run it.

S22: So if I've been to the shops and walking back for a couple of hours I know that like if my back starts aching then I'll slow down

d) Activities in general as slower/taking longer
S7: It completely slowed me down because I have not worked over a year now I've stopped working because I was in a very bad, I could not move anyway so I was in a sick, I'm still on a sick.

S14: You know it's just slow down in a small way and just work to some way of getting it. Do it but doing it in longer, takes longer to do it. Takes a long time to do in an hour you do it in two and a half hours now you know.

e) Slower shopping
S3: even you know, going down to the corner shop for shopping and bringing the trolley up I couldn't, I had to stop half way up. Well I've got a friend that lives near the corner and I used to go in to her flat and sit for about half an hour and then make me way out with the trolley)

S15: if I can do it myself I will do it myself and I don't go on a big shopping spree that I have an awful lot to carry and to stow away and that, I rather go down twice.

f) Slower housework.
S2: I will start doing my housework, I cannot continue I cannot do everything straight away I've got to do one, like if I'm hovering I can hover the downstairs, I've got to wait to do the stairs and I'll go along then I'll go upstairs clean the bath and have gaps in between which will take most of my morning

S19: So one day you might get up and if I clean downstairs I usually do each part as it goes and you then, so you do the kitchen part and you'd have a 10 minute break and sit down and relax and try and unwind a bit because you get very sore, very tense and you know you get up and you'll get on with the next bit, and then you take a break and then you get on with the next bit whereas other days, like today I got up and I thought right you know I'll get on with the kitchen and I've done the kitchen and the kitchen weren't too bad and I'm thinking so how the hell has it taken me this long to do it, you know, and the reason is because I know I've got the niggle, and I'm having to do it slowly and therefore it's taking me longer.

g) Life in general as slower
S1: You just, it's, you do just slow down basically, you know where, it's a bit like going on holiday, you go somewhere down on the coast and the lifestyle is a lot slower. You come back to London and you feel like everything's going past you at 90 miles an hour. So I mean it, it is the same feeling that where I've been going along doing what I would normally do, I've had to come down to sort of being down the coast and go slowly like.

Sub-category ii): The contracting social world.

a) Pain results in unwillingness to go out
S6: I've got a young daughter, well I say young, 28 and 24 years old and we used to go out every week with them, used to get my hair done, not get my hair done as at a shop, but do my hair, do my housework, do their dinner and all go out and enjoy a family evening out. Now we don't do that anymore because I can't because I might feel alright in the morning but come the afternoon the pain will start it will get worse and by the time they come round to take us out at 8 o' clock I don't want to go and we don't go, we haven't been out for over a year as a family group.

S11: I've always been sociable, clubs and all that sort of thing but I didn't want to go when I had that pain..... Cos I always love to mix with people and you know I've got a lovely social life, but when I felt like that I didn't want to go.

b) Inability to go out to work
S4: in my job I used to say, I was very active I used to do the street markets, so there was a lot of meeting a lot of people, getting up at, well I used to start early and come home late so a very active life, but that's completely changed.

S6: I used to be sales lady in an electricity board, which I enjoyed very much, because once again, I liked meeting people, I liked talking to people I used to sell in there and I really enjoyed that. And then I broke, I fractured my left ankle and that come to an end,

c) Fear of going out
S12: Oh yes. I go nowhere. I go nowhere only to the local shops, oh no, I go nowhere, nowhere at all, because I wouldn't go on my own. I would be afraid. And I wouldn't go out at night because I can't see, I wouldn't see where I was walking and if I (.) lost my balance at all I would go, so I wouldn't go out at night and I used to like going out at night.

d) Difficulty getting out (either due to difficulty walking or using transport) -restriction in opportunities for informal socializing with friends and neighbours
S13: So now, as I explain to people, I live in a box. I can't get out unless somebody comes with a car to take me because I can't walk far enough..... Oh before I had the osteoporosis, oh I was out nearly every day, out and about somewhere or other, you know, like my neighbour and I used to always be going out round the shops and round the market, all that sort of thing. That's all stopped now. I just can't do it.

S17: I only go out very occasionally, by voluntary car, like today to the hospital, and on the little trekker when I have to go out somewhere and people don't see me much.... Oh no. I'm a very gregarious, was a very gregarious person I love meeting people. I have friends that unfortunately are like myself, and then some of them disappear and some of them move away, but the ones that I have got left, I love seeing, I mean I wish I could see more. I would love to get out and go round a lot more.....as I say, if there's a day like today yes I think ooh I'll get the trekker out and I'll just go round the corner and go just to the shops and I might see someone to talk to, you never know you see, you do that if you go out, I see neighbours.

e) Difficulty going to social events/ participating in social events
S5: there's a film exhibition on in town somewhere that one of my daughters went to see last week and she knows that I'd love it, and her friend said well why doesn't your dad come and she says he can't walk and I can't walk round an exhibition and I'm not going to be wheel, I'm not going to go in a wheelchair

S10: Well I can say that I've changed from what I was before, before OK I was mobile, yeah I go out a lot, whatever I want to do I do, but now I don't go out much, there's some place you want to go say like a function or there's something some celebration that my people are having I will not be able to go, but before I go, I do go, but now I can't .... when you go out you see people, people see you but staying at home nobody knows you exist you see what I mean, even to go to relations you know whenever you want, you cannot go,

S16: I don't know how to describe it, you know there's things that my friends have done afterwards which I couldn't do, I couldn't go swimming and things like that, activities and, felt like I was missing out on.... if I want to play with my grandchildren, you know they're only little, they want a bit of fun and you say you can't you know which is, they're too young to understand all these problems.

S20: I mean lots of things that I would want to do I'm a sixth form tutor and they're going on an adventure weekend now I'm somebody who's done windsurfing parasailing, whatever, they're going to be doing those things over that weekend and when I said to the senior teacher organizing it well I would do something, I would love to go but will my ankle be able to cope with it, well he said bluntly no, so I'm going to be the only sixth form tutor not going on the sixth form weekend which again impacts professionally as well as the sheer frustration of not being able to do the sort of, that sort of thing that I would normally incorporate into most holidays or so sometimes your friends are going away, some friends were doing some paint balling and it was racing around and I can't run on it so I couldn't go with them paint balling so there are social, so there's the academic, there's the professional, there's the social, yeah.

Sub-category iii): The fractionating of mind and body

a) Having to think about things previously taken-for-granted
S1: I'm in pain I'm finding it hard to get dressed, I mean to that degree sometimes I find it very hard to get me socks on..... Whereas most people get up get dressed don't think nothing of it. You know you sort of sit there and you think oh get me socks on in minutes 'cos got to get going like (laughs) got to get up and move.

S20: the other thing is my PhD is at Leeds University and normally I would just drive up one day and drive back the other day, it's 200 miles, I've not dared do that because it is my right leg which is the break leg and it, and I have done, the longest journey I've done which is quite recently that was 100 miles in one day, and so in fact it's still impacting on my life because I would drive up to Leeds without thinking about it.

b) Need to plan/loss of spontaneity
S4: Well it's the routine, as I said I don't normally like routines, I'm not a routine, I like to sort of get up and do things and we decide to do things on the spur of the moment, whereas now I can't. I have to think about what I'm going to do before I do it. You know like if something I don't know, somebody shouted to me now look somebody's, somebody's collapsed here, would you come out and help me, and I think first because I know what's going to happen, whereas before you would just you'd go.

S19: I was very rarely one for making plans. You know I'm renowned for being a sort of organizer, so if there was a party to be run and all the rest of it I'd be the one to do it but for me to actually plan something for myself if you like was very rare because I just used to think to myself oh I do so and so today and I'd do it, just like any other person does, whereas now it's a case of OK we're back here today OK well how're you feeling today, you know and it's like you've got a thousand questions that go through your mind before you even do it.

c) Mental desire to do things body can't do
S6: in here (points inside) I want to do it here I want to do it (points to head) but down here it (points to body) doesn't let you do it anymore and I resent it.

S9: Well I have to think twice now. I have to think twice. Normally you say oh yeah I'll do that, now I think hang on a minute, I might not be able to do that. I'd like to do it but I can't. It's not that I don't want to do it, I don't think I could do that.

d) Having to train oneself to think before acting
S7: so whatever I do I have to very be careful how I do it, what I do and how I do it. Sitting down, stand up walking, anything I do I have to think first then act. Like before you act first then think later (Heidegger) but now I have to think first, how am I going to do it, then do it. It's like completely, my life is reversed, completely set back like I'm starting to live my life again trying to learn to live again just like I'm on a training programme.

S16: You wouldn't be aware of being careful (before the pain) I think that's how, you're a little bit wary now, you thinking oh maybe I shouldn't do that because of this, that, the other and I do think twice on a couple of few items.....when I'm lifting something I think now how's the best way to go about this without causing a lot of pain, and you know stress in the back sort of thing, and thinking about you know, bending knees and lift it gently if you can lift it, if not leave it to someone else.

S22: I have to train myself with everyday stuff. It was hard at first because the pain started while I was pregnant, then after the baby, I was too busy to even think before I done something, like if I started rushing around, if I was late going somewhere I started rushing about and start, then I'd bend over without bending my knees or something, then I'd hurt it again so I think actually hurt myself helped me train myself better so I know if I rush around and bend down without thinking I'll hurt myself so I have to bend down then pick up something or pick my son up and bend my knees first. That was hard cos sometimes if they cry suddenly you just go and grab them you know and that way you sort of twinge it again so I've had to train myself so sometimes I don't respond as quickly as I could but then I know that I've responded in the best way, so that's one of the ways I train myself.....I have like problems with my day to day jobs even daily housework even things simple like lifting the baby up, I have to think about it before I do it. So I have to remember to bend my knees and so I have to sort of train myself to think that way and I have to adjust like that.

e) Body slower than mind
S8: you suddenly realize you can't move very fast even though actively it's in the mind you can, because my brain hasn't slowed down.

f) Distinction between coping with mental and with physical aspects of having pain
S19: pain-wise I was able to control it quite well, you know and mentally as far as the pain was concerned I was able to control it very well, but mentally as far as my own self-being was concerned I, it was wrecked I mean I just, I got severely depressed)

S20: it wasn't living with the immobility but after a while it got to your head..... I mean was on crutches I was effectively housebound for about 5 6 months, I was going into school every day teaching and being collected, so I was to all intents and purposes doing, pretty well doing everything that I could possibly go to. And I was doing an evening class and I even managed to make arrangements to continue that believe it or not. The getting to the head, that's a difficult one (.) I got, I think it was 2 or 3 ways, first of all I used to get very very tearful, I had mood swings, some days I was, you know I had a couple of beloved friends who phoned me upevery day I had one of them who'd had a mastectomy at the same time as my accident, we used to have these conversations lying in bed together, different beds, different parts of the country but you know what I mean. And one friend phoned me up and said how are you and sometimes I was I was OK and it would be a 10 minute conversation sometimes I would just spend an hour crying down the phone to them and they would actually stay on the phone, 2 hours phone call until I actually was apparently to all intents and purposes OK,

Category 2: Challenge to identity (Modes of reflection)

a) Reactions of other people

S9: the worst thing is when people come up to you you haven't seen for three or four years saying bloody hell is it you it is you isn't it you've lost some weight, where you hobbling for you hurt your leg? See, that's when it's worst. I've lost a good seven stone over the last 5 years I suppose, 6 years, and I was happy then, but I'm not now..... when people say it bloody is you, aint you lost some weight you feel worse than ever then. You do it makes you think bloody hell I must be bad then. It makes you feel worse than what you are.

S17: I only go out very occasionally, by voluntary car, like today to the hospital, and on the little trekker when I have to go out somewhere and people don't see me much. When they do see me out they're a bit taken aback to see me in a thing, and they used to say, my husband had it said to him, oh I know your wife she's the lady that runs everywhere. And this was my reputation and people obviously I expect they think it's a bit strange that I've gone to pieces or, cos it's only been within the last two years really.

b) Other people's comments on their actions/behaviour

S1: I mean few weeks ago, isn't it, come round I was supposed to clean all the biological filters and all that, and I'd been sitting there gearing meself up, oh I'll go out in a minute and it was cold as well like. I'll go out in a minute. He turns up he says ain't you done it yet? And he'll go come on then let's do it and he'll basically do the work, the hardest part for me. You sort of appreciate it but you think oh you know it's not fair, he comes round to see me he ends up doing you know things that I can't do you know which that makes that does make you feel you know bit annoyed 'cos you know it's not the sort of thing you expect someone to come round and see you would be doing your pond like you know.

S6: I get nasty, not nasty, well I must get nasty cos the kids are always saying to me what's the matter with me and there is nothing the matter with me. And this is the way I feel, nothing the matter with me, but they're always asking me what's the matter but so obviously I must be firing out to them a discontentment you know, which I don't mean to but it must just come, I just get agitated.

c) Offers of help

S6: We've got very good friends called *** and **** and ***** and ****. But I don't mind them so I'll cook the dinner and do it when they come but once I sit down that's it, I've sat down and I won't move, you know and they're really kind and they understand that but um if anyone comes unexpectedly while they're visiting then I have to get out of the chair I hate it. I hate to have to have a hand up. I really resent that.

S8: When we go shopping she says oh I'll carry it for you and I'll say no, no, no it doesn't affect, and she'll say yeah but you know it'll make you even more tired. I don't like it.

d) Certain environments highlight what one can't do.

S5: I would like to join my wife say in a simple shopping spree which I can't unless I'm prepared to take a walking stick and sit down every 10 or 15 minutes and the gap's getting longer, shorter and shorter, so in the end I give up and say let's go home, you know, I can't do that, I can't go away for a weekend because what's the point in going to a hotel or somewhere and just sitting in somebody else's lounge I might as well sit in my own lounge which is more comfortable

S8: It hasn't actually lost my confidence because I try to avoid places which will show that I'm not confident. (...) at the moment I've given up swimming. And things like that, because I think I've gone less active and I've put on weight with it, as I say anywhere where there's a lot of activity, walking, or even if I take my young one to the playground and there are other parents there, I sort of take a very backward role now and I've got to point of saying to him, do you know do you think you've outgrown things like that let's go round here you know (laughs) It's just so it's not exposed and I suppose I'm with a lot of the younger mothers as we'll you know having only a seven year old, because it can show you up.

e) Own standards reflected in environment (ability to maintain own standards)
S10: it's so frustrating to me it puts me off so many things, right like domestic work, I cannot do domestic work, my house come my house you look at it, it's dirty but I can't sweep it even if I use the hoover, I still have to bend down to do some other things, do my carpet, all these things, I can't do that.... I leave it like that there's nothing I can do about it (inaudible) I felt well OK, let me give it ago, well I managed to do it but it's not the way I want it to be,

S12: I was a good worker. I love cleaning and you got a kick out of it and it looked nice, the windows looked nice, the curtains were washed and the paint was, got a wipe over and that, but now, I look at it now and I feel, it worries me, it depresses me, it depresses me. Think if I got down on the floor to wipe I wouldn't be able to get up without holding on to the table or something to help me up. (asked to elaborate on why finds it depressing...) Well because it isn't the way I'd like it to be, the way I used to keep it.

S18: I mean I've got quite high standards at home of tidiness, cleanliness, order, and that's all, that doesn't help you see that is another aspect, perhaps I should mention,living in a clutter and not keeping my standards up in the house or the garden is, does affect one's, I think gets you down a bit, subconsciously, do you understand that? I mean probably as a young person you , I mean I used to look out of the train window and see people's ramshakled gardens and think why on earth can't they tidy it, it's not very hard or do some order to their garden or make it look pretty and now I understand. As people's houses get older the paint peels and all that, I can see how it's happening, standards have had to drop..... It's not self-esteem I don't think, I think what it is is I never like to leave anything in a mess behind me. (.) I would like to be thought of as always being orderly and tidy and up to date with everything and I'm not.

f) Changes in mood/ character
S3: Well I got so quick tempered so bad tempered I used to just lash out and my husband used to say now look calm down, calm down. But it was annoying me because I couldn't do what I wanted to do.... I got very quick tempered and if I couldn't bend or do anything I used to just lash out. You know I used to break things (laughs).

S9: I get bad-tempered now quicker than ever. I've always been bad- tempered all my life but I get worse now,

S16: I used to like running and maybe a bit of tennis at times, and I don't know I was more outgoing and I feel like this has all restricted me now I can't do it any more.

g) Physical ability (e.g. inability to do certain activities, need to sit)
S6: Whereas we would be actually out with them or they would be coming over cos like we used to have a lot of people come over and now I think, oh I'll just leave it another week before I give them a ring or, I just say oh no I'll just leave it this week perhaps we'll see you next week. And they're quite nice to me out friends, because they know what lifestyle we used to lead and they go oh you must have a seat and I go no I don't wanna, wanna seat, but I have to sit down and that really bugs me. You know. Whereas I would be standing up at the bar (laughs) or standing along wherever, you know and it feels awful that people have to squash along to make way for me (laughs). You're treated like this old infirm person and you don't wanna be an old infirm person, before the time's, before I think the time's ready for it,

S8: if it is damp and I'm sitting in the car, I find it embarrassing getting out, because I'm very stiff, mainly on my right side and I feel as if I must look 70, not sort of in my early 50s, and I've got a young child there and I'm sort of hobbling along.

h) Feeling old (linked to private experience codes)
S13: I in myself feel a lot older than I ever did but everybody says for my age I seem to be alright you know and that but I feel, I know I'm a great-grandmother but I really feel one now where I never did you know, because I could get up and dance with the kids and play with the kids, chase them round the garden and I can't any more.

S18: Well I feel like an old woman whereas before I did not. I think it's as simple as that.....Because I creep about sometimes, I can hardly move. If I get out of bed at night and I creep about and I get out in the morning and I'm all stiff and sore and, it feels a struggle to get going. I just feel I've made myself prematurely old I suppose.

i) Dependency – needing help from others

S1: I mean I love fishing but unless someone's actually going to take me cos the amount of stuff that I do take you know I've geared it down, I still need someone to go with just in case like you know.... and you feel awkward in that respect because I'm always used to carrying me own weight, you know I don't like people having to do things for me.

S7: So I mean I rely on someone else because my husband went to work and my neighbour she used to come around daytime to make sure I ate my sandwich and I had my cup of tea and things like that, at least I can do that I mean, to rely on somebody else to me was like, what?, it was like completely new, another life for me.... I have to think about very hard what I do now, so my life is completely, to what it was, very active always on the go, working always on the go, now it's completely set back. So it is a very very what do you call, irritating because you rely on somebody else all the time. But before you could do things yourself straight away without asking anybody, you do it, now I have to ask somebody else to do it, so I'm always thinking something else about what I need to do now, whether I'm able to do it.

S11: Well they (son and grandsons) come and you know help me with the shopping and cooking for me and different things, while I was really bad but I don't like to rely on them I want to do it myself.

j) Inability to fulfill roles/ responsibilities

S12: Well it was important to me that I was able to help other people as well as helping myself and the main thing that I was, that it was my own I was able to live my own life I was able to do my own thing and I hadn't to rely on anybody for anything.... it's disappointing, it's humiliating it's really taking all your freedom from you isn't it ..... I used to do everything. When my daughter had her children I used to babysit at night for her. I used to clear her cupboards out, I used to babysitting, when they went to sleep I used to clean out her cupboards for her and that and I loved doing it. But I can't do me own now.

S14: Pain unbelievable at times can't, can't do half the things I used to do. I can't play with the kids. It's very hard to go upstairs Find it very hard to how to put it, fulfil my marital functions

S19: being the kind of person that I am, I do like to please people, it's in my nature to please people. It gives me a lot of self satisfaction to know that the smallest thing can bring a smile to someone's face you know. And when you get to the stage where you can't help them out and you just say to them look I can't do this today, you know and you can see, you can see this, especially if it's something you really planned to do like going out for the day or something like that, or going down and seeing the kids. You know I mean a lot of my I think depressions come along when I have to phone the kids up and say look I can't come and see you today I'm not going to be able to make the journey, and you just hear it in their voices, you know they just feel so let down, you know.

k) Use of props (e.g. needing cushion, needing stick, needing wheelchair)

S10: when people see me they don't know what I'm going through they see this woman, oh this woman she's carrying a walking stick and she (inaudible) I don't like to carry this stick but I cannot help it.....I hate it I do hate it but I cannot help because if I don't use I can't climb the bus I have to use it to support myself then hold the bus rail to go in because I'm not mobile

S22: I felt a bit frustrated that I couldn't sit on the sofa without a pillow you know, and I felt a bit embarrassed like if somebody came I'd take the pillow away so they wouldn't know that I've had to put a pillow behind my back, I know it sounds silly but cos you know like, so but now they all know I sit with a pillow cos in that way because everyone knows about my back, before everyone didn't know I didn't tell everybody for some reason for a little while, you know I was just sort of coping with it, and I didn't tell everyone I had a torn disc at first, just didn't tell them, I don't know why I didn't tell them but I just didn't want them to know for some reason I don't know why, so in a way I had to hide it as well like it's a bit weird, I know it sounds weird but I didn't want them to know that I needed special treatment or something like that, I wanted to be treated like normal, so.

l) Change in weight/fitness

S8: at the moment I've given up swimming. And things like that, because I think I've gone less active and I've put on weight with it,

S9: Well it aint very nice, like 30 years ago I was 21, 22 stone. I used to do a lot of fighting, bareknuckle, wrestling, there weren't no fat on me I was just heavy (...)once I had big strong legs, hairy, blonde hairy legs, I haven't got a hair on 'em now, and my legs have just shrunk away to nothing. (....) I ain't the same as I was. I ain't fit I suppose I've lost weight.

Category 3: Evaluating the impact of pain

This was viewed in the present grounded theory as largely operating through the process of social comparisons.

Sub-category i): Conception of what 'normal' is has had to change

a) Life as fundamentally altered (comparison with pre-pain life)
S9: You can't do the things you used to do and when I was so fit and doing everything it's harder. And when you can't walk round the shops, I get people sometimes, get that for us will you or something like that, you know what I mean, I'm not being lazy but I can't even walk from my place to a paper shop I have to get in the car. I've tried it a couple of times but no good I couldn't do it. It ain't for want of trying. You might think oh I don't feel too bad today but that's worse cos you inclined to take a liberties and wallop you stumble, you start wobbling and if there's nothing you can get hold of, you're over. Gone, you know, you just, it's a different life. You've got to sort of forget about the past.

S14: Well the thing is I'm, you come to realize that something you worked for for 20 odd years is gone and there's no, there's nothing left so you have to look to another career you know, which I think I'm very very lucky that I can pick up another career, it's just that your whole life is turned into disarray like you know because you wake up one morning and you realize that you, that there's no way that you're going back to what you used to do which I loved doing the job I done like you know. You realize that (.) you realize that you've nothing left, you know you wake up and I suppose I'm lucky in a way because you wake up you realize then you think (inaudible) like I have got two kids one is nine the other's 11 and it's a long time before they'll be reared so what do you do. You can either, you can do one of two things you can sit there feel sorry for yourself or get up and do something you know. Which for me was very hard because I had no education when I was young, you know, so I decided to get off my posterior and do something about it you know.

b) Self as fundamentally altered (comparison with pre-pain self)
S2: (I feel) Angry, very, very angry. But then it has to, I have to go through that and I know that but then I also know we all have to go through this. (Can you tell me more about that feeling of anger?) Not being able to do things the way I used to do it. I know I used to do more and I think that's what makes me more angry, and I always tell my own daughter as well how, in the beginning I used to swear that if I go to my doctor I'll be able to go through, I'll be the same person and now I think I'll never be the same person.

S4: I cannot do a lot of the things I used to do 'cos I used to be a very, well I used to like all the DIY at home or whatever and I can't do 90% of it, I do little bits and pieces to keep myself occupied, but the strenuous things I can't do anymore. So that also gets me down knowing things I used to do I can't do. Knowing what an active person I used to be.

S19: from being someone that was so active to have to do things and sit down at a desk it is, it is just soul destroying you know because my whole personality revolves round sport, with being physical, that is what makes me shine if you like. I'm not the kind of person that sits behind a desk.

c) Difference from other people/sense of unfairness: comparison with people older and yet better off (upward comparison)
S6: this is where the resentment starts because I think why can't I be like the others cos I see my sister in law who's 67 she's digging her garden she's coming round taking me shopping, she's running here she's running there.... and I think she's able to do that why aren't I able to do that.

S13: It does, does make you sometimes think to yourself what on earth have I done in life that I should end up like this (laughs). Like her upstairs to me she got a sister well into her nineties and she flies off here and flies off there, all on her own.

S20: I'm going to be the only sixth form tutor not going on the sixth form weekend which again impacts professionally as well as the sheer frustration of not being able to do the sort of, that sort of thing that I would normally incorporate into most holidays or so sometimes your friends are going away, some friends were doing some paint balling and it was racing around and I can't run on it so I couldn't go with them paint balling so there are social, so there's the academic, there's the professional, there's the social, yeah.

d) Threat to normal person status (comparison with disabled)
S7: I thought I was going to have a nervous breakdown when I was in the pain so much because to me it's completely set back at all like I was what do you call, an invalid. Like a completely disabled person I feel like I could not lift anything, I couldn't pick up anything.

S8: you do need to walk but I just don't want people to see how I've got, really..... I think it's (.) I think it's a fear of being labelled, you know because you're not really disabled but it's not like being properly disabled at all, because being disabled, you know, you really in most cases where people are disabled it's something which cannot be rectified or it's just made comfortable where you know that, if you can get up and walk and keep going, (.) you can look different, whereas somebody who's properly physically disabled is not going to look different whatever they do.

e) Sense of difference from others (e.g. feel older than those around, illustrated through comparisons with others and with pre-pain self)
S1: you know oh slow down like you know like the kids are tearing down the road like, hold on slow down cos I'm you know I can't keep up with you lot. And it does make you feel old.

S6: Well it's affected my life, let's go back to 1995 I was very happy, outgoing, sociable, dancing singing, entertaining, everything, not like a 50 year old at all much younger sort of person..... Whereas I would be standing up at the bar (laughs) or standing along wherever, you know and it feels awful that people have to squash along to make way for me (laughs). You're treated like this old infirm person and you don't wanna be an old infirm person, before the time's, before I think the time's ready for it.

S8: I can't walk up hills anymore because of the pain from the hip. I just can't and everybody's at the top and I'm still stopping and resting like some geriatric bus trying to get to the top. It makes me feel a lot older, than what I am.

f) Difficult experience to not be able to do things they used to be able to (comparison with pre-pain self)
S12: It is a terrible experience, it is, when you can't do, I can't get up on a chair, and I can't reach to take down a curtain, or anything like that, well that is a terrible experience, when I could do everything.

g) Change in abilities expected with normal ageing have come on too quickly (comparison with normal ageing process)
S5: (I feel) Angry and realizing my age because part of its probably age and I do not like to feel I'm getting older this is what bugs me. I still run a very successful little business and I still work as many hours as I want to work. And I want to continue, but it makes me feel as if old age is coming in too fast, not gracefully. (.) Yeah. That's nicely said isn't it.

S8: Don't like it, I suppose. Well not if I've been active. I know we all move with time and we get older but perhaps it's part of it I feel it's been forced on me rather than what I've wanted to do it's all happened very quickly. Rather than something I've decided well I'm getting a bit older I'm getting a bit tired in life, I'll do things gradually, it's just all been taken away from me you know

S18: How, I mean there isn't anything I can do that's comfortable basically. I mean OK I don't notice it when I'm playing golf more often than not, but of course I'm extremely tired, I haven't got the stamina or endurance which was another of my strong points, tenacity, my tenacity's gone, in anything. So I suppose it was, the longer it goes on, the more I'm thinking well maybe it won't go away or well I still want to believe it will (laughs). (.) I feel, I feel quite worried about the future. I never worry about the future but my husband is ten years older than me. I worry for him because I, if something happened to him whether I could cope. I think it's, it's a sudden realization of old age actually when I'm not really old by my standards, possibly by yours I am, but.

Sub-category ii) Evaluate change as 'normal' e.g. what would happen anyway with age

a) Difficulty doing particular things is seen as less important than it might have been at an earlier stage of life (comparison with pre-pain self)
S5: (commenting on change to social life brought about by pain) If I was 30 I'd be shattered, but at this age I would accept it.

S21: No I wouldn't say it has affected me too much, probably if I was younger and I wanted to go to a club or something it would wouldn't it, but as I'm older I don't do things like that so.....I suppose another thing is I can't really play sport any more but perhaps since I've got older it doesn't bother me so much if I was younger it would.

b) Difficulty doing things part of normal life trajectory e.g. what expect at particular age (comparison with generalized older other)
S15: But it's life isn't it. You have to expect that things go wrong as, in particular as you get older, I don't think there is a person who hasn't got anything wrong as you get older, or very very few.

S21: Oh I do avoid that where at one time I would get up and dance and now I just think oh they'll just think you're a stupid old fool or something (laughs) yeah I do because I used to love doing that, always loved dancing. As you get older anyway you will find yourself avoiding doing lots of things you used to do whether it's because of pain or whether it's because of your age, you find yourself not doing them things anyway.

c) Difficulty doing things not as severe as other people of similar age (comparison with general other)
S11: It's still a task to get upstairs but I'm going out again, you know, socializing. (.) And um yeah I'm trying to get back to normal again..... Well I can do really everything that I used to do. (.) I'm not too bad really for my age. (.) And I want to do everything that I used to do.

S13: Well I see three people, very elderly, well I say very elderly about my age, going about in wheelchairs, people got them in wheelchairs or they've got their own wheelchairs and getting them about. And I think oh well perhaps they're worse off than me cos they've got one of them chairs. And there's two or three blind people I see trying to get across the road and I think oh God it must be awful not to be able to see. I can read, I can see the television. I can see the garden

d) Lessen sense of impact (downgrade significance of changes, downward comparison)
S15: I mean I've got a very good friend and she was very very ill, had a treble by-pass and she has two hip-replacements, I mean she's housebound, that I think is terrible but she, she'll phone, she never complains and I admire her greatly. And I go and see her quite often, just for an hour or so in the afternoon, and, which is nice and relaxing for her and myself. But I just carry on and try as good as I can.

S18: I don't particularly feel sorry for myself because I mean one rationalizes it and thinks well I might not be here at all or I might be in a wheelchair a paraplegic or whatever,

Category 4: Accommodating to the pain (response to constraint)

Sub-category i): Accommodation

This is characterized by the themes of acceptance of constraints imposed by pain, the alteration or normal standards (unless the constraints were not too severe), and the acceptance of help

Acceptance:

a) Acceptance of limitations (to some extent)
S1: But you do, you know, you just you do adapt it's it's I suppose second nature really. I mean you go on holiday you slow down on holiday it might take you three or four days to sort of come down to that pace, um I've had four years to sort of slow the whole system down and sort of think about it whereas someone's that's probably going through the first stage of what I've been through would be finding it very hard to to adapt and tearing out there lifting things and ending up in pain..

S22: So I accept my back, I have a bad back, and I try not to let it stop me doing as much as I can, so. That's another part of training myself, like accepting it which I've had to do.

b) Acceptance temporary-one day will get better (working towards part-way normal)
S18: I think it's gradual because I actually, well I had massive bruising and I just thought oh, as the doctor didn't seem very bothered and he said, eventually when I asked him to look at my ribs and he said I hadn't cracked a rib and he didn't think it was a break I just thought well you know I'll bear with it for 3 months or whatever and it will have gone, so I think it was gradual, this gradual realization oh dear, maybe I've, I don't want to use a rude word, buggered my life up. ..... So I suppose it was, the longer it goes on, the more I'm thinking well maybe it won't go away or well I still want to believe it will (laughs).

S22: I think I've accepted it now. I've accepted it for the time being. I wouldn't like to think that I will never be able to do it. I'm thinking in my head when my back's better I'll do it, so. so I haven't I won't accept that I'll never do it, bit stubborn like that, I think when my back's better I will gently start doing it again and so. (.....) I know it's not never going to get better, it'll probably get better but not 100% and I've accepted that as well been told that as well so I accept that I won't be 100% but I know I'll be able to do some more things than I'm able to do at the moment so that makes it better I suppose.

c) Acceptance (pain not severe)
S3: I just do what I want to do day by day and it doesn't annoy me the pain now it doesn't annoy me. I can even you know vacuum the bedroom push my bed right up to the wardrobe and push it back again and before I couldn't do that with the pain in my back.

S11: I was in terrible pain, yes. ...It's improved, it's improved a lot. .....It's still a task to get upstairs but I'm going out again, you know, socializing. (.) And um yeah I'm trying to get back to normal again.

Normal standards altered:

d) Balance between activity and pain (use of pacing)
S1: but you've got to slow down you've just, you know you've got to think well if I do fifteen minutes of this and go and have a cup of tea and relax um you know I can come out and do another fifteen twenty minutes I can, that is the way you have to gear up for it. It's the only way you know, otherwise you end up doing an hour or so and you end up two days in pain like.

S21: Obviously it's a bit annoying sometimes if I can't do something but no it's OK at the moment, yes I've learnt to cope with it..... It was a very gradual process of finding out what I can do what I can't do and knowing the signs of don't do that any more and go and lie on the floor and do some exercises..... at the moment the pain hasn't been too bad with the acupuncture and knowing what I can do and what I can't do. It isn't too bad at the moment. But if I have got things to do and it's bad I would sort of do a little bit and then perhaps lie on the bed and do a little bit more.

e) Acknowledgement that certain things could no longer be done **(aspirations downgraded)**
S7: you have to think twice before you make a choice to do it. And it's very hard because the things you try to do sometimes you manage but then sometimes you don't so you have to really think like um moving around anything like that, hovering in the house you might be able to do it on the ground floor but then started to staircase you might not, I can't do it, so you have to, you don't do that, you can't. Like plugging in, one day plug in I might able to do it but the next time I might not able to do it, so it depends, it varies as well so you always rely on somebody else to do it. I just have to swallow my pride and I said oh God I've got it now I have to live with it now, so the only thing is to think positive.

S9: Well I've accepted for a few years, quite a few years now, but last two or three years I've got worse, deteriorated and I realize that I can't do that now. I've sort of accepted it although it hurts I can't, you know what I mean

S10: now I hardly do anything, ...it's something I have to live with

S13: Well it just takes over your life. I mean at present it's took me all my time to get from the front entrance to the lift, whereas a few years ago I'd run it. So now, as I explain to people, I live in a box. I can't get out unless somebody comes with a car to take me because I can't walk far enough. I get out of my box three times a day to get my meals..... But you've just got to make light of it. I think well I've got it, there's nothing I can do about it is there, so I've got to make the best of it.

S16: I used to like running and maybe a bit of tennis at times, and I don't know I was more outgoing and I feel like this has all restricted me now I can't do it any more..... Well I'm just thinking that I can't do it anymore and that's it, we've missed out, feel frustrated when you see the athletics and running was my sport and you can't do it, well you feel a little bit sad I'd say, too late now, it's passed us by..... Yeah accept it, accept it, there's nothing else you can do you've got to accept it, (.) I'm not happy about it but what can you do.

f) Activity substitution/ modification (substitute particular activities or find ways of doing same activities but in different way (reinterpret what normal is now)
S4: I hate planning anything I hate it, but because I've had this pain for so long I've have to plan things. I've got to do it in routine to get me through the day so I have to, so I do the same things to get me through the pain but they may be things well I'll say to my wife let's go out today, oh alright then, we'll go. We'll do it but she'll know if I'm in any pain we'll stop, or if things get worse we'll come home. So that's the only things that go off a tangent but basically everything else is a routine which I have to, I accept it. If you understand what, I accept it, but I don't accept it. I mean does that sound..? (Well tell me more about that. Can you expand on it?) Can I expand, well, yes I had to do these things but I don't like doing them.(.) Cos I'm only doing it because of the pain that I've got. So it's not something that I would set out and do in this, the way have to do it in the routine I do it. In my normal life I wouldn't, alright everybody has a routine I suppose everybody does have a routine but sometimes the routines don't work but it doesn't make them any, it doesn't make them feel bad. (.) So if I did something different if I stayed in bed all day, I know I'd feel bad because my pain would be worse.

S14: I used to enjoy getting up early in the morning to go to work. And I used to enjoy on holiday I used to enjoy going walking. I can't do them anymore. It's just something that I'll have to work around you know..... You know it's just slow down in a small way and just work to some way of getting it. Do it but doing it in longer, takes longer to do it. Takes a long time to do in an hour you do it in two and a half hours now you know. It's something like you still have a go. If you don't your finished I think. Same as going on holidays isn't it you just have to, instead of going to the mountains you have to go the valley don't you. You know it's the same thing. Even though you enjoy going for a walk you just have to do it on the level don't you. And take the mobile just in case you can't get back. (laughs) Yeah.

S15: I have a trolley and my trolley is excellent, it's so light and so easy to pull, and as I said on the way back I take a minicab now. I walk down hill because I'm on the brow of the hill a little bit, not a big hill, but when you have a load you feel it..... I just carry on and my body will tell me I think, whether I can do it or not.

S22: I can't do anything really active like sports or something or, you know stuff like that. I'm not supposed to do energetic sports I'm supposed to do, I can go swimming I'm not a real swimmer so I just go there for a bit of exercise rather than fun. But I could do like, I used to enjoy aerobics and stuff so now I have to go for the gentler ones. (....) I can't lift the washing basket but I can kick it along or push it along or bend my knees and just lift it if it's light or, stuff like that. I can hang the clothes up but I hold the pegs in my hand so I don't have to keep bending down and you know I sort of train myself like that so I still do stuff I just do it differently.

Acceptance of help:

g) Use of help - impact attenuated by using people's help to assist them (constraint absorbed)

S7: You know I mean, some yeah it can affect but it didn't affect me that much because he understood what I was going through, he was very understanding and he helped me with everything in the house. He took over my role. I mean like before I was a working mother, I used to go work, come home do all the housework, cooking, cleaning, washing, everything. He took over that role from me. You know he goes to work, come home, does the cooking, washing, cleaning look after the children, everything, housework, he did everything, he took over what I was doing, he took over completely that role. And he was very understanding. He knew I was in bad so, it ??didn't affect me that much as well he was understandable and that made me feel good as well.

S13: But that's got to be made up but she will come downstairs and help me. Really I am really privileged I've got people that do come and help me but otherwise that would be a bugbear, having to do all that. Cos that's when I have to get on my knees and say oh dear, oh dear. And get to a chair and sit down, but apart from that I don't let it get me down .....But I feel I'm a nuisance. I say to my son every Saturday, I wish I wasn't such a nuisance.....I do what I can. I do all the top stuff and dust but it's the down bits I can't do. Cos to get down for anything I have to sit on me bottom and then it's a job to get up....I feel miserable about it (needing help) for about 20 minutes and I think oh well I can't help it and that's it. It's not through my fault it's just something that's come upon me. I think it's not my fault what's the use of brooding over it, you know. Then I get over it and I go and find a book and sit and read or if it's half past 11 I put my cooking programme on and I forget all about it. I don't brood over it at all. I don't know what I'd do if I brooded over it. No. What's the use you've got it, you've got it haven't you. That's just how I take it now.

S17: I've got a daughter who is absolutely a joy..... she does anything we wanted, I mean my son unfortunately lives in Sheffield so we don't see him much, but even he came down the other Sunday and cooked lunch for us, from Sheffield, went over to Julie's and stayed the night there and went to a meeting in town on the Monday morning. So we have really a lot of, we're very, I consider we're very very fortunate.... So really as I say as far as the pain is concerned I have had a lot of help.

S21: my husband would be very good I mean if I couldn't vacuum the house he would do it for me and he does most of the gardening and.....He doesn't mind and he's very good so, very supportive so. Probably if I didn't have him I would be a lot more depressed, a lot more worried but because I've got him who helps me and supports me I don't have to worry.

Sub-category ii): Subversion

This is characterized by the themes of non-acceptance of the constraints imposed by pain, the desire to maintain pre-pain identities, the avoidance of activities in order to maintain pre-pain or 'normal' identities and an unwillingness to accept help or use publicly visible methods to help them with the pain.

Non-acceptance:

a) Original standards of what normal life is remaining.

S8: I suppose you want to pretend you're still keeping up with things really. And psychologically you want to think you are which I suppose not a bad thing because you'd give up.

S22: I still try and do as much as I can so.... I don't really miss out on going out or anything like that. If I go to like, to the shops or anything I know I'll be in pain afterwards but I still go, it's like that, I still go, cos I don't want it to stop me doing it. Because like if I go to like all these cultural events that last half a day I know I'll be tired by the end of the evening so, but I still go but I just take a couple of paracetamol in the evening, so that's about it. It doesn't really stop me, that's what I'm trying to say, it doesn't really, it could stop me but I try not to let it, so.

Desire to maintain 'normal' pre-pain identities: identity takes precedence over activity:

b) Activity not maximized – coping aimed at maintaining identity rather than maximize activity

S16: I try and disguise it and don't tell anybody. (laughs) I mean my friends know and a few neighbours but sometimes though it's, when it gets bad and my wife'll do too much walking and I start walking with a bit of a limp then and I say that's it I've got to go home now....Well the pain plus I don't like to be looked at when I'm hobbling along.

S19: I mean I love to swim but I just cannot get, it's my head, I just cannot get my head into motivation to go swimming, you know, a because I've put on so much weight cos I've put on what 4 stone, well I did put on 4 stone I've lost 2 of it now, and that really does blow your mind you know for going from a size 10 to a I was up to a size 20 so I'm now down to a 16 again which is quite nice but I still feel physically in myself I, um, I know it's not me but at the same time you know you want to go swimming and so therefore you know it's the vanity side and also it's the case that knowing that I used to be I used to compete a lot, I used to you know do competitions and all the rest of it you know .....I just think to myself like you know, I'm going to do it I will get there one day I know I will get in the pool one day, but for some reason that is my main hang up I cannot get myself into a swimming pool and that is unusual for me because I really love my swimming. I used to train 3 miles a day and every day at 5 o' clock in the morning and then again after I'd finish work and um. I don't know I don't know what it is, maybe because I feel I'm going to let myself down that I don't feel I'm going to be able to do what I want to do..... because I, if you like because I, I could swim you know the way I used to. Everyone used to renowned me as a fish, you know I mean I'm always perceived to be the person who's always in the water you could never get me out of the water, and if you like it was my, it was one of my areas where I knew I was good, I knew I was respected for what I, you know for what I did, and I obviously used to train other people and all the rest of it, and to have to go back to the beginning is I think the hardest point for me is to know that I've actually got to bring myself down to such a low level and to actually pick myself back up again and do it. And I think that's my biggest hang up you know.

c) Avoidance of particular environments, activities that might be interpreted as disabled, old etc.
S6: get up, do my housework, have my shower, get ready, keep myself like I used to keep myself. phone my daughter, try and make arrangements and keep happy but if, when push come to shove and people want to come over I make an excuse, but I still like talking to them on the telephone like try to keep, that's how I keep normal. Whereas we would be actually out with them or they would be coming over cos like we used to have a lot of people come over and now I think, oh I'll just leave it another week before I give them a ring or, I just say oh no I'll just leave it this week perhaps we'll see you next week. And they're quite nice to me out friends, because they know what lifestyle we used to lead and they go oh you must have a seat and I go no I don't wanna, wanna seat, but I have to sit down and that really bugs me. You know. Whereas I would be standing up at the bar (laughs) or standing along wherever, you know and it feels awful that people have to squash along to make way for me (laughs). You're treated like this old infirm person and you don't wanna be an old infirm person, before the time's, before I think the time's ready for it,

S8: Well as I say I avoid situations where I'm going to be noticed with it. I avoid anywhere sort of damp, yet I like the water you see. I avoid going too near anything. I sometimes think oh you know it's a psychological experience but I, and I've challenged it, but I'm absolutely crippled with it absolutely, you know if we go down to the Thames or anything, and I can come away, and in the car by the time I get to the other end it's dreadful. (.) It completely changes your lifestyle because you're looking to ways to avoid it, where you're not going to be noticed. It hasn't actually lost my confidence because I try to avoid places which will show that I'm not confident....As I say I don't really want people to see what I'm like even though S*** I saw like that. (.) It's difficult I suppose because I still want to be seen as my children get older and my grandchildren sort of, trying to do everything they're doing and half the time I don't feel like it. And I'll make excuses about that or I will go I mean A*** my daughter says oh you know we'll take our time, she's very good actually, because she's a dancer and she's had dance injuries so she knows. And she'll say well you know we'll just, oh well we'll go here, or we'll go what we know you can do, although it's kind I don't really like it. Although it is kind and considerate and I'll go along with it because I've got no choice or to bail myself out..... I don't see as many friends as well, because they're all sort of, or I'm getting out of the car and I'm hobbling to them and that you do cut down you know and um like my daughter said one day why don't you give them a phone call and I'm going well what's the point because you know they'll suggest this and I don't want to do that, so I just don't bother and I think you can lose friends or somebody'll ring up and say you know what Chris I haven't heard from you for ages, and I'm saying oh actually I'm busy even if I'm not I'll say well actually I'm busy I'm involved in something, I make whatever I'm involved in I will sort of embroider it so that it's sounds as though I'm really over the top with it and really I'm not it's just that I don't want to be be seen like that, with them.

S12: I used to go into Waford, I used to love to go into Watford, and I haven't been now since long before Christmas. I want a pair of shoes and I don't like to go into a shop on my own because I don't want the assistants, you know some of them are very good, but I would want to be able to go in and do it myself, select what I want and try them on. So I'm still working on that one....Because taking my shoes off and on, and putting them on again and tying them up and I can't, I just can't bend, I can't get down to it.

d) Familiar and private environments and people OK because meanings publicly known-unfamiliar and public avoided
S6: Oh so if they do. We've got very good friends called Ken and Rita and Terry and Ellen. But I don't mind them so I'll cook the dinner and do it when they come..... but um if anyone comes unexpectedly while they're visiting then I have to get out of the chair I hate it.

S9: If I'm standing indoors, like I get a bit wobbly or sometimes bang I might be out the back I'll sort of stumble, hit me head on the wall, or something like that. If I fall .... If I'm near something strong I can pull myself up, but not always, sometimes if I'm in the middle of a wide pavement and I've gone down there's nothing to get hold of. People look at you as if you're drunk or something and there's nowhere to hide, you know what I mean. A lot of people know I'm like this but strangers they think I've been drinking or something.... Somedays I don't go out of the house. If I'm a bit more wobbly.... I stop where I am indoors, best place.

Unwillingness to ask for/ accept help or use publicly visible aides:

e) Unwilling to ask/accept help
S6: Because I think you're giving up when you start accepting help and letting someone else do you're running about and I think well while I can do it, I should do it.

S22: I don't like being treated differently I don't like people to, even at home if somebody does, in the beginning when people used to offer help a lot I used to feel really thick, I know it's stupid, like embarrassed actually, that's probably one of the reasons why I would keep, kept turning the help down and then when I started to accept my bad back and then I used to think about it and I used to think maybe I should have let them help me or something, I don't know, but there wasn't that much help but when I did get it I didn't accept it so it's a bit silly actually.

S16: Although you know I tend not to ask too much, most of them are a bit, you know I feel if it's something that's got to be lifted I feel, especially if it's not very heavy but I know that something not very heavy could still aggravate it, you know I feel a bit reluctant to ask for help with something like that..... I suppose embarrassment and just well, sort of feel a bit wimpish if you're going to ask someone else to lift something that seems you know within anyone's capability so.

f) Lack of use of visible props to ease pain (eg use of cushions) although will use invisible ones (e.g. medication)
S5:there's a film exhibition on in town somewhere that one of my daughters went to see last week and she knows that I'd love it, and her friend said well why doesn't your dad come and she says he can't walk and I can't walk round an exhibition and I'm not going to be wheel, I'm not going to go in a wheelchair

S22: I felt a bit frustrated that I couldn't sit on the sofa without a pillow you know, and I felt a bit embarrassed like if somebody came I'd take the pillow away so they wouldn't know that I've had to put a pillow behind my back, I know it sounds silly but cos you know like, so but now they all know I sit with a pillow cos in that way because everyone knows about my back, before everyone didn't know I didn't tell everybody for some reason for a little while, you know I was just sort of coping with it, and I didn't tell everyone I had a torn disc at first, just didn't tell them, I don't know why I didn't tell them but I just didn't want them to know for some reason I don't know why, so in a way I had to hide it as well like it's a bit weird, I know it sounds weird but I didn't want them to know that I needed special treatment or something like that, I wanted to be treated like normal, so.

Sub-category iii): Confrontation/Rebellion

Along with the sub-category of subversion, this response is characterized by the themes of non-acceptance of the constraints imposed by pain and of a desire to maintain pre-pain standards of what normal life is. It differs in that activity is maximized over pain, so, in contrast to subverting constraints, this mode of response consists of a direct challenge to the constraint of pain by doing things regardless. Hence it shares the themes of non-acceptance

Desire to maintain pre-pain activities:

a) ***Desire to be considered 'normal': original standards of what normal life is remain.***
S2: I'll do my normal chores I have to do and I'll stick to that which I've been sticking to all my life, regardless of the pain like I'll do my prayers for about 20, 25 minutes which I must sit down and do it to get up after I've sat down it's worse because now the pain in the legs is worse as well but I'll still do it, I'll still do it the same position as I used to do because changing the pattern is only giving in, to me it's giving in so I will not change.

S20: I wasn't prepared to let this stop my life, which was possibly, I think it was the right thing to do, it possibly didn't exactly help the ankle too much but I had to keep my head, I had to keep thinking positively because otherwise I would have just (.) I think I'd have just played the sick patient you know and I'm damned if I'm going to, I'm just not prepared to do that……

Activity is maximized despite pain:

b) Work continues despite pain

S16: I'm employed as an electrician and you've got to try and carry out all the parts of the job and when it comes to a lot of bending work or lifting heavy items that's, I feel you know something goes in my back and it's like a couple of weeks before it goes back to its normal pain, it's a lot worse then, you know you've got to attempt these things otherwise they're going to get somebody else, you know, they're not there to give you handouts

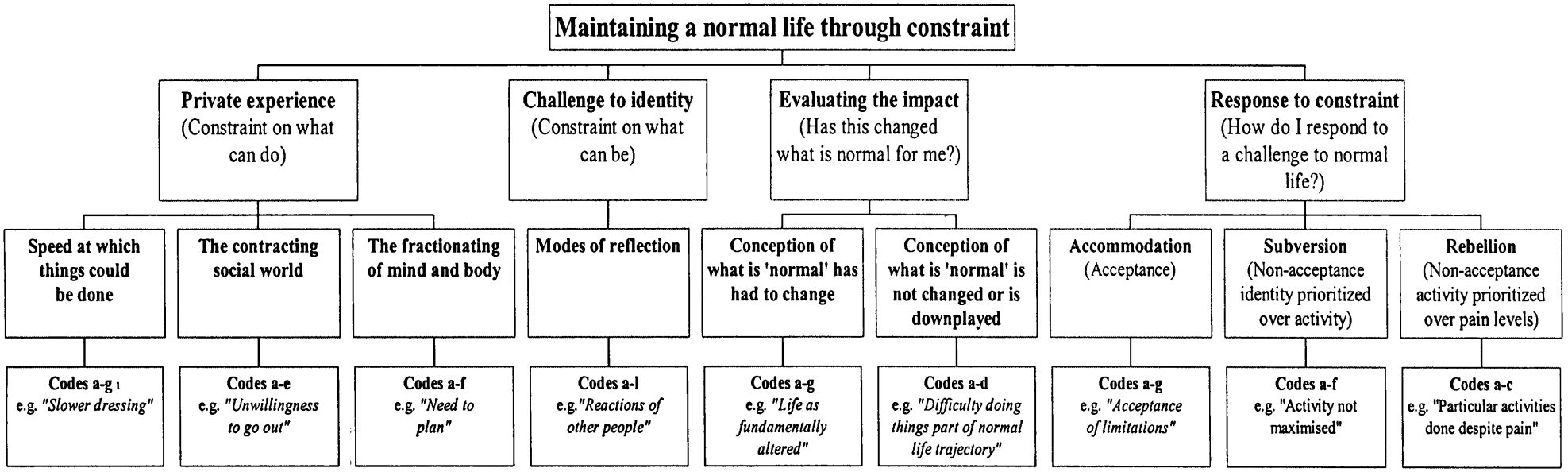
c) Particular activities done despite pain (non-acceptance of pacing)

S18: I do it until I drop until it's agony, absolutely excruciating…. I push myself to do it,

S21: I tend to sometimes do things regardless I think because it annoys me but then I'll regret it. (..) Well if I see the house looks dirty and I've got visitors I'll clean the house and think right OK I'll suffer afterwards.

S22: the things I accept are the things I know that I can't do, cos I can't do it but things that I know I can do and I'll be in a bit of pain I'll just do it myself so there are two different levels there. If I know, because it's something I can't do I can't mop the floor because we've got quite a large kitchen, I can do, when I get half way it really starts hurting my back so I can't do it but if I walk or carry the shopping home I can carry it all the way home and I'll be in pain so I still do that, so.

Diagram of the relationship between the initial codes and the final categories



[1] Codes a, b, c etc. and their accompanying open codes and quotes are shown on the previous pages of Appendix E.