

Pain Beliefs and Coping
Strategies of People with Mild/
Moderate Learning Disabilities
in Chronic Pain.

Su Thrift

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As part of the degree of Doctor of Clinical Psychology
(DClinPsy) - Department of Clinical Psychology,
Leicester University.

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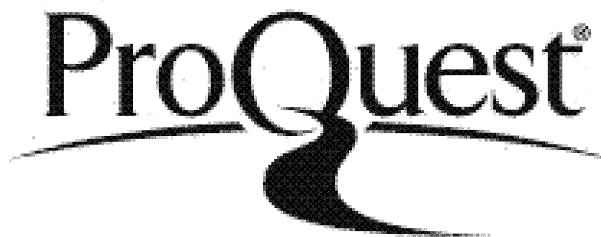
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Abstract

Pain Beliefs and Coping Strategies of People with Mild/Moderate Learning Disabilities in Chronic Pain.

Su Thrift

It has been shown that pain beliefs and coping strategies, identified by the adult and child pain literatures, play a mediating role in the experience of chronic pain. Certain pain beliefs have been linked to negative outcomes such as increased levels of disability or psychological distress, and can influence the success of pain interventions.

Differences between the pain beliefs and coping strategies of adults and children have been attributed to various factors (eg cognitive developmental level). Some of these factors are also relevant for people with learning disabilities. However, there has been no research into the pain beliefs and coping strategies of this population. This is due, in part, to beliefs that people with learning disabilities do not, or cannot experience pain.

This study aims to use in-depth interviews and a Grounded Theory Approach to explore the pain beliefs and coping strategies of eight adults with mild/ moderate learning disabilities who experience chronic pain associated with Osteoarthritis or Rheumatoid Arthritis.

The analysis identified various pain beliefs and coping strategies which were compared to those identified in the adult/child literatures. Differences and similarities, and the factors/ processes involved in these are discussed. Many of these are associated with the wider experience of having a learning disability (e.g. level of understanding, power or reliance, being different and being taken seriously).

Most important is the finding that many of the participants experienced that others, whom they needed to acknowledge that they are in pain, did not or were not able to, further adding to the distress the participants experienced. Possible reasons for this are discussed.

Clinical implications of these findings include the need for appropriately tailored pain assessments and interventions for people with learning disabilities, and support for staff/ carers/ professionals to acknowledge and respond appropriately to the pain of people with learning disabilities. Some suggestions on the implementation of this are given.

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INTRODUCTION.

1) THE NATURE OF PAIN.

WHAT IS PAIN?

A definition of pain that holds wide credence is that of the International Association for the Study of Pain (IASP) (Merskey 1986).

"An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life."

This definition stresses that pain is always subjective, and the role of learning through individual experience. However, pain is a complex concept with many interacting parts, some of which are absent from the above definition.

The definition of pain is distinct to that of **nociception** (the process of receiving sensory information about a painful stimuli), with pain now generally accepted to be an **interaction** between nociception and cognitive/affective (eg beliefs, attitudes, expectations, memories, emotions), situational (eg meaning and /or relevance of pain, response of others) and cultural factors (Melzack and Wall 1965, McGrath 1989, Carter 1994, Twycross 1994).

The experience of pain is therefore far wider than it's sensory aspects, although much effort has been spent finding ways to assess and quantify this accurately (McGrath and Hillier 1989). Less time has been devoted to understanding the contribution of psychological factors to the pain experience.

CHRONIC AND ACUTE PAIN.

Clinically and in the literature, the experience of pain has been divided into the experience of **chronic** and **acute** pain. This distinction is mainly on the basis of two variables; function and duration.

Acute pain is seen as functioning as a warning signal about potential tissue damage. The function of chronic pain is less clear, although it may be to ensure the inactivity sometimes necessary for successful recovery from serious illness/ injury (eg Wall 1979 in Pearce and Mays 1994). However, in the literature there are three types of chronic pain. That associated with a chronic medical condition; that associated with a specific illness/injury but lasting longer than would normally be expected; and that developing or persisting in the absence of identifiable organic pathology.

As the functional distinction is unclear, chronic and acute pain are often defined in terms of **duration** of pain, with pain considered to be chronic if it persists for longer than six months (Pearce and Mays 1994).

This duration continuum is seen as inadequate by some (eg Turk and Melzack 1992), who prefer a categorical approach in order to include more discrete categories of pain, such as acute recurrent (as in migraine) and chronic progressive (as in arthritis, terminal cancer).

On a different level, Payne and Walker (1996) argue that the main differentiation between acute and chronic pain, relates to the cognitive and behavioural processes of adaptation that take place when someone experiences persistent pain. For example, if someone believes an acute episode of pain to be self-limiting, they are likely to respond to it and view it's meaning differently to pain that they see as never-ending. With pains involving acute recurrent episodes, some sufferers manage each episode as an individual attack and remain fully functional in between attacks, whilst others are completely disabled by the threat of attacks and become chronic pain sufferers.

CHRONIC PAIN AND PSYCHOLOGICAL DISTRESS.

Chronic pain then is a remarkably common condition, with arthritis and musculo-skeletal problems as the most common cause. It can have dramatic effects on the psychosocial wellbeing of the individual and their families, and cause immense distress.

One of the Clinical Psychologist's roles is to alleviate distress, and improve psychological wellbeing. Drawing on a growing body of research, Clinical Psychologists have developed interventions for use with both adult and children chronic pain sufferers. Successful control of chronic pain usually involves changing the cognitive-evaluative components of the experience, whilst the sensory components remain the same (Weisenberg 1994). Therefore, many of these interventions have been based on Cognitive-Behavioural theories and research about the role of cognitive factors in chronic pain, for both adults and children. This research will now be discussed.

2) PSYCHOLOGICAL ASPECTS OF CHRONIC PAIN.

THE ROLE OF COGNITIVE FACTORS.

From the mid 1970's, proponents of cognitive theory have studied the influence of cognitive factors on the individual's experience of chronic pain. Much of this work has centred on the individual's **cognitive appraisal** of their pain, and the effects of **coping styles** on the experience of pain (Gamsa 1994).

Cognitive Appraisal/ Pain Beliefs.

From a Cognitive - Behavioural perspective, individuals are seen as active processors of information (Turk and Flor 1987). The experience of pain is thought to be mediated through an individual's cognitive appraisal of sensory-neural activity (Vlaeyen et al 1990). This cognitive appraisal involves beliefs such as attributions of meaning and causation of the pain, expectations, self-efficacy, personal control, and variables such as attention, problem-solving, coping, and imagery (Turk and Fernandez 1991, Gamsa 1994 in review of literature).

Definitions of Pain Beliefs.

Pain beliefs are a part of the individual's larger belief system, and they represent the person's own particular understanding of their pain experience. Williams and Thorn (1989) defined them as "the patient's own conceptualisation of what pain is and what pain means for them".

These beliefs are probably best judged, not by how 'true' or 'false' they are, but by how adaptive they are in enabling the believer to function in their world (Williams et al 1994). As, whether 'true' or 'false', adaptive or maladaptive, such beliefs make up the individual's internal reality, shaping their perceptions of themselves, their worlds and their behaviour (DeGood and Shutty 1992).

The Role of Pain Beliefs.

Pain beliefs are thought to play a prominent role in most aspects of the pain experience including, maladaptive avoidance behaviours (Phillips 1987 in Vlaeyen et al 1990), the perception and function of pain, pain report, the individual's ability to cope with pain, their levels of psychological distress and their response to treatment plans (Williams and Keefe 1991, Bennett-Branson and Craig 1993).

Causal attributions and efficacy expectations are thought to be especially important in the pain experience (Turk and Rudy 1986). Belief in one's ability and expectations of what will occur (based on memories of past experience, others' expectations etc) determine what, and whether coping behaviour is initiated, the effort expended and how long it will be sustained.

Beliefs about having control over pain have also been shown to be important in maintaining psychological wellbeing. Attribution of control of chronic pain to internal rather than external factors, is thought to reduce feelings of helplessness and hopelessness (Jensen et al 1991), and leads to adaptive coping (Crisson and Keefe 1988). It seems that it is not essential to actually have the control, but it must be perceived as available by the individual (Siegel and Smith 1989).

DeGood and Shutty (1992) split pain beliefs into three categories ranging from the general to the highly specific. The first category of beliefs are basic philosophical assumptions about the world and self. These assumptions are about fairness, suffering, justice and responsibility. For example, a belief that life should be 'pain free', which can intensify feelings of suffering when pain is experienced.

Category two beliefs tend to be more rooted in everyday life, more generalisable across situations and stable over time (DeGood and Shutty 1992). These include belief patterns such as locus of control, attributional style and self-efficacy. Category three beliefs are specific beliefs about what should be done by oneself or others to control the pain. For example, a category two belief becomes a category three belief, when the emphasis moves from general beliefs about self-efficacy, to beliefs about one's own ability to perform in a specific situation.

'Negative' pain beliefs have been shown to lead to vicious circles of decreased activity, increased disability and no opportunity for corrective feedback. Alternatively, a sense of mastery gained through coping with pain can establish and strengthen 'positive' expectations and beliefs (Turk and Fernandez 1991).

Given the wide ranging effects of some pain beliefs, a number of pain researchers and clinicians have argued for the routine assessment of patients attitudes towards, and beliefs about, the experience of pain and its treatment (eg Williams and Thorn 1989, Shutty and DeGood 1991) as part of the multi-disciplinary assessment prior to treatment.

Measures of Pain Beliefs/Cognitions.

There are numerous measures which aim to assess attitudes to, and beliefs about, pain. These measures have been developed with a range of populations, with different pain problems, and focus on different beliefs and attitudes. There is no final list of what beliefs are central to the pain experience, although common themes are emerging, and links between certain pain beliefs and maladaptive coping are developing.

The Pain Cognition Questionnaire (Boston et al 1990) is a 30 item questionnaire composed of **patient-elicited** pain cognitions. These have been grouped into four factors; active coping strategies, hopelessness, helplessness, and passive optimism. High scores on helplessness and hopelessness are associated with increased pain intensity, distress and behavioural disruption.

Vlaeyen et al (1990) developed a Pain Cognition Questionnaire reflecting 'what Chronic Pain patients think of their pain'. They developed 81 'Cognitions' from patients descriptions of their pain beliefs, which a further subject group rated on a Likert 5 point scale, "To what degree do you agree with the following statement?". This reduced the items to a 50 item Pain Cognition List which group into five factors, and is used as an assessment tool.

The Pain Beliefs and Perceptions Inventory (PBAPI) (Williams and Thorn 1989) has 16 items which were originally grouped into 3 factors; Time (the belief that pain is and will be an enduring aspect of life), Mystery (the belief that pain is mysterious and poorly understood), and Self-blame (the belief that pain is somehow caused or maintained by the individual). Following work by Strong et al (1992) amongst others, the Time scale has been divided into Constancy and Pain Permanence (Williams et al 1994). This scale was developed from the pain beliefs described by 90 Chronic pain patients. These descriptions clustered into seven categories, three of which best fitted further testing with 121 other patients.

Williams and Thorn (1989) found that the belief that pain is 'enduring', was associated with greater subjective pain intensity and decreased compliance with interventions. A high score on the 'mystery' scale was associated with low self-esteem, high levels of somatization and psychological distress, and poor compliance compared to those who believed they understood their pain.

The PBAPI (Williams and Thorn 1989) was developed with patients awaiting compensation for industrial injury and with mixed pain complaints, and the influence of these variables is debatable. Strong et al (1992) suggested that the reason that their factor analysis found four, compared

to the original three factors, may be because their subjects experienced different types of pain to the subjects in the original study.

They went on to question how confidently we can use measures designed with one particular type of pain, with a different patient group.

Turk and Melzack (1992) state that most of what is known about chronic pain patients has been learned by studying highly selective groups, such as those referred to specialised pain clinics or laboratory volunteers. Skevington (1995) says that such samples are far from representative of pain patients in general.

COPING STRATEGIES.

According to the Cognitive-Behavioural model, individuals make spontaneous attempts to cope with their pain. Coping has been conceptualised as "the person's constantly changing cognitive and behavioural efforts to manage (reduce, minimise, master or tolerate) the internal and external demands of the person-environment transaction, that are appraised as taxing or exceeding the person's resources" (Folkman et al 1986). Coping strategies do not have to be adaptive or successful to be seen as attempts to cope (Siegel and Smith 1989).

The way a person copes with a stressful situation such as chronic pain, is thought to be mediated by their cognitive appraisal of that situation (Lazarus and Folkman 1984). The individual's beliefs and expectations about their pain constitute a large part of this appraisal (as outlined above). Therefore, people's coping strategies are hypothesised to be linked closely to their concepts and beliefs about pain (Williams and Keefe 1991, Strong et al 1992).

It is thought that negative appraisals such as low levels of self-efficacy, and high levels of catastrophic thoughts (ie negative self-statements and overly negative thoughts about the pain), may interfere with the effectiveness of people's coping strategies (Bennett-Branson and Craig 1993). For example, if someone believes that there is nothing he can do to change his pain experience, then he is unlikely to make attempts to modify his pain. So an understanding of pain beliefs are important to an understanding an individual's efforts to cope.

Jensen et al (1991) in a review of the literature on coping with chronic pain, concluded that pain beliefs and coping have a strong relationship to adjustment to chronic pain. People who believe they can control their pain, who avoid catastrophising, and who believe that they are not severely disabled, function better than those who do the opposite.

It is important to point out that the current data is largely correlational, and therefore cause and effect are not clear.

Measures of Coping Strategies.

One of the most commonly used measures of coping strategies in the pain literature is the Coping Strategies Questionnaire - CSQ (Rosenstiel and Keefe 1983). It has various scales of cognitive and behavioural coping strategies including diverting attention, catastrophising, ignoring pain sensations, and praying and hoping.

Rosenstiel and Keefe (1983) found that patients scoring high on the helplessness scale were significantly more depressed and anxious. Those scoring high on 'diverting attention' and 'praying' scales reported higher levels of pain and more functional impairment. Those scoring high on 'catastrophising' had poor emotional adjustment.

The CSQ's clinical use is well established, despite the inherent difficulties in interpreting most pain measures which have been designed with highly specific populations. The CSQ has been used in the form of it's scales rather than it's items by all but two studies (Tuttle et al 1991, Swartzman et al 1994). Studies have generally yielded factors that have not replicated cross-sample and are difficult to interpret (Swartzman et al 1994). Swartzman et al (1994) had "experienced clinicians who work predominantly with chronic pain patients" classify the CSQ. They found that the items in the CSQ formed 5 rather than 8 scales with their whiplash patients. This corresponded well with Tuttle et al (1991) study on a heterogeneous sample of chronic pain patients.

Brown and Nicassio (1987) developed a scale to measure 'active' and 'passive' coping strategies in chronic pain amongst adults with arthritis. They defined 'active' strategies as those aimed at eliminating the problem

situation, and 'passive' strategies as those aimed at psychologically controlling the stressful effects of the problem.

Their study found that individuals scoring high on 'active' coping had lower levels of pain and functional impairment, greater beliefs in internal locus of control, higher general self-efficacy, lower levels of depression and helplessness. Those high on 'passive' coping showed the opposite pattern.

Some of the issues from the child pain literature relevant to people with LD (eg cognitive-developmental levels, difficulties of communication) will now be outlined.

COGNITIVE FACTORS IN CHILDREN.

A major difficulty for paediatric clinicians is to gain access to the child's experience of pain. It is assumed in work with adults that a shared language is used, yet gaining an understanding of the adult's pain experience is still extremely difficult (Barr 1994). In children, it is not certain that they have the same vocabulary, use it in the same way or are as articulate in describing their pain experience (Harbeck and Peterson 1992). As a result, there has been a paucity of research until relatively recently, due to erroneous beliefs that information gained directly from children concerning their own pain experience would be unreliable (Zajdermann and Bierdermann 1991)

Children begin to learn about and understand pain through their experience, as shown in the IASP (1986) definition outlined earlier. They then describe pain in the language that represents those experiences. However, even without the appropriate language, children can still communicate what pain means to them (McGrath and Craig 1989).

Theoretically, the child's cognitive appraisal of their pain experience will be influenced by a variety of factors including their cognitive-developmental level, previous experience, and parental support (Siegel and Smith 1989).

Cognitive Developmental Factors.

Cognitive-developmental factors are thought to influence the child's understanding of the causes of their pain, and methods of treatment.

Basically, the child's understanding of pain progresses from being unable to verbalise a reason why pain 'hurts', to a concrete, perceptually dominated causation. Pain as a 'thing/ it', defined by its location and physical properties (pre-operational stage - 5-7 years). Understanding then moves to semiabstract understanding, where pain is defined in terms of feelings/sensations and synonyms used to describe its qualities (concrete operational stage 8-10 years), and then to abstract definitions including psychological and physical factors, and an understanding of the warning value of pain (early formal operational stage - 11- 14 years) (Gaffney and Dunne 1986, Harbeck-Weber and Peterson 1993).

Based on this stage approach, Gaffrey and Dunne (1986) showed children at 5 to 7 years giving descriptions of their pain in a concrete way (eg "There's something in my belly" or "It's sore here"). Whilst children of 11 to 13 (concrete operational to formal operational) talked about damage, and physical and emotional consequences of pain.

Savedra et al (1981/2) interviewed 214 9-12 year olds and found no developmental differences in their responses. However, this may have an artifact of the narrow age band. Ross and Ross (1984) also failed to find any developmental transition in knowledge, understanding of pain or the ability to describe specific pain experiences, across their 5 to 12 year age group of 994 children.

Much of the literature in this area depends heavily on Piagetian ideas, where the way children think changes qualitatively as they progress through set stages. The stage theory has generally been criticised for the assumption that children's development occurs in a vacuum with little acknowledgment of the role of experience, social or cultural factors (Nelson 1986).

The child health literature has been criticised for exclusively and unquestioningly applying the stage theory (which reflects conceptual change about physical concepts such as conservation) to concepts of

health, and for labeling responses in terms of 'operations'. Eiser (1989) argues that researchers have done this because, after arguing that children think so differently from adults on such issues, they need different types of explanations.

Alternative theories exist such as functionalist theories which see children as 'theory builders' with their concepts developing and shifting with experience (eg Carey 1985 cited in Eiser 1989). Script Theory suggests that cognitive changes are due to a gathering of experiences related to pain and a developing 'knowledge' of how to think, behave etc.

This discussion mirrors the debate, within the developmental psychology field, which questions whether children do think and learn in fundamentally different ways to adults. However, there is not space to develop this discussion further here. The most conclusive finding of this research is that children's thinking about pain changes throughout childhood, from global concrete to specific abstract explanations (Harbeck-Weber and Peterson 1993).

The level of the child's thinking/understanding must be considered when assessing pain beliefs and giving explanations about the pain or treatments. Cognitive distortions about pain (associated with unsophisticated conceptualisations) in children can result in heightened emotional reactions and fear (Bush 1987). Children have been shown to have grotesque fantasies when the information given to them about their pain is incomplete or when explanations are developmentally inappropriate. This can lead to maladaptive behaviour and increased psychological distress, which in turn can lead to more pain.

Successful coping has been linked to having accurate information at the appropriate 'cognitive-developmental level', and having many different strategies for flexibly coping with the pain (Peterson and Toler 1986).

Children's Pain Beliefs.

Some of the pain beliefs found to be influential in the adult's experience of chronic pain, are also influential in children. For example, the level of control experienced, level of self-efficacy and catastrophising thoughts (Branson and Craig 1988).

However, these variables are slightly different in children. For example, the degree of control/ independence with which a child is likely to feel comfortable may be different to the level an adult may expect. Gaffney and Dunne (1986) showed that younger children had a more passive perspective about pain which gradually shifted with age, to a perspective that included a degree of perceived control.

Family member's attitudes and responses to pain have been shown to influence the child's beliefs about, and attempts to cope with pain (McGrath and Craig 1989, Bennett-Branson and Craig 1993).

Children's Coping Strategies.

Little is known about children's spontaneous coping strategies, although there have been a number of studies (eg Branson and Craig 1988). It is vital to have an understanding in this area or clinicians must base their work on understandings gained from adult studies, which may not be appropriate, and vital differences may be overlooked.

Savedra et al (1981/2) found that 85% of the 214 9-12 year olds they asked used at least one coping strategy. The most frequently reported strategy was medication. Others included rest or relaxation, presence or attention of others or food/drink.

Ross and Ross (1984) tried to tap into more 'self initiated' and 'internal' strategies for coping with pain. They found that only 21% of their subjects reported using such strategies. These included distraction, thought stopping/ fantasy and physical procedures such as fist clenching. A small group of these were taught these techniques by professionals, and were therefore not truly spontaneous. Curry and Russ (1985) found three basic behavioural categories of coping in children, information seeking, support seeking and direct efforts to maintain control.

COGNITIVE ASSESSMENT/ INTERVENTIONS FOR PAIN.

A substantial part of the literature concerned with the cognitive aspects of the pain experience focuses on interventions for chronic pain. In fact Vlaeyen et al (1990), stated that research into the cognitive variables involved in the pain experience has lagged behind the introduction of multiple cognitive-behavioural interventions.

These cognitive interventions (based on thorough assessment of the individual's pain beliefs/concepts and coping strategies), aim to alter the pain cognitions associated with maladjustment, such as catastrophising (Lawson et al 1990), enhance the individual's coping strategies and their confidence in their ability to cope (Williams and Kinney 1991).

Self-efficacy theory suggests that such cognitive interventions work by changing people's perception of their ability to cope with the pain. This change is thought to increase the individual's persistence in applying, and success at using, coping strategies (eg Bandura et al 1987). Such interventions also reduce the anticipation of pain that can cause distress and anxiety, which in itself exacerbates pain, and maladaptive pain behaviour (Lawson et al 1990, Gamsa 1994, Weisenberg 1994).

A thorough understanding and accurate assessment of the individual's pain beliefs and coping strategies prior to treatment, enables the development and accurate evaluation of appropriate individualised interventions (Lawson et al 1990, Vlaeyen et al 1990). It also helps health care professionals to better understand the individual's experiences, communication about their pain, and their coping attempts, and will give the individual more control over the pain and his treatment (Zajderman and Biedermann 1991, Harbeck-Weber and Patterson 1993) which in turn can reduce the level of pain experienced.

Pain beliefs can influence the willingness of patients to accept or adhere to treatment. A thorough assessment of these can lead to an understanding of what may lead to resistance against treatment, and provide ways of presenting interventions in ways that are compatible with the individual's beliefs about pain (Williams and Keefe 1991). For example, Phillips (1987) (cited in Weisenberg 1994) showed that chronic pain patients often adopt

an avoidance strategy based on the belief that increased physical activity would cause harm, whereas often for chronic benign pain the opposite is recommended for treatment and rehabilitation.

SUMMARY.

Clinical Psychologists are often involved in helping patients manage their chronic pain more effectively, reducing their levels of disability and psychological distress. The role of specific pain beliefs and coping strategies in the experience of chronic pain has been identified, and correlational relationships found between certain beliefs and levels of distress/ adjustment. A thorough understanding of which beliefs and coping strategies lead to maladjustment and distress, and how this occurs is vital for effecting change.

There are some similarities and some differences between the pain beliefs and coping strategies of children and adults. This seems to be linked to factors effecting these beliefs that differ between adults and children. For example, level of independence and self-efficacy, and the importance of views of carers. Other researchers have suggested differences in pain beliefs and coping strategies between other groups, such as people with different pain related illnesses/injuries (eg Strong et al 1992). Differences between populations must therefore be established and recognised in research in chronic pain.

3) ISSUES FOR PEOPLE WITH LEARNING DISABILITIES.

Despite, a substantial and growing literature covering the various aspects of the pain experience of children and adults **without** a Learning Disability (LD), the literature pertaining to people **with** a LD is almost non-existent. The little that does exist, suggests that the experience of pain is significantly different for many people with a LD, compared to the non LD population (ie Biersdorff 1994).

GENERALISING THE ADULT/CHILD LITERATURE TO PEOPLE WITH LD.

Varni and Walco (1988) amongst others (eg Harbeck and Peterson 1992, Tesler et al 1993) have argued that an accurate understanding of children's pain experience cannot be gained by just downwardly applying the knowledge of adults' experience of pain. They said that children's varying stages of cognitive development would effect their conceptualisations of, and communications about pain, and therefore work with children must develop a separate, if not parallel, database from adult work, sensitive to the differing variables.

Similar arguments can be applied to understanding the experience of pain for people with a LD, who by definition have differing levels of cognitive ability to adults without a LD.

Many are also affected by some of the other variables thought to be important in the experience of pain for children. For example, many adults with a LD are more dependant on their families and carers than adults without a LD, and can be heavily influenced by their attitudes and beliefs (Baxter 1994), and the models they present of appropriate ways to behave. These attitudes/ models are usually influential because people with a LD often associate with limited numbers or groups of people (Firth and Rapley 1990).

In addition, there are factors unique to people with a LD that are likely to affect their experience of pain. The conceptualisation of pain is gained by learning by experience over time (see IASP (1986) definition). Something with which people with a LD have difficulty, by definition (Schwab 1992).

PREVIOUS LITERATURE ON LD AND PAIN.

The little research that does study the experience of pain for people with LD has often been in the form of case studies (eg Keizer 1951, Thrush 1973 cited Biersdorff 1994). Much of this has described cases where individuals have shown no 'Pain Behaviours', and have therefore been thought to be indifferent or insensitive to pain. This research has relied on observable 'pain behaviours' because of the difficulties communicating with many people with a LD.

One such study (Biersdorff 1994) assumed that when none of the 'involuntary basic pain behaviours' were displayed during an injury or illness that is typically painful, that the individual was either 'insensitive' (due to abnormalities in the peripheral or central nervous system) or 'indifferent' (ie takes longer to evaluate pain or interprets it differently to non-LD) to pain.

To gain an idea of the incidence of these phenomena, family members were interviewed about their LD relatives' behavioural reactions to pain. There are a number of criticisms of this study, and therefore the current study will not be following a similar design.

Firstly, despite a recognition of the cognitive aspects of the pain experience (see definition of 'indifference' above), there is no recognition that the individual with a LD and their relative may differ in their expectations and interpretations of behaviours representing expressions of pain.

Secondly, with pre-verbal children where pain behaviours have been extensively studied, there has been no established group of 'basic pain behaviours'. None of the wide range of behaviours that have been associated with a child being in pain, are uniquely or always present (Ross and Ross 1988). It is thought that different behaviours are seen depending on the nature of the pain (eg Chronic versus Acute - Varni and Walco 1988). Pain behaviours are also susceptible to conditioning and learning, and are dependent on context (Turk and Melzack 1992).

In addition, studies in the adult/child literature have shown that third party (eg nurses) reports of levels of pain based on 'pain behaviours', poorly correlate with patients reported levels of pain (Bennett-Branson and Craig 1993). This is not surprising given the subjective nature of pain. Biersdorff (1994) acknowledges the difficulties with third party report, yet studies relatives' interpretations of the person with LD's pain experience. She then bases strong conclusions on these reports.

INTERVIEWING PEOPLE WITH LD.

Until recently it was thought that children could not verbally communicate useful information about their pain (Ross and Ross 1984). This has been shown not to be the case, and children are now seen as the most valid source of information about their pain. However, some similar views still remain about devising research procedures for people with a LD to communicate their experiences.

Third party reporting of subjective experiences is not uncommon in the LD literature. Carers have often been asked to make judgements regarding the subjective experiences of the person with a LD, such as their social support networks (eg Krauss et al 1992), quality of community living situation (eg Lord and Pedlar cited in Biersdorff 1994) and of pain (Biersdorff 1994).

A major concern is that these judgments may differ considerably from the experience of the individuals themselves. As McGrath and Hiller (1989) note, pain perception is as subjective as perception of colour, sound, smell or taste, and like these it is impossible to know exactly what an individual's pain experience is like, even though we can measure some aspects of it (eg location, duration)

Increasingly, people with a LD are being seen as the only valid informant for many areas of their lives (Dagnan and Ruddick 1995). A qualitative approach is used by many of these studies, as a way of understanding and viewing the world as the individual themselves see it (Atkinson 1988).

However, there are methodological problems in seeking to represent the views of people with a LD in a valid and reliable way. Studies have identified some of these and suggested ways to gain the most valid responses from this population.

Factors Affecting Interview Responses.

Research has shown that in adults without a LD, numerous factors influence people's responses to questions, making them less than a totally accurate reflection of their reality. A number of studies have found that people with a LD are more prone to these factors than the general population (eg Lowe and De Paiva 1988, Streiner and Norman 1991, Sharrock and Gudjonsson 1993, Heal and Sigelman 1995).

For example, social desirability; "faking good" or "faking bad" (implying conscious attempts to alter responses); acquiescence and suggestibility. A disposition to 'nay-saying' (saying 'No' regardless of the question), although less common than acquiescence, has been noted in response to 'taboo' or negative topics (Heal and Sigelman 1995). It is thought that this is used to present oneself in a socially desirable light by denying association with taboo subjects or actions.

Often people with a LD are discouraged from talking or thinking about negative aspects of their lives (Lowe and DePaiva 1988), for example loss and grief, or lack of occupational and social opportunities. It will be interesting to see how readily the subjects will talk about their experience of pain, generally seen as a negative experience.

Studies have also shown that subjects with a LD often have concerns and worries about the purpose of research, for instance that it was designed to check on them or catch them out (Atkinson 1988, Lowe and DePaiva 1988). Such worries could lead to refusal to participate, a feeling that they have to, or attempts to cover up difficulties, which would not give valid responses to questions.

Type and wording of questions.

In addition, studies with people with a LD have shown that more open and exploratory questions, compared to closed questions, reduce acquiescence or 'Nay-saying' and therefore increase the validity of responses (Flynn 1988, Atkinson 1988). With 'either-or' type questions people with a LD tend to choose the latter response. However, the validity is greater for these than closed questions. Researchers are advised to pose questions with multiple formats to detect response biases (Heal and Sigelman 1995).

It is suggested that questions be kept as simple as possible, with as few parts/ concepts as possible. More complex questions yield lower appropriate response rates. Re-wording or repeating similar questions, and prompting gives the opportunity to check whether questions have been understood and the subject to reconsider earlier, or give more complete, answers. The interview should proceed at the subjects pace (Lowe and DePaiva 1988).

SUMMARY.

The central role of pain beliefs and coping strategies, in the experience of chronic pain for both children and adults, has been discussed. There has been no corresponding work within the LD population. This is vital as factors thought to effect these beliefs seem to be different for people with a LD. Problems interviewing people with a LD and various ways to overcome these, have also been outlined.

4) THE SUBJECTIVITY OF CHRONIC PAIN.

As Turk and Melzack (1992) note, many researchers and clinicians desire an **objective** measure of pain. However, a central impediment to the increased understanding and control of pain is it's inherent **subjectivity**. Pain is a difficult phenomenon to describe, and two individuals attempting to describe what is seemingly the same phenomena may use different descriptions. Similarly, a patient and health care professional may use different languages due to their differing experiences and frames of reference, making communication and mutual understanding difficult (Turk and Melzack 1992). This is likely to be even more marked when the patient has a LD.

It is vital to help devalued groups speak for themselves, so that professionals and the wider community become aware of their true concerns and experiences (Heal and Sigelman 1995). In the case of chronic pain and LD, this is vital for a more thorough understanding of their experience of pain, a reduction in their distress and more effective management of their pain. Given the subjectivity of the research topic, qualitative methods are seen as most appropriate for this study.

QUALITATIVE RESEARCH METHODS.

What is Qualitative Research?

The qualitative research paradigm is a large umbrella covering numerous different approaches and methodologies. Dey (1993) cites Tesch's (1990) review which distinguished over 40 types of qualitative research, characterised by the different perspectives and purposes of the researchers.

Primarily, qualitative data conveys meanings in forms other than numbers. The goal of qualitative research is the development of concepts to gain understanding of complex psychosocial phenomena, giving due emphasis to the meanings, experiences and views of the participants (Pope and Mays 1995).

Qualitative approaches have always been part of the methodological repertoire of psychology. However, there has been a tendency to see them as an adjunct or precursor to the main task of quantitative data analysis (Henwood and Nicolson 1995).

The Use of Quantitative and Qualitative Approaches.

There is a long-standing debate about the relative merits of quantitative and qualitative approaches and methods. Two main strands of this debate relate to technical and epistemological issues (Bryman 1988 cited Henwood and Pidgeon 1995).

Technical Issues.

The technical strand suggests that the choice between qualitative and quantitative methods is simply a practical choice, dependent on their suitability in answering specific research questions (Bryman 1988 cited in Henwood and Pidgeon 1992, Jones 1995, King 1995). This idea is not especially new to psychologists, who are trained to tailor particular approaches to particular methods.

Whilst quantitative methods are appropriate for researching well understood phenomenon and/ or well-delineated constructs, many areas of study are poorly understood and/or classified. Qualitative approaches can

be flexible and powerful, opening up many new areas to research (Britten 1995), and producing detailed descriptive, or definitive aspects of a phenomenon not previously researched. Qualitative research is invaluable, and most appropriate, where there is a need for psychologists to take a generative approach when existing theory/measures are incomplete, inappropriate, inadequate or absent (Henwood and Pidgeon 1992). Or when a study focuses on the meaning/s of a phenomenon to the participants, or complex and multi-dimensional beliefs and attitudes (Judd et al 1991).

It is vital that the appropriate level of measurement for data is identified. If this is ignored, then the data can appear to be more precise and show more than it actually does (Dey 1993).

Good qualitative research is often a prerequisite for good quantitative work. As, until something has been 'classified' it cannot be 'measured' (Pope and Mays 1995). If quantitative comparisons are to be made it must first be ensured that like is being compared with like, by classifying consistent categories of phenomenon within clear boundaries. It is more important to have meaningful categories than to obtain precise measures, as numbers are meaningless unless based on serviceable conceptualisations (Dey 1993).

ii) Epistemological Issues.

The epistemological part of the qualitative-quantitative debate involves more fundamental questions regarding the nature of science and the generation and legitimization of knowledge. Here, quantitative and qualitative approaches are often seen as distinct, often incommensurable research paradigms (Henwood and Pidgeon 1995).

The quantitative research paradigm (Empiricism) seeks to establish **objective** knowledge through the testing of specific hypotheses against phenomena in the empirical world. The qualitative research paradigm, (Constructivism) broadly speaking, suggests that meanings do not merely reflect the world as it exists, but are **constructed** by people, within cultural, social and historical relationships (Henwood and Nicolson 1995), and reflect the individual's understanding of their experiences. People experience their 'constructions' of their world as reality (Charmaz 1990).

As a result, in qualitative research, perceived meaning is more important than 'Objective Reality'. In fact a key assumption is that there is no objective truthful perspective "out there", but that there are a range of different perspectives on various phenomena, with each person's perspective having its own validity.

These different epistemological positions naturally result in differing research methods and practices. In qualitative research gathering non-numeric data is seen as preferable in order to explore, and be sensitive to, the multiple interpretations and meanings which may be 'constructed' about a phenomena by individuals.

Qualitative approaches are also held to be **inductive**, that is, beginning with the observation and moving towards hypotheses and theory. Quantitative approaches are generally concerned with testing hypotheses and existing theory, or **deductive**. Here the researcher decides in advance what constitutes the required data, and constructs questions in ways to elicit answers that can be contained in these predetermined categories.

Silverman (1994) argues that in more traditional deductive methods "the existence of typical respondents is explicitly presupposed. These respondents are implicitly supplied with standardised mental structures that match the analysts reasoning and use of language" (p93).

With groups of participants or areas not already well studied, qualitative research is an invaluable approach. Structured quantitative interviews would require the researcher to develop questions that construct worlds about which not enough is known. This would not necessarily provide the appropriate categories of responses seen as relevant by the participants (Grant 1995, Smith 1995).

Quantitative versus Qualitative Approaches?

Unhelpfully, qualitative and quantitative approaches have been/ are presented as adversaries. This rigid demarcation does nothing to encourage movement or interaction between the two, or promote continued understanding of various phenomenon (Pope and May 1995). Different research methods allow access to different levels of knowledge, and

combining methods can lead to building a wider picture. In reality, researchers take many different positions along a continuum between pure inductive and pure deductive stances.

The Qualitative Approach in this study.

A qualitative approach is the appropriate tailored choice for this research study for various reasons described in more detail above. The study concerns a subject area which is poorly conceptualised. It is not known if the existing concepts, theories and measures from the non-learning disabled population will be applicable or appropriate to people with a learning disability. The researcher is therefore unable to construct a structured quantitative interview schedule for this population, preferring instead for the participants to construct their own worlds. There is a great need to 'classify' before 'quantification' in this area. The experience of pain is also a very subjective and complex phenomena, and as this study focuses on the meaning of pain and pain beliefs, a qualitative approach is the most appropriate level of measurement for this study, and is likely to produce the richest account. Specifically a Grounded Theory approach will be used.

Rigorous Qualitative Research.

Qualitative approaches have been criticised for lacking scientific rigour, particularly damning at a time when scientific knowledge is generally regarded as the highest form of knowing (Mays and Pope 1995). The criticisms include that qualitative research is just an assembly of personal impressions, strongly subject to researcher bias, and lacks generalisability and reproducibility.

Henwood and Pidgeon (1992) strongly question the evaluation of qualitative research by conventional tests of validity and reliability, where bias is defined to be a deviation from some empirical truth. As already outlined, the qualitative paradigm sees multiple realities.

In quantitative interviews the researcher sticks closely to the schedule (specified order and often wording) to enhance reliability. The presumed 'underlying truth' can be established if the researcher is objective enough. For characteristics of a quantitative researcher to influence the way in

which subjects respond to the instruments would be considered a flaw in the methodology (Silverman 1994, Smith 1995).

However, qualitative approaches sees participants responses not as 'True' or 'False' reports on reality but in terms of displays of perspectives and positions (Silverman 1994). The qualitative paradigm sees that there is no such thing as a relationship free interview, and the participants actively shape the course of the interview rather than passively responding to set questions (King 1994).

Although, qualitative research does not require the researcher to be 'objective', this does not mean that the issue of researcher bias is ignored in this approach. It is just as important in qualitative or quantitative research that findings are not simply the result of the researcher's prior expectations and prejudices, or that informants do not distort or conceal their social reality (Silverman 1994).

In reality, there is no sharp distinction between qualitative and quantitative research, but rather a continuum. It would be naive to discount the role played by the researcher in both qualitative and quantitative research. Both 'produce' data by shaping what they select/ attend to, how they collect and analyse the data (Dey 1993). In practice, research often employs a range of methods producing a variety of data. It is better to focus on the data and analyses produced than to imply rigid distinctions between styles of research methods.

Ensuring Quality Research.

There are ways to ensure and evaluate good quality qualitative research. Many of these have come from the Grounded Theory tradition. For example:-

Grounding - Writing comprehensive definitions summarizing why categories have been labelled in certain ways. This makes explicit the initial conceptual classifications perceived by the researcher. The researcher stays close to the data (importance of goodness of fit) and any speculations which exceed the data are clearly labelled as such.

Openness - The researcher needs to be open enough to the data and the situations, whilst guided by existing knowledge. They should not force data into pre-existing codes. Any a priori categories or concepts, values, interests or presuppositions imposed onto the process of data collection or analysis, should be explicitly stated (Henwood and Pidgeon 1992).

Presentation - All evidence needs to be presented in a form that enables independent interpretation by others (Fitzpatrick and Boulton 1994). Providing examples of the raw data to illustrate categories allows the reader to evaluate the 'fit' of the findings to the data for themselves. The explication of corroborating evidence should be as crucial to qualitative as quantitative analysis, and a vital element in producing an adequate and accessible account (Dey 1993).

(See Discussion for further methods of evaluation).

GROUNDING THEORY METHODS.

Grounded Theory, derived from the original work of Glaser and Strauss in the 1960's, is one of the many approaches that falls under the umbrella of qualitative research. The issue of 'grounding' involves not only the application of a specific method, but also epistemological questions outlined above. It is used to develop inductively derived theory about complex phenomenon.

Grounded Theory methods are a logical and consistent set of data collection and analytic procedures. These strategies make explicit what is often left implicit in many varieties of qualitative research (Henwood and Parker 1994). They therefore undermine the definition of qualitative research as intuitive and impressionistic, and quantitative research as exclusively rigorous and systematic (Charmaz 1995).

The key features of Grounded Theory are that it aims to develop a theoretical analysis of the data that fits well with the data and furthers theory development, rather than only testing previous theory as in more traditional research design. The researcher derives their analytic categories directly from the systematic inspection of the data, and not from preconceived concepts or hypotheses.

The 'groundedness' of the approach comes from the methods forcing the researcher to attend closely to what happens in the world they study (Charmaz 1995), often finding oneself going in unanticipated directions (Charmaz 1990). It is also 'grounded' in that it builds directly on interpretation of processes within the data. Thirdly, this method is cyclical, comparing original data with theory, and theory with emerging themes to ensure goodness of fit. A key idea is constant comparative analysis, to be aware of similarities and differences existing between instances, cases and concepts to ensure that the full diversity and complexity of the data is explored.

Any emergent theoretical account will be the result of this constant interplay between data and conceptualisation. This typically generates rich, deep and well-integrated conceptual systems, organised at different levels of theoretical abstraction which articulate well with the data (Henwood and Pidgeon 1992).

Many researchers within psychology now argue that Grounded Theory offers systematic approaches for discovering significant aspects of human experience that remain inaccessible to traditional verification methods (eg Rennie et al 1988, Henwood and Pidgeon 1992, Smith et al 1995))

Charmaz (1995) concludes however, that most Grounded Theory works are still at the stage of developing clear categories by which to explicate processes in the worlds that they study, rather than constructing tightly framed theories that generate hypotheses and make explicit predictions.

RESEARCH QUESTIONS.

How do the pain beliefs and coping strategies of people with mild/moderate Learning Disabilities compare to those identified in the child and adult pain literatures?

What factors and processes are involved in any identifiable differences?

What are the clinical implications of this?

METHODOLOGY.

DATA COLLECTION.

Eight people participated in this study; five women and three men. Their mean age was 50.6 years (range 31 - 61 years). Of these, four lived with family members (mother or sister), two in residential placements, one alone and one with her partner.

Four of the participants had some degree of hearing difficulty (two had severe impairments). Of these two had a marked speech impediment. An additional participant also had a speech impediment.

All participants met the three pre-set criterion for this study. These criterion were judged by the health/social worker most closely involved in the participant's care. All the participants had mild/moderate learning disabilities, sufficient verbal communication skills to hold a conversation, and all were currently experiencing chronic pain (ie pain for more than six months). In fact, all the participants had been in pain associated with Rheumatoid Arthritis or Osteoarthritis for at least three years, many for much longer periods of time. None of the participants had ever had interventions that looked at their pain beliefs.

The individual interviews were conducted in either the participant's home or day care setting, based on the participant's preference. These lasted for between 45 and 60 minutes each. Individual interviews were favoured because of confidentiality, the varied location of participants, and to help all participants to have adequate chance to describe their experience of pain.

Selection/ Recruitment of Participants.

A comprehensive range of Health/Social Care professionals within learning disability services in Leicestershire were contacted for potential participants. These included all Community Nurse and Physiotherapy teams, Psychology and Psychiatry departments, various Social Workers, Physicians who conduct medicals for the Leicestershire Learning Disability Register and staff running the Register itself. In total, 15 potential participants were identified.

The Health/Social worker most actively involved in cases that were ongoing, contacted these people to explain the purpose and content of the study, and to ask if they would be willing to take part. The remaining people were contacted either through their residential accommodation or directly by the interviewer. This process was important in order to attain valid consent (given the problems of acquiescence outlined in the Introduction). It was thought that people would find it easier to say that they would not participate, to workers that they already knew well and who had no direct involvement in the study, than to the interviewer directly.

Ten participants remained following this procedure. The others either did not want to participate, were no longer in pain or did not have sufficient verbal communication skills. One further participant did not want to take part in the study when the interviewer went to meet her, and one was not able to talk about her pain in detail.

The difficulty in finding potential participants is an interesting finding in itself, given the large numbers of people with chronic pain without learning disabilities. The implications of this will be considered in the Discussion.

RESEARCH DESIGN.

For reasons already discussed, this study followed a Grounded Theory approach. Therefore, the research design, rather than being a linear process, with data analysis distinct from data collection, was an iterative, cyclical process. In practice, this meant that analysis of the data occurred in parallel with, and guided further data collection. As themes began to emerge from the analysis of initial interviews, the researcher returned to gather more data (theoretical sampling).

Although this process will be described in stages for ease of understanding, efforts will be made to capture the cyclical nature of the process.

Interview Guide.

An interview guide rather than schedule was used in this study for the following reasons, which are discussed in more detail in the section on qualitative research in the Introduction. Given the lack of work in this area, it is most appropriate to use a guide rather than structured schedule to enable participants to construct their own worlds.

In addition, the purpose of the interview guide is to focus the interviewer onto specific topics whilst allowing the flexibility to follow any avenues that develop as the participants describe their pain beliefs and experiences. As a guide, not a schedule, there is no set order to these questions. If a topic has been covered fully earlier in the interview, it is seen as unnecessary to cover it again when it arises on the guide.

These points were especially pertinent for this participant group of people with LD, who needed some structure to remain focused on the subject of pain, whilst being able to raise and discuss the issues important to them. This is further explored in the Discussion (p101-102)

In this study the semi-structured interview guide was based on themes from previous adult/child studies of pain beliefs. The guide covered five areas - Identity, Causes, Consequences, Time line and Cures/Control, with open-ended questions and more specific prompts for each area (See Appendix 1).

The cyclical nature of this approach meant that themes emerging from initial interviews modified the interview guide for later interviews.

The Interview procedure was also guided by research (outlined in the Introduction) about interviewing people with a LD.

INTERVIEW PROCEDURE.

A few minutes were spent discussing topics unrelated to the study, to put the participants more at ease.

Information for Participants.

The interviewer explained to the participants, the purpose of the study (ie to look at what people think, feel and do when they are in pain), the confidentiality of materials and their right to stop the interview or not answer certain questions.

Permission to tape the interview was then sought. Various points of information were repeated as necessary during the interview.

Despite the steps taken to attain consent in this study (as outlined above) some participants remained unclear about the purpose of the study and my role as researcher not clinician. These difficulties will be explored further in the Discussion (p103).

Main Body of Interview

The interviewer used her discretion as to what level to begin the interview. Some participants were highly focused and began discussing their pain as soon as the interviewer arrived. Others had more difficulty becoming, and remaining focused. In these two cases, participants were asked to mark the location of their pain on to a diagram of the human body (see Appendix 2) and discussions began from there, becoming more abstract.

Every effort was taken to ensure that no assumptions were made, by the interviewer or participants, as to the meanings of questions or answers. All noted ambiguities were followed up by the interviewer.

DATA ANALYSIS METHODS.

The key aspects of the analysis process in Grounded Theory will be described. For more detail see Strauss and Corbin (1990).

As already noted, this was not a linear but cyclical process occurring at and progressing through different levels of measurement (data collection, description, classification, connection and account) and becoming

increasingly abstract. Again the process will be described here in stages, although in practice, due to its cyclical nature, the analysis occurred at different levels concurrently or returned to a lower level of measurement to deepen descriptions or elaborate on properties of categories/ concepts.

The 'fit' of emerging concepts, categories, properties, dimensions and connections to the original data was continually tested, and ideas reviewed as a result. It was also vital that no stage of the analysis was prematurely 'closed'.

The taped interviews with participants were transcribed verbatim, with comments regarding non-verbal communications included (such as emphasised words or a raised voice). These scripts were read many times to familiarise the researcher to the material. Then the specific data handling strategies of Grounded Theory were used to analyse the scripts through the different levels of measurement.

Open Coding.

This is a central process concerned with naming and categorising phenomenon through close examination of the data. Whilst reading and rereading the transcripts, the researcher broke down the data into its constituent parts, by noting, appropriately labeling and defining any emerging 'concepts'.

For example -

"'Cos I've got a bit in me arms. I'm always rubbing me arms. Like me mum used to do when she..when she was here..she used to suffer with pains in her arms...'Cos it' Rheumatis. It's Rheumatis." (8:96-99)

Here concepts of 'coping strategies' (rubbing) 'constancy' (always) and 'identity' (having Rheumatism) emerge. Importantly, these three concepts are related to having a 'family 'model' (mother) in terms of how she coped and her 'identity'.

Various strategies were used to 'fracture' and concurrently group/order the emerging concepts with precision, specificity and increasing abstraction, including -

Asking Questions of the Data - Such as "What is really meant here?", "How does this relate to pain?"

Constant Comparison - This is key to the Grounded Theory approach. It involved comparing each emerging concept to previously identified concepts, within and across cases. If concepts contained similar ideas to existing concepts then they were subsumed to help elaborate the existing concepts. If they were different then they were noted as a possible new concept. This process continued until saturation was reached (ie no new concepts were added or elaborated).

'Concepts' were then raised to 'Categories' (increasingly abstract) by repeatedly grouping them into Categories of similar concepts, and subsuming or dividing categories as necessary. The properties (characteristics/ attributes) and dimensions (locations of properties on continuums) of these categories were developed in parallel. Interrelationships between categories became increasingly more apparent.

Axial Coding.

When the data had been sorted into these categories, the analysis focused onto 'Axial Coding'. This process involved connecting the categories, and identifying several main categories within which all others could be grouped.

The categories were related through the **Paradigm Model**. This specifies categories in terms of events or incidents that give rise to them (**Causal Conditions**), the **Phenomenon** itself (central event/ incident to which a set of beliefs (in this case) are related), it's **Context** (specific set of conditions within which beliefs occur/ develop), **Intervening Conditions** (broad structural conditions which influence beliefs within specific contexts), **Action/ Interaction Strategies** (that which occurs in response to, or to manage a phenomenon) and the **Consequences** of these beliefs.

Selective Coding.

In a fully successful Grounded Theory a 'Core Category' emerges. This is the central phenomenon around which all other categories can be integrated. Selective Coding is the process of selecting the 'Core

Category', systematically relating it to the other categories, adding in variations and further refining any categories as necessary.

Integration at this level is not vastly different from Axial Coding and occurs using the Paradigm Model, but at a higher level of abstraction.

The 'Story line', (the descriptive narrative about the central phenomenon of the study) is used as a guideline by which to arrange and rearrange categories in the account of the analysis.

Memos.

Throughout the data collection and analysis 'stages' the researcher writes memos of thoughts and ideas relating to the data, categories and emerging theory. These encourage thoughts about themes in the data and ensure that ideas which may be useful at later stages are not lost.

RESEARCHER'S ASSUMPTIONS.

Qualitative Methodology requires that the subjectivity of the research process and the part played by the researcher in co-constructing 'reality' must be acknowledged. As noted in the Introduction, this co-construction is not unique to qualitative methods, although it's frank acknowledgment often is. As Dey (1993) states, the danger lies, not in having the assumptions, but in being unaware of them.

Therefore, all assumptions existing before and guiding the study must be acknowledged. In this case, a brief literature review for the research proposal and interview guide (outlined above), and the Biersdorff (1994) paper formed part of the researcher's assumptions, and guiding thoughts. This study was motivated by surprise and concern at the pronounced differences suggested between the experience of pain for people with and without a LD.

In addition, themes of 'Stoicism' and 'Ridicule' (see in **Pulling Through** and **Knowing** respectively in Analysis) especially struck the researcher during the data collection.

ACCOUNT OF THE ANALYSIS.

Content of the Account of The Analysis Section

The categories (all of **Pain Beliefs** and **Coping Strategies**), and their corresponding subcategories, developed using the Grounded Theory approach outlined above, will be described and explained in terms of their properties, dimensions and connections with other categories, according to the Paradigm model. Variations will be also be described. Extracts from the interview transcripts will be used to clearly illustrate all aspects of the categories.

These categories of Pain Beliefs and Coping Strategies, will be presented as a **dynamic** process in which categories connect to other categories, but also loop back into other categories, in certain situations.

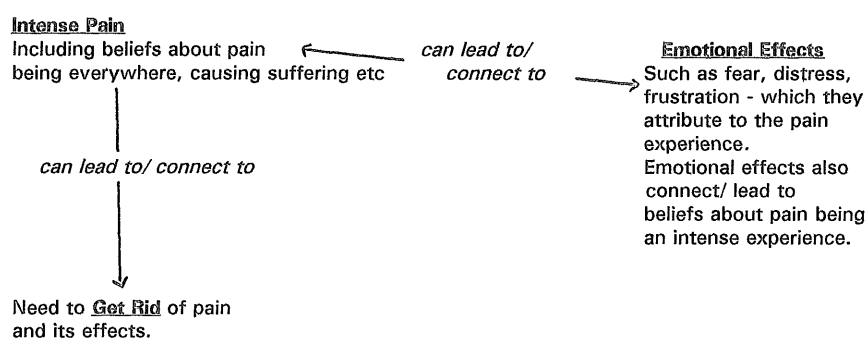
In addition, four over-arching, more abstract categories, which link to and influence all preceding categories will be described.

Diagrams of this Account (Figures 1 - 6)

A simplified overview of these categories and their interconnections will now be presented as a 'guide' for the reader (Figure 1).

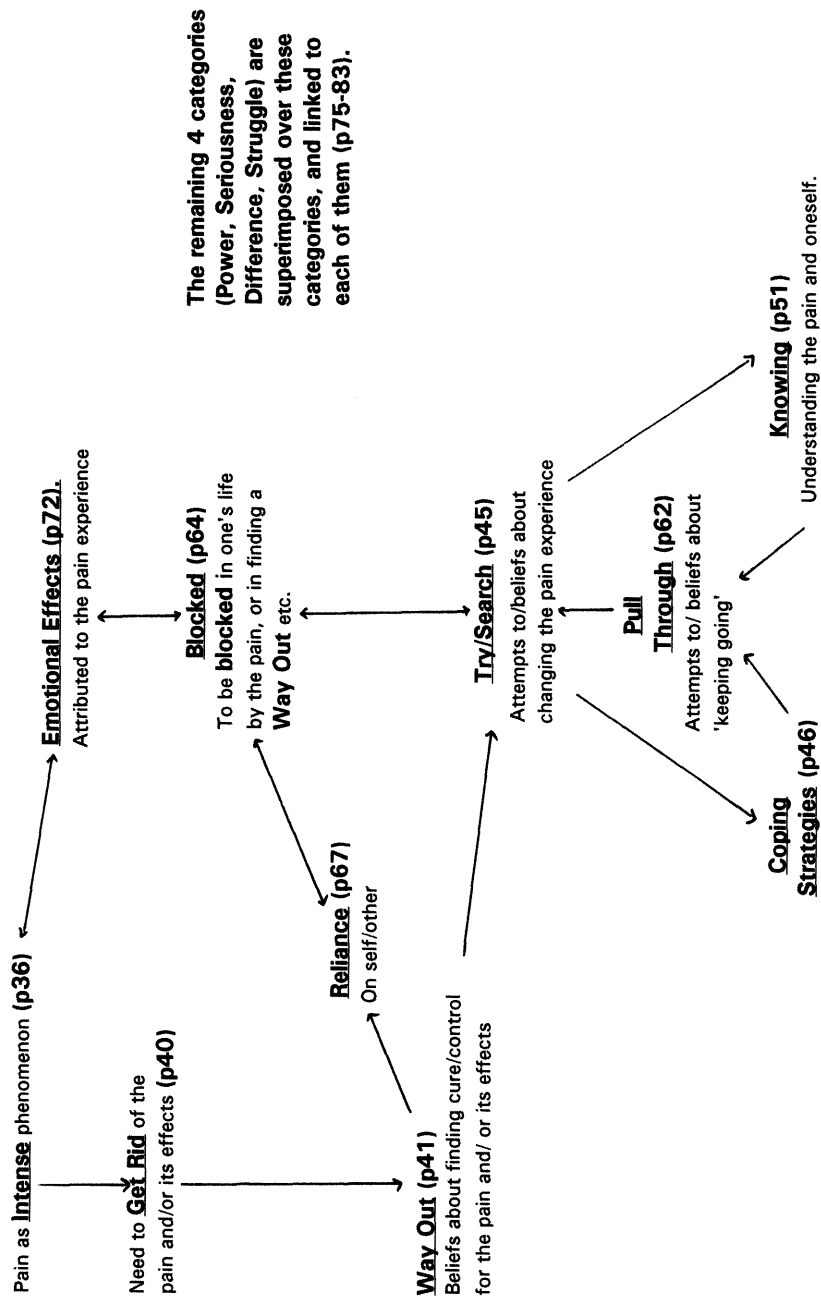
It should be noted that the arrows on this diagram do not imply causal relationships between beliefs or coping strategies, or that connections are of equal magnitude or importance.

Examples of connections are as follows:-



Although the diagram is presented as a series of linear connections which seem to begin at the top left hand corner, this is for ease of presenting complex information. Actual connections are cyclical with no set beginning point. They differ across individual cases and situations.

DIAGRAM TO SHOW THE PAIN BELIEFS, COPING STRATEGIES AND INTERCONNECTIONS THAT EMERGED FROM THE ANALYSIS.



Notes for the reader

Further diagrams (figures 2 to 6) will be used throughout the Account of the Analysis to illustrate categories and interconnections.

All names of categories, subcategories and dimensions will be in **bold print**.

In the participants' quotations :-

- **CAPITALS** are used for emphasised words
 - (+) used when volume increased on certain words.
 - *italics* for raised voice tone.
 - . = 1 sec, .. = 2 sec, ... = 3 sec. Longer pauses given in numbers)
- (Other comments written in brackets)

PAIN AS INTENSELY UNPLEASANT PHENOMENON.

These participants had all experienced chronic pain linked to their arthritis, for varying periods of time (3 years to 50 years).

They expressed beliefs that their pain is an **Intense** phenomenon, that is existing at a high degree, both in terms of sensations and the experience in general. That they used such strong words to describe the experience emphasizes and illustrates these beliefs.

It's just awful. Horrible pain. Terrible pain.	(4:357)
Oh, it's horrible.	(5:208)
PAIN(+)... AWFUL. (5 secs)	(6:217)
'Cos sometimes I'm sitting here...in AWFUL, awful pain sometimes on Saturday mornings.	(8:237-238)

These quotes also show the **Intense Unpleasantness** of their experience of pain.

The theme of **Intense** is also illustrated by different participants in different ways. For example, Participant 6 **Pleads** with the interviewer to get rid of his pain (see **Get Rid** later). There is an **Intensity** to his urgent **Pleading** reflecting his **Intense** pain.

Participant 1 states that:-

...it's terrible duck, I mean **NOBODY** should have to have pain what I'm having (1:42-43)

and ..there are times when I don't know where I am, and I want it to end sometimes...I wish my legs would come off,...you know? (1:299-301)

Participant 4 that she ...can't bear the pain. (4:193)
again reflecting the pain's Intensity.

Included in this category are beliefs about the pain being **Everywhere** in their bodies, and their lives in general. That pain took over everything, and **Effected** (see later category) every aspect of their lives.

This is well illustrated by the style shown by many participants during their interviews of repeatedly showing **Another Place** where they experienced pain. It being all over their bodies, **Everywhere**.

Participant 5 showed **Another Place** 26 times during her interview. For example:-

And also I've got it in BOTH (+) of me hips, and in me back. (5:12-13)
I've got it here in me knee look...And that one as well... And each side of me face.
(5:38-39)

Horrible... I've got it here in me head, here as well, up here.(5:214)

I - Is there anything else you want to say about your pain?

S - No...It's all up here..all up here..and up..up..all up there.(6:295-296)

This style of repeatedly pointing out **Another Place** also suggests ideas about how pain is increasingly **Spreading**, that is, further extending in it's influence, throughout their bodies, and their lives.

S - Burning. And then when the burning stops. I have great big pains here (indicating up her thighs into her hips and lower back). All round here, and it travels up here.

I - ..all up your leg.. to your back?

S - Yeah. And then I limp, cos I'm putting all the pressure on this (left leg). Now this is beginning to hurt me. (1:109-114)

Participant 4 saw pain as a malevolent 'force', seemingly with a persona of it's own, trying to 'get her'.

Well, I just go in a wheelchair when it plays me up. (4:159)

But, if you're in that much pain, you've got to have a wheelchair, 'cos the pain, it can't get you, can it. (4:164-166)

It is awful. I cry with it you see. The pain, it just gets me (4:337)

These beliefs about the **Intensity** and **Unpleasantness** of pain leads them to beliefs about themselves and their situations. What it means to be in pain.

Terrible.. (8 sec pause)..I'm in a poor way (2:4)

...Dr Turner said, I know what you're suffering. I know that you're in pain. (4:286-287)

.. 'cos I, I..I suffer like me mum did. You know, (8:109)

Due to the **Intense** pain, participant 2 is in a "poor way". The others hold beliefs about how pain results in, or even equates with **Suffering**. An intense negative experience of distress.

Dimensions.

Beliefs about pain **Intensity** have 2 dimensions; Duration and Variation.

Duration

This dimension covers beliefs about how long the individual has been in pain. The dimension ranges from **Short term** to **Long Term**, although the interpretation of what is **short** and what is **long** differs between individuals.

It's well ages...ooh, about 3 years now.. (2:6)

Ooh, a long time now.(3:4)

I've had it a long time now. (4:81)

Oh, long while ago now (5:2)

Ooh, years. Right from when I was..when I were little. I had it then. (5:308-309)

LONG WHILE..now. Long while.. (6:31)

Oh, I had it long while now.. about 3 or 4 years now...Since I lost me mum...'92..(8:101-102).

This dimension is mainly unipolar. The participants believed that they had had pain for a long time. It is interesting that the participants used such similar language, clearly stating that the pain has been with them for what seems like a 'long while now', despite the range of between three and over fifty years.

This dimension stretches into the future as well as back into the past. Beliefs about how long the pain would last for again can range from long term (for ever) to short term.

This leg (pointing) it keeps going on. I mean ... I won't have it all me life will I? I keep telling myself "no, no". You know. (1:18-20)

I - Do you think it's ever going to go away?

S - I don't think so. (4:142-143)

Constant/ Variable.

This dimension of pain Intensity ranges from constant to variable (ie 'I have pain all the time' to 'it varies').

Right now I'm fine. But there are times when I don't know where I am.. (1:299-300)

Sometimes I'm not in so much pain. Sometimes I am. So it goes on.. that's how it goes, you see. Starts and..I'll be alright one day and then the next day it's worse. (4:90-92)

YES, YES,... yes, yes, yes... Always. Always. Umm...SHARP (6:13)

Not all day. When it comes it's errrr...painful. (7:58)

The participants believed that the constancy or variability of the pain Intensity was dependent on certain factors.

Mmm. But on some days it's.. in hot weather..it goes. (2:51)

The sun makes it worse. And the summer does. It hurts me when the sun's out... (5:187-188)

It does hurt. Especially first thing in the morning, you know when you want to get out of bed.. (5:180-182)

I mean.. I'm alright some days. Some days I'm alright, some days I'm not. Sometimes I'm as right as rain, one day. But I'll tell you.. I've only got to go to shop down here...and I'm bloody bugged. (8: 29 - 32)

In these cases it depends on the weather, time of day (especially the morning) or certain activity. Participants had expectations that pain is always worse/ better at these times/ in these conditions.

GET RID.

Given this experience of Intensely Unpleasant pain, the participants had strong beliefs about needing to Get Rid of both the pain and its effects on their lives. Getting rid of the pain entailed being free from the sensations and effects of pain. This was a central belief; what the participants desired more than anything.

But there are times when I don't know where I am, and I want it to end sometimes...I wish my legs would come off,... you know? (1:299-301)

I - Do you know what they want to do with the operation?

S - Put plastic knee caps in I think.

I - What do you think about that?

S - I don't mind as long as it gets me out of pain. (4:233-236)

S - Awful. It's painful sometimes. But I can have them broke if I want to (hands).

I - Do you want to?

S - I don't mind, as long as I get out of pain with me hands. (4:25-28)

S - I WANT...I want arthur...I want.. arthritis.. to go.

I - You want it to go away. Mmm.

S - I want it to go. Yes. (6:190-192)

With some participants there is a theme of Rip It Out. This captures the participants willingness to undergo anything to be free from pain. This includes drastic measures such as breaking hands and hip replacements. A belief that the doctors can do 'what they want' as long as it results in the pain going away.

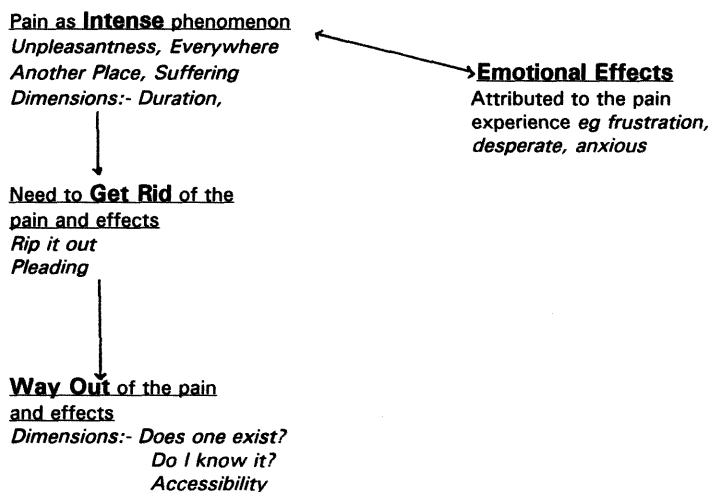
Participant 6 Pleads with the interviewer for a way to Get Rid of his pain. He returns to this theme six times in the interview without prompting. It is a major concern to him.

...PLEASE..please...Do something...please. Do something. It's painful. (6:31-32)

..PLEASE..seeing to it for me..please..please..please..please..seeing to it for me. Please. I've got..I've got a.. lot of..pain. See to it for me. (6:76-78)

The strength of the **Get Rid** belief is dependent on various others beliefs. This need to **Get Rid** is linked to, and seemingly motivated by the beliefs about how **Intense** the pain experience is, and how effective is their **Way Out**. The more **Intense** the pain, and the less effective they believe their **Way Out**, the more desperate they are to **Get Rid** of the pain.

Figure 2:- Diagram showing specific categories and interconnections.



WAY OUT.

As shown in the diagram above, **Getting rid** of the pain requires a 'route', a **Way Out** of the pain. This involves beliefs about finding a cure for, or effective management of, the pain for oneself or from someone else. For these participants their **Ways Out** were believed to be **Coping Strategies** or/and **Cure**, increased **Reliance** on others, and/or increased understanding or **Knowing** what was going on and how to change it. These will be described in detail later.

Dimensions.

Way Out has three dimensions.

Does a Way Out exist?

Firstly, the degree to which the participant believes that a Way Out exists. This dimension ranges from no way out to a complete cure with not sure in the middle.

S - I want to wake up one morning duck.. with it gone.

I - Mmm. Do you think that is likely to happen?

S - Well it will one day when I've been hospital. (hip replacement) (1:187-189)

I - So what do you do to try and make the pain go away?

S - Well NOTHING (+). THEY won't give me anything.

I - Is this the doctors?

S - He's the same. He don't give me NOTHING.... (5:40-43)

Both participants believe that there is a Way Out. They have expectations that there is a cure. The first believes that there is a Complete Cure and that after the operation, the pain will be 'gone'. The second, that she is not being given the Way Out (see Withheld in Blocked later).

This is in contrast to the following participants who do not believe there is a Way Out or little hope of one.

S - She tries to but it's hopeless, you know 'cos it's very painful.

I - It's hopeless. (5 Secs). Do you think it's ever going to go away?

S - I don't think so. (4:140-143)

Can't make it better. No matter what you try or rubs or anything like that.. it's still the same. (4:343-344)

I know S (social worker) can't do much for me... I mean, I mean the doctor can't do a lot for YOU (+) (8:89-90)

No hope of a Way Out is a miserable prospect.

I - Do you think it will ever go away completely or do you think you will have it for the rest of your life?

S - I don't know. It would make us miserable if we did. (7:192-195)

Beliefs about having Ways Out are clearly linked to beliefs about who holds the Power to provide/produce these. The quotes above show how these participants see the Power being somewhere other than with themselves, often with distant others (see Power later)

Do I know the Way Out?

Another dimension of Way Out is Do I know it? Believing that a Way Out exists, leads the participants to question whether or not they, or others, know 'it'.

The dimensions of the subcategory range from not at all (i.e I have no understanding of what is happening to me, or how to change it) to completely (i.e I believe I know what is happening to me and how to influence it).

I - What are you thinking about?

S - Thinking about getting...getting me legs better.

I - And how are you going to do that?

S - Don't know. I've got no idea. (4: 179-182)

Phone -----,ask for -----, ----- (repeats name and number).

Yes.. ----- KNOWS.. ----- (6:82-83,85)

Participant 6 believed that his keyworker could describe the pain to the interviewer more clearly than he could himself.

Accessibility of a Way Out.

The final important dimension is the Accessibility of the/a Way Out. The two preceding dimensions are Is there a Way Out? and Do I Know it? Finally there is Have I Got It? This ranges from Yes to No. This is closely linked to Blocked (see later).

For example, see Quote 5:40-43 under dimension 'Does a Way Out exist?' above.

There is conflict here if the participants believe there is a difference between the position they believe they need or expect to be in, and the position they find themselves in (ie needing to **Get Rid** and find a **Way Out** but not **Knowing** one or not believing one has **Power** to produce one or it not being available to them). This situation is then uncomfortable for some participants, and leaves them feeling confused and that the situation is poorly controlled.

I don't know what to do with myself some days. (8: 52)

Even participants with the desire to **Get Rid** of the pain completely and seeing available **Complete Cures** and **Ways Out**, had experiences in which these were not always forthcoming. Therefore, much of their time is spent **Getting Rid** of, or minimising the **Effects** of the pain on their lives.

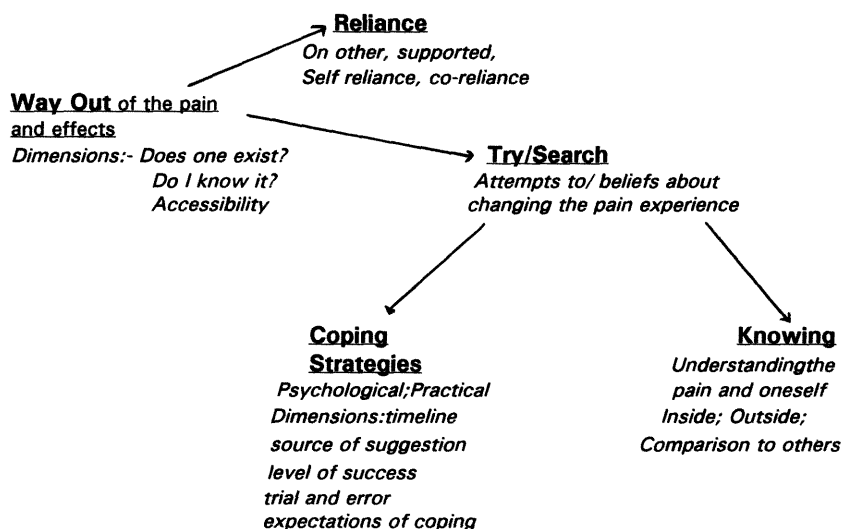
When I walk a long way I get pain and that. I have to stop a bit and then....rest a bit...and then do another erm.. lot and then stop again. (7:128-130)

Some whilst they wait for the **Complete Cure**.

When I have a bath it takes it off..a little bit. I could lie in the bath, and get up in calm. But, five minutes after, it comes back. There's nothing really, what ever I do, nothing to take it off.. I keep thinking, oh well, I'm going to have it done (operation) so this could be the end. (1:209-213)

The dimensions of **Does a Way Out Exist? Do I Know It? and Is it Available?** described above, also apply to this subcategory of **Getting Rid of Effects**. Participants also use **Coping Strategies, Reliance** and **Knowledge** to achieve this goal.

Figure 3:- Diagram showing specific categories and interconnections



TRY.

Motivated by needing to **Get Rid** and find a **Way Out** (of the pain itself and/or it's **Effects** (see later) participants described beliefs about **Trying** to do so. **Trying** involves making some concerted effort to change the pain experience (although not always using their own **Power** - see later category). They held beliefs that they, or others, made attempts to modify their pain, to reduce it's impact on their lives, or to understand it better.

I want to clean me windows, I try to, well I try to clean round, to keep this clean (pointing at carpet) (1:57-58)

I try to, but I lift me legs up at night in the air, and I put them down but when I get up, when I've done that and get up, I pull this leg back and it's painful you know. I stand up there and cry. (4:97-99)

She tries to but it's hopeless, you know 'cos it's very painful.(4: 140)

Well, I try to help myself through. (5:313)

They said, they said ..you've got to do, you've got to try to. do a little bit yourself now. (8:219-220)

Unexpectedly, even participants who held beliefs that they had no Way Out, or that there was no Way Out (see before), continued during the interview to state that they Tried. Interestingly, these participants were often motivated by other people to Try (see quotes from 4 and 8 above).

SUMMARY (refer to diagrams)

Beliefs about and interconnections between Intense pain, needing to Get Rid of this and find a Way out (cure or control), and how these are complicated by their dimensions have been outlined. The participants expressed various ways that they Tried to do this, including Trying Coping Strategies and Searching for Answers (see Knowing). These will now be discussed.

COPING STRATEGIES.

All participants gave examples of Strategies used to cope with or control the pain, and/or it's Effects on their lives. Some participants were very limited in their strategies for controlling pain, and even on repeated discussion only described Medication and Exercise.

I - What do you do when it's very bad? (6 secs). Do you do anything?

S - Take tablets.

I - Does that help...Does the pain go away?

S - No.

I - Do the staff do anything to help?

S - Give tablets. (3:146-152)

When I get up in the morning I have cramp as well..and me mum says walk about a bit, walk about to get your errr... get out of bed and walk about. So I did. But it's still there, we still have it. (7:51-53)

Other Strategies for pain control.

Some participants described other strategies that they used, or that others used with them, to try and reduce either the pain or it's impact on their lives. These strategies split into two subcategories - 'Practical' and 'Psychological' Coping Strategies.

Practical Strategies.

Of the strategies described, the majority are contained in this 'Practical' Strategies subcategory. They include **Resting** (stopping physical activity), **Exercise/ Routines** (specific exercise for affected parts of the body or more generally, or specific routines to enable the participants to continue their daily life), **Warmth** (ensuring that one is warm or taking action to make oneself warmer), **Rubs/Oils** (for massaging affected areas etc), **Bath**, and **Medication**.

Not that these Strategies do not have psychological components in the way they work, or have no psychological benefits. However, the participants mainly described these Strategies in terms of their physical, external, practical properties.

Well, I have a bath. When I have a bath it takes it off.. a little bit. I could lie in the bath, and get up in calm. But, five minutes after, it comes back. (1:209-211)

S - They rub me hands an' that... With that oil stuff...Grape seed int it?

I - Oh, right... What does that do, P?

S - Ease the pain an' that. (2:119-122)

I get up...I get up...in the morning... I get up...I get up...in the morning...walk round.. bedroom...pain.. GOES OFF (+) (6:71-72)

Got to keep having a rest ..and soaking and.. while I'm resting I'm not so bad.

(8:268-269)

Psychological Strategies.

There were by far fewer 'Psychological' than 'Practical Strategies', most participants not giving any of these at all. A couple of participants gave 'Practical' Strategies when asked quite specifically about 'Psychological' ones.

I - Are there things that you do to try and take your mind off it?

S - I do try, yes.

I - What do you do?

S - Move me legs about, like this.

I - And that takes your mind off it?

S - It's exercise. You've got to move your knees ain't you? It eases me knees a bit.
Loosens me knees a bit, for walking.

I - How does that effect the pain?

S - Stops it. (5:394-402)

I - Do you have ways of trying to cope? Things that take your mind off it?

S - Erm...we always try to do these exercises at home meself. (7:24-26)

'Psychological' Strategies included **Distraction** (focusing one's attention onto something other than the pain), **Humour** (looking for the funny side of the pain experience), **Telling Others** (talking to others for support or to gain action. Includes beliefs that "getting it off your chest" helps, - see later category **Know**) and **Being Comforted/Reassured** (To soothe troubled thoughts or emotions by self or other).

This leg (pointing) it keeps going on. I mean... I won't have it all me life will I? I keep telling myself "no, no". You know.(1:18-20)

...I wanted to let it all out..so I did last night..and he come with a cup of tea ..sat on here(sofa)..comfort me a bit, then I went bed. (1:147-149)

Well, it started..with that flu jab an' that. So, I came out the Country Dancing.... and took up pottery ! (laughing). (2:74-75)

..I don't like thinking... something to make me sleep.. go away...from everybody. You know. (1:194-196)

S - Then I just cry going into the bathroom. But my sister gives me a song...you know..um.. sing a song of sixpence pocket.. blackbird.

I - Right. So you sing that or she sings that?

S - She sings that, but she wants me to copy her, you see, going up the stairs.

I - Why does she want you to do that?

S - To take me mind off the pain. (4:35-41)

Sometimes,... that's me mum on there (photo on table). Sometimes I talk to her. She'd know what to do, she would. (1:249-250)

I told the bloke who come on on January.. I said I got, got to, I've got to have a bit more support, I'm sure I can. (8:116-117)

Dimensions.

There are many dimensions to this category of **Coping Strategies**.

Timeline.

There is a timeline dimension for how long term the participants believe cure/control of the pain to be - ranging from **short to long term**.

When I have a bath it takes it off.. a little bit. I could lie in the bath, and get up in calm. But, five minutes after, it comes back. There's nothing really, what ever I do, nothing to take it off...I keep thinking, oh well, I'm going to have it done (hip replacement) so this could be the end. (1:209-213)

The contrast here is between short term controls and longer term cures.

Source of Suggestion.

Who suggests or initiates the coping strategy. This ranges from **self-initiated** to **other initiated**, and is heavily influenced by the participants expectations of who should be in control (see **Power**), or who is responsible for initiating **Coping Strategies**.

Usually suggestions come from others (often **Distant Others** see **Power** and **Reliance**) and there is an expectation that that should be the case.

(see above but also)

S - Well NOTHING (+). THEY won't give me anything.

I - Is this the doctors?

S - He's the same. He don't give me NOTHING.... (5:41-43)

Level of Success.

Strategies have varying levels of **Success** from not at all, through eases, to stops it. See above under **Strategies** but also-

Well I'm taking tablets, and they're not moving it, it's still there. (1:120-121)

I get up...I get up...in the morning... I get up...I get up...in the morning...walk round.. bedroom...pain.. GOES OFF(+). (6:71-72)

I - You're rubbing your knees there.

S - Yeah, I'm always doing that, darlin'. Every day..Yeah, and me hands.

I - Does that help the pain?

S - Well,... it does a bit (tone implies not much) (8:133-137)

Success is influenced by:-

i) Expectations of how complete the pain relief should be. Some participants believed that for Strategies to be Successful they would have to remove all the pain.

ii) Belief in the initiator. The participants level of trust/ belief in the others ability to help them, is vital.

For example, participant 4 describes an apparently similar Strategy used by both her physiotherapist and sister. One seems Successful, the other is not.

S - I have a physiotherapist. She does me arms, like this and down like that (miming), and then she does the other arm like that. And then she does me hands with oils, And she rubs them in the joints, and that.

I - And what's that like?

S - That's lovely that is. 'Cos that's getting into the joints.

I- So do you think that helps?

S - It helps me hands. (4:199-206)

S - She (sister)put rubs on. She's spent no end of money on, lots of money on rubs and things like that for me, but don't do anything. She puts it on me legs and it burns into me legs but it don't do anything. (4:321-324)

iii) Beliefs that it is inevitable to have pain and no way of coping with it, are likely to reduce Success rates of any Strategy. These beliefs are held in varying degrees and at varying levels of constancy by participants.

I don't cope at all (6:219)

She tries to but it's hopeless, you know 'cos it's very painful.(4: 140)

Trial and Error.

This dimension relating to Coping Strategies, ranges from continued use even though unsuccessful, to unsuccessful so discarded. It refers to the participants beliefs that although the Strategies they used were unsuccessful many continued to use them. Few stopped using ineffective Strategies.

Other people also continued to suggest or use ineffective **Strategies**.
See above including 4:35-41, 3:146-152, 7:51-53.

Expectations about how one should cope.

Participants expressed beliefs about how one should cope when in pain as well as generally. These ranged from 'suffer/give in' to 'endure/strong'.
(See **Suffering in Intense** earlier, and **Pulling Through** later)

Some struggle with this. Participant 1 has beliefs that she should be 'strong', but would like to 'give in'.

I'm fed up. If it weren't for you coming I could cry me eyes out, but I told myself I must not do it. I'm holding it back too much.. so the Home Care says.

KNOWING.

This is the second category of **Ways Out**. It is a large category which encapsulates the participants' beliefs about needing to have, or gain an understanding, a 'knowledge' of the pain phenomena/ experience, for and from oneself and from other people. The participants expressed the importance of needing to **Know** what is happening, has happened and will happen to them, with regards their experience of pain and the progression and **Effects** of this.

This leg (pointing) it keeps going on. I mean ... I won't have it all me life will I? I keep telling myself "no, no". You know.
(1: 18-20)

There are also beliefs about needing to **Know** in a wider sense than purely cognitively. They need to **Be Known**. To **Know** themselves, and be **Known** by others. To appreciate, recognise and identify what they are experiencing, but also who they are and how they fit into the wider picture.

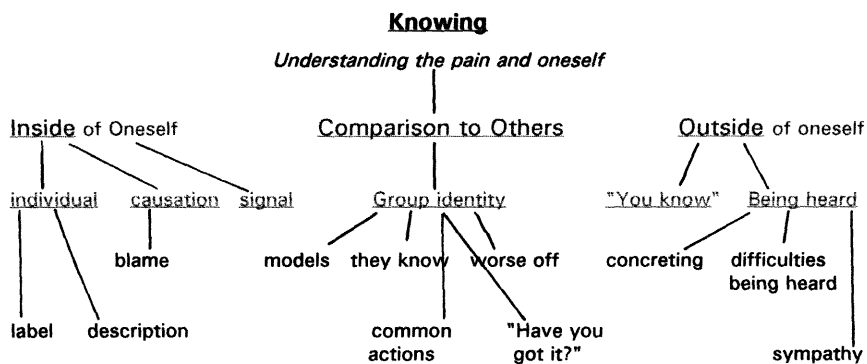
Searching for Answers (parallel to **Try**).

This category is made up of ways used to gain this **Knowledge**. To gain a sense of what is happening and will happen. It includes searching for answers within oneself (**Inside**), by comparing self to others (**Comparison**)

and by asking questions of others (**Outside**). The subcategories dimensions range from **never** to **always** **Searching**.

Participants appeared to **Search For Answers** to different aspects of the pain experience. For example, some wanted to know why the pain happened, some how to control it.

Figure 4:- Diagram to show subcategories of beliefs within the Knowing category.



Searching for Answers - Inside.

This subcategory consists of the individual's beliefs about what is happening to them with regards the pain and why this is occurring. These beliefs all relate to internal characteristics of the participants, factors individual to them, or Knowledge, understanding they have gained from within themselves.

Individual Identity (of pain/ self).

This consists of beliefs about their experience related to their identity and that of the pain. What is this pain? Why do I have this pain? What does that make me?

Labels.

Usually a disease label. The pain is believed to be directly, linearly linked to the disease. The participants labelled themselves.

I got an illness.. (1:104)

'Cos I've got arthritis in it (5:20)

..I have ARTHUR..I HAVE ARTHURITIS.(6:108)

'Cos it's like Rheumatis. (8: 98-99)

Descriptions.

Belief about what process is occurring rather than just the label.

It's bones; I've got arthritis you see and the bone's a bit crumbled (crumbled), it's broke away sort of thing. I mean, you can see it (points to right knee). (1: 6-8)

S - Yes er, it's something to do with the joints.

I - Right... Do you know any more than that?

S - No,no..it's the joints. Leg. Into the bone in the leg. (9 secs). (4: 352-355)

'Cos there's two little bones in it...and they're pulled apart like that (miming).

(5: 407-408)

There were varying degrees of understanding what was occurring; from basic understanding of the process of decay to no more than the label.

This subcategory also includes beliefs about -

Causation.

Beliefs about how this pain began, what caused it originally and currently, day to day.

eg accidents.

A common belief was that accidents, such as falling, caused the pain.

I don't know duck. I put it down to when I were little, I were always tumbling...cutting me knees..when I were a little girl, and I think that's what brought it on really. I'm tumbling now..I fell in the kitchen.. got big bruise here (pointing)..before Christmas that was. Tripped over the.. telephone wire, it was in the way. I've had to move that in here now. I can't be trusted. (1: 166 - 171)

Well I think it's when I...when I got felled down at Glenfield..a bloke hit me with his motor bike at Glenfield..coming out of the ..Social Club. (8: 144-146)

Other beliefs include various illnesses and one participant believed a Flu jab caused the arthritis that caused her pain.

S - ... I tell you how it started me duck..I had flu injections..and she didn't use the syringe.

I - Sorry? What did she do?

S - Just broke the end off.. and stick it straight in.. (2: 6-9)

Current causes/ exacerbation of pain.

Includes belief that too much activity causes/exacerbates the pain.

It's when I errr..do too much and that. When I walk too much. When I walk a long way I get pain and that. I have to stop a bit and then...rest a bit...and then do another erm.. lot and then stop again. (7:127- 130)

This category leads into:-

Blame.

Beliefs about who is to **Blame** for the pain experience.

The dimensions of this category range from believing that the **Blame** lies with 'oneself' to 'others' to 'noone'.

The quotes above (1: 166-171 and 2: 6-9) illustrate self-blame and other blame respectively.

The participants question themselves as to who is to **Blame**, who is responsible for the pain and it's Effects on their lives..

I try to, well I try to clean round, to keep this clean (pointing at carpet in living room), but it ends up with John doing the cooking and I do half of the cleaning and he do his, you know. (1:58-60)

Yes. Yeah. Sometimes I'm really down, and urhh..him.. I don't know how he sticks with me. (1: 198-199)

I didn't ask to be like this (2:62) It's not my fault.

Pain as a Signal.

Belief that pain is a signal that something awful may/will happen. Some of these beliefs are linked to past experience.

eg Linking pain with death or heart attack.

But ma sister, bless her, she was in bed all day. She'd got polio before she died. She was in pain all day long. She'd got a wheelchair but she wouldn't sit in it. I said "B, you won't get out of it now," an she said "I don't want to". So she died in bed. (1: 220-223)

I feel like I'm going to have a big...massive...mighty heart attack. That's how I feel duck. You know. (1:- 232-233)

I feel that my leg's come apart. Cos you get that feeling when you get a big crack like that. (4: 151)

Searching for Answers - Comparison to Others.

This subcategory includes beliefs about the pain experience gathered by comparing oneself to other people. To Know how they fit in to the wider picture.

Group Identity/ Identification with others in pain.

Belief that others have pain too. Beliefs about being able to relate to these others in pain, maybe differently to those who have no pain. Beliefs about being like them or the same as them.

'models'

This belief especially holds for family members who have had pain. Participants believed that they are like these people, responding to and coping with the pain experience in the same way.

I know what my father went through 'cos he had arthritis. (1: 45)

I think I take after me dad. 'Cos he had Arth...Rheumatoid Arthritis. And me sister's got a touch of it, and me other sister has. (1:179 -181)

S - I think me mam's got it in her feet (10 sec pause)

I - Have you got anything else that you want to tell me about your pain?

S - You have to suffer with it (2:123 - 126)

Participant 2 expects to 'suffer' with her pain, as maybe her model has.
As does participant 8.

'Cos I've got a bit of pain in me arms. I'm always rubbing me arms. Like me mum used to do when she..when she was here..she used to suffer with pains in her arms... 'cos I, I..I suffer like me mum did. You know. (8: 96-98)

They understand me.

These fellow sufferers are believed to be able to understand, to **Know** what the participant is experiencing. This feels safe. A sense of belonging and also control because the experience is not so incomprehensible.

There were me hobbling, she was going like this (miming), we were pulling each other round (laughing). I said "you could cry". (1:156-157)

But he (partner - not in pain) says " I know what you're going through" but he doesn't. He don't know the PAIN of what I'm going through. (1:301-303)

Fellow sufferers are believed to know how it feels "You could cry", whereas it is believed that some others who do not feel pain, could not **Know** what the sufferer experiences (tends to exclude **Distant Others** see later)

A couple of the participants asked the interviewer "Have you got it?" (eg 5: 218, 274 and 2:42). Maybe to see whether she could truly **Know** their experiences.

Common Actions.

Participants imply that they believe that, given similar circumstances, people act or respond in the same or similar ways.

..been worrying me ... you know like you do get init? (1: 34)

That's what you do. (5: 158)

Well you do, don't you. (5:30)

Worse Off.

The difficulty with identifying with fellow sufferers is that some people within the group are believed to be Worse Off than the participant. The participant needs to identify with the 'group', but fears becoming like those who are Worse Off.

S - Well, it's like this, Su. At the Day Centre, there's someone worse than me. And she looks like that (miming shriveled limbs), like that,..it's terrible..all black and blue.(4 secs)

I - Does it make you worry sometimes?

S - It does. I think, I ain't gonna get like 'er. (9 sec pause) (2: 45- 49)

S - 'Cos I've seen some people who are a lot worse off with arthritis, you see.

I - Worse off than you?

S - Yes. Can hardly walk, or anything. Not even to feed themselves even.(deep inbreath)
And we don't want to get like that do we? (5: 141-145)

S - .Yes, yes,yeh..*name*, has got bad legs..

I - A friend of yours has bad legs?

S - Yeah..yeah..he's got bad legs as well..He can't WALK! (+)..no,can't walk at all.. (6: 284-287)

Searching for Answers - Outside/ With Others.

The need for others to Know what is happening to/ for the sufferer, and to understand or Know them as people. This seems to be in the form of empathy/ sympathy, for reassurance and a sense of safety or control, and/or to gain action.

Acknowledgment by/ Sympathy from others.

Need for sympathetic understanding and acknowledgment from others regarding feeling pain and the effects on one's life.

I told her that, I told her about..I got to...I got to erm..I said I only got to..I've only got to go in there (kitchen) for a few minutes to mash meself a drink.. and get something to eat..and I told her I have to sit down for a bit, you know. (8: 4- 8)

Wants the other person to acknowledge his difficulties and distress.

Sometimes,... that's me mum on there (photograph on table). Sometimes I talk to her. She'd know what to do, she would. (1:249-250)

Mmm...I'm glad you come. I've got some things off me chest. I find talking about it does some good ..I don't know. I could talk about it to him (Partner) but not properly 'cos..he can't understand.. not like with a woman. (1: 325 - 328)

S - When they see me, they KNOW what pain I'm in. My doctor said, Dr Turner said, I KNOW what you're suffering. I know that you're in pain.

I - So he's an understanding doctor?

S - Who? Dr Turner? Oh he's lovely he is. He understands when you explain it to him, you know. He's ever so nice. (4: 285 - 290)

These quotes show that the participants want others to understand or Know them but, as we saw in the previous category, believes that only some of these can do so. People Knowing is reassuring for them.

"You know"

Although also a style of speech, this phrase seemed to suggest more given the number of times it is used, by different participants. It suggested that the speaker either expected the interviewer to Know what was being experienced, or would like this to be the case.

Participant 1 uses "You know" repeatedly in her interview.

eg

You know. And my life seems different, you know like I can't do nothing.

(1: 56-57)

She also talks about how good it is to be able to talk to someone who 'understands' her (1: 325-328 quoted above).

Participant 4 used it specifically when trying to describe the pain sensation.

It feels awful. Like a..like a...you know like if you, if somebody gets hurt on the road... (4:57-58)

Like er...like, you know you have a needle. (4:72)

Participant 5 expected the interviewer to Know all about her and her family.

S - Yeah. She's lost her husband... Didn't you *know*(+)?

I - No. I don't know your mum.

S - She spoke to you on the 'phone didn't *she*?

I - Yes. But I 'phoned her to arrange to see you. I didn't know her before that. (5:89-93)

This category has dimensions ranging from **passive** to **active**. On the **passive** end of the spectrum the participant expects the other to **Know**. On the **active** end, the participant attempts to **Tell** the other about their experience.

I told the bloke who come on on January.. I said I got, I got to, I've got to have a bit more support, I'm sure I can. (8:116-117)

Ensuring being understood/heard by others.

To ensure that these important others **Know** the extent of their pain, take it and the sufferer **Seriously** (see later category), and to help themselves explain the abstract phenomena of pain, many of the participants use the following method.

Concreting.

Making pain into a more **Concrete** phenomena. This seemed to be used by the participants to help themselves and others see the 'reality' of the phenomena, and make sense of it. This is done linguistically, and as a style by which they direct the interview.

eg 'Tangible'.

A belief that the pain is real, you can 'see' it and 'touch' it.

I - You've got arthritis. How long have you had that?

S - Look at me hands. (4: 21-23)

That's it there look. (showing wrists) (5:2)

I've got a bit there look. (5:47)

Do you want to have a look? (5:220-221)

With regards 'style', participants sometimes reverted to **Concreting** when asked questions that were difficult for them to answer. Either showing the

interviewer Another Place (see Intense) that was affected, or offering to show the exercises they used.

This was especially marked in the interview with participant 5, who showed Another Place repeatedly during the interview.

(5: 2, 15, 46-7, 52, 84, 97, 190, 214, 220, 246, 357, 359, 362, 367-8, 414)

I'll show you my knee. Look (+). (5:84)

That's a bit of it there look.... (5:190)

... I've got it here in me head, here as well, up here. (5:214)

...that, under there, under me feet there.. You see, I've got a bit under there. (5:245-246)

It is a bit, yeah. And in me knuckles, and that, look. Look at that look (+). (5:362-363)

I've got it in me knuckle there look. And that one there look.(5:367-368)

It is understandable that in some cases people with limited verbal skills will use non-verbal means to express experiences. Or this may simply reflect our cultures dualistic view of body and mind. However, participant 5 had 'good enough' verbal skills to describe events in detail. This seemed more of a difficulty with understanding/ describing the more emotional/ cognitive aspects of the experience. She 'showed' the problem in the hope that the experience could be understood from visual cues.

As in:-

Visual Verification/Identification of Problem

This is a belief that if the problem is 'real' it can be seen visually. One can prove it's existence. Their experience should then be taken **Seriously**.

And they couldn't see anything what was the matter with it... Then they all start laughing at me. That was the staff in the hospital.. I thought "blow you". (5: 129 - 131)

Yes. When they see me, they KNOW what pain I'm in. My doctor said, Dr Turner said, I KNOW what you're suffering. I know that you're in pain. (4: 285-286)

Difficulties telling someone.

The participants believe that sometimes others do not 'hear' that they are in pain, or respond inappropriately to being told.

Ridicule.

The belief/expectation that if one tells someone about one's pain, or show that they are in pain, that they would be subjected to derision or mockery. Others will not respond in the way one needs. This belief is frequently linked to previous experience.

In one case, beliefs about Ridicule stopped the participant from telling people that she is in pain, although this was obviously important to her. She returned to this theme throughout the interview.

I don't like it. It's painful. If you tell anybody, they laugh at you. One of them did this morning.

..they laugh at me when I tell them.

And if I tell anybody, they just laugh at me..

And they couldn't see anything what was the matter with it..Then they all start laughing at me. That was the staff in the hospital. I thought "blow you".

And if I tell *them*(heavy emph), they laugh at me.

... And if I told anybody they'll only laugh at me. One did once.. LAUGHED at me. When I were trying to tell 'em.

(5: 23-24, 26, 86, 129-131,174-175, 210-212)

Well, we've got one girl there and she laughs a lot at me. (regarding her pain)

(2: 113)

I was limping and people kept looking at me, I thought "you can look at me, I'm not bothered, I'm in pain" and then, er, this boy .. out the window "eh fatty bum". He called me fatty all the.. but I ignored that, I got an illness, I don't care what other people, what they think. If I want to limp, or what, I'm going to.

(1: 101-105)

Participant 1 seems less concerned about what other people who Ridicule her think. Nevertheless, she does seem not to expect others to take her Seriously (see later).

Given the general beliefs that they do not have effective ways of coping with their pain and/or it's Effects, and some difficulties in being Known, one questions why these participants continue to Try as they obviously do.

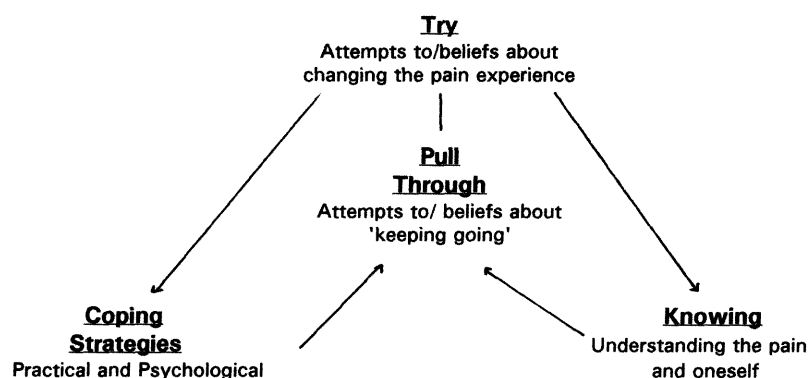
'PULLING THROUGH'/STOICISM.

The answer seems to revolve around two beliefs. Firstly, beliefs about the lack of **Choice**. One participant succinctly summed up this belief with her repeated use of the phrase "**Well, what do you do?**".

Especially first thing in the morning, you know when you want to get out of bed.....You can give up altogether... And what do you do? (5:181-183)

One has no choice but to continue **Trying**.

Figure 5:- Diagram showing specific categories and interconnections.



Participants also held beliefs about what their psychological response to the pain experience should be. This ranges from **pulling through** to **giving up**. This can and does change over time. There is a sense of believing there is no **Choice** in either position.

In **Pulling Through** the expectation is that one 'keeps going' and is 'strong'.

You know. We pull through do we duck. (1:202-203)

..well, you got to make your fingers go...you ain't got to give up...(2:19-20)

Some believe that they have to **Pull Through** to help others.

S - Well ,you got to haven't you.

I - Are there times when you do get down with it?

S - Yeah...but we have to help one another. Me mam's got it in her back. (2:89-92)

S -...I put up with it.

I - You put up with it.

S - You have to do.(5:114-116)

I - You talked about trying to... cope with your pain?

S - I have to do.

I - How do you cope?

S - I have to try and help me mother you see. (5:192-195)

Despite sometimes wanting to give up.

Especially first thing in the morning, you know when you want to get out of bed.....You can give up altogether... And what do you do? (5:181-183)

Those who have 'given up' (eg 4 and 8) seemed to have become more dependent and depressed. They continue to Try, but seemingly only because of the motivation of others.

They said, they said ..you've got to do, you've got to try to. do a little bit yourself now.

(8:219-220)

EFFECTS/CONSEQUENCES OF PAIN.

The beliefs and processes described above, take place alongside the Effects that the participants believe result from the pain experience. However, these processes and beliefs (eg Cures being Withheld, beliefs of no Way Out) also feed into and produce further Effects (see diagram).

The beliefs in this category are about the way that pain has altered their lives; the results/ implications of having pain or having to live with the pain.

These split into two subcategories, the 'Practical' Effects and the 'Emotional' Effects, although there is some overlap between the two.

'PRACTICAL' EFFECTS.

BLOCKED.

Participants described believing/feeling that they were **Blocked** or trapped, in various aspects of their lives by their pain. This takes the form of being unable to do what they want, or expect to be able to do, for various reasons.

There are various areas in which the participants believed themselves to be **Blocked**. They believed they were **Blocked** in their activities, both the activity itself and the level at which they conducted an activity.

You know. And my life seems different, you know like I can't do NOTHING. I want to clean me windows, I try to, well I try to clean round, to keep this clean (pointing at carpet), but it ends up with J doing the cooking and I do half of the cleaning and he do his, you know. (1:56-60)

Yeah. I told you..he sleeps in here, I sleep in there an'..we're getting nowhere. You know. We pull through do we duck. I wouldn't do without him for all the world (tearful). We're engaged. We've been engaged..how long? 6 years? We've been going for 12 though. And we've got NOWHERE in marriage. (1:201-206)

I say...people ought to be thankful that they can walk. I'd give the world to walk.

(4:106-107)

I have to have a wheelchair when I'm going out anywhere. 'Cos I can't walk very far. Or stand still for a minute. And what do you do? (5:62-64)

Awful... It feels awful..AWFUL,AWFUL,...yes (4 secs). I in bed. go sleep..CAN'T move...Can't move in bed (3 secs).Arthritis..come on.. in the night..painful ..in bed...painful.I can't...I can't ...I can't...I can't.get out of bed...go to toilet...I can't.

(6:196-199)

I told that, I told her about..I got to...I got to erm..I said I only got to..I've only got to go in there (kitchen) for a few minutes to mash meself a drink.. and get something to eat..and I told her I have to sit down for a bit, you know. (8:4-8)

Participants believed they were **Blocked** in their ability to move, stand, walk, do housework and other activities, and have relationships amongst other things, and/ or do these at a 'normal' level (eg time required, speed).

They also believed that they were **Blocked** in their attempts to reduce the impact of the pain experience or 'cure/control' it. Either that these coping strategies were being **Withheld** from them in some way, so that they could not get to them, or by not having any/ many **Coping Strategies** that were successful.

Withheld

This belief was about others refusing to grant or put into action, either consciously or not, **Strategies** that participants believed would reduce the pain.

I want something, somebody, to phone now and say "you're in tomorrow", you know like. (1:72-73)

I mean, alright, I know people can't say "tomorrow", but if you paid Private it could get you in today like. With me being on the social (tearful, wavering voice) no job, I got wait. (1:77-79)

S - Well NOTHING. THEY won't give me anything.

I - Is this the doctors?

S - He's the same. He don't give me NOTHING... (5:41-43)

..but I got to, I got, I got, I got to,.. I told erm... I told the bloke who come on on January.. I said I got, I got to, I've got to have a bit more support, I'm sure I can. (8:115-117)

Blocked Coping Strategies splits into 2 further subcategories; believing that they are blocked by not knowing any strategies (described in **Way Out** subcategory), and believing that the **Coping Strategies** they have are unsuccessful.

I - Are there things that you do to help you take your mind off the pain?

S - I try to, but I lift me legs up at night in the air, and I put them down but when I get up, when I've done that and get up, I pull this leg back and it's painful you know. I stand up there and cry. (4:95-99)

Plenty of exercise on it. But it just comes back to crunch, about how..... I can't get much exercise because the pain's that bad, I can't bear the pain. (4:191-193).

Dimensions

The dimensions of this category range from not **Blocked**, through **limited**, to **totally Blocked**. This varies between individuals, but also within individual cases or dependent on activity, for some people.

It seems that those who believe that they are at the **totally Blocked** end of the continuum, for most of the time and most activities, are also most **Desperate** (see **Emotional Effects** later).

eg Participant 8 believed himself to be so **Blocked** in all activities in which he wished to engage, that he spends his days sitting and avoiding movement as much as possible.

I mean, I can't do nothing for meself hardly. I've only got to go down there (pointing down road) and I've got to stop about (puts up 4 fingers).. (8:54-56)

'Cos sometimes I'm sitting here...in awful, awful pain sometimes on Saturday mornings. There's a bloke who lives up there and I give him the money now to.. bring these up (papers) every Saturday morning for me. I just give him the money, you see, so that he can bring it up for me. 'Cos I, I mean, I mean.. I'd go down myself except it creases me. (8:237-242)

Participant 5 is more **limited** and is less **Desperate**. She has difficulty standing and walking for as long (see above) as she wants, but still continues with housework.

Make me own bed and...go round with the duster. Things like that. (5:315-316)

This category is therefore dependent on how the participant sees the dimensions of the pain itself. Whether they believe it to be unremitting or variable (see **Intense**).

This whole category is closely linked to and influenced by the participants **expectations** of what is 'normal' activity, ability and independence for an individual, when both 'well' and 'ill'. Participants imply that they believe that they should be able to do more than they do, or at a different level.

Some participants express beliefs about how they should behave when 'ill'. For example, **Suffering** (see earlier) and doing nothing.

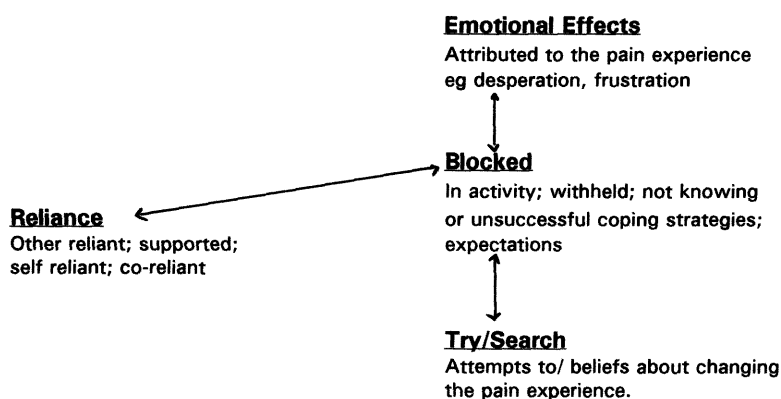
I - Have you got anything else you want to tell me about your pain?

S - Umm...You have to suffer with it. (2:124-126)

I mean, I mean, I know I know you can't, you can't do nothing, I told Mrs S, I can't do... I can't do nothing for myself.. (8:43-45)

This is linked to family 'models' for these 2 participants.

Figure 6:- Diagram showing specific categories and interconnections.



RELIANCE/DEPENDENCE.

This category consists of the participants beliefs about who they rely upon practically in terms of everyday living activities and pain control. The complicated interaction between the extra support that is related to the experience of pain and that related to the learning disability, needs to be held in mind.

This category is distinct from the category of **Power**, by being what actually happens practically day to day rather than wider supposed control. However, it is heavily influenced by **expectations** of who should hold the **Power** (see later category).

Dimensions.

The dimensions of this category range from other-reliant through supported to self-reliance. Some participants also expressed beliefs about others relying on them or being co-reliant (i.e dependent on each other).

Now ma sister yesterday, I went to see her at her house..she fell, hurt her back. There were me hobbling, she was going like this (miming), we were pulling each other round (laughing). (1:154-156)

Well, I try to help me mam. Which I can. (2:76)

Yeah...but we have to help one another. Me mam's got it in her back. (2:91-92)

I have to try and help me mother you see. (5:195)

Being other- reliant means expecting that the other will do everything for them; suggest how they should live their life, complete self-care activities, suggest coping strategies for the pain etc.

She gets me washed. I can't get in the bath 'cos I haven't got a rail to hold onto..you know a bath rail.. so I sit on the ..how she does it is, I sit on ..er put the toilet seat down.. sit me down there and wash me. It's the only way she can do it. Can't get in the bath. (4:133-137)

Ooh.... you know when I put me trousers on, me sister puts them all on the heater. But if they're not on the heater, you put them on and the pain shoots, shoots in your legs. Coldness. But she warms me trousers, and me jumper and me underwear..and me vests. Not me vests. On a Saturday she puts all me vests out on the heater and all that, and I have a wash, and then she washes me hair. She washes me hair on Sunday afternoon. And um.. she puts all the clothes on the heater to keep um warm. The heat gets into them you see. (4:299-307)

It includes beliefs about not being able to perform a certain activity on ones own.

Can't walk very well. I erm.. how can I put it..er.. when I'm walking on me own, without the frame, I think I'm down, you know. Going down. (4:109-111)

In reality, even the most independent participant was not totally independent for everyday living activities, and most relied on others to a great extent for suggestions of pain control (see earlier).

The level of dependency can change depending on in which activity the participant was engaged, for some but not others.

And John brought me a cup of tea up. I said "I'm getting up now". He said "slowly". He waits at the door, I get meself up and he lifts me legs over and I walk to the bathroom.

(1:135-137)

I...get, get, hold of the arms.. of the chair that I'm sitting in and they help me get up, you see. (5:119-120)

Participant 1 and 5 who expressed beliefs about being co-reliant needed to be other-reliant or supported to complete certain activities such as getting out of a bed/ chair.

There seems to be various ways that Other-reliancy develops.

For some participants it comes from finding oneself Blocked in efforts to help oneself, or in finding Ways Out, ending up Other-reliant.

I shout..get somebody up...upstairs...help me get out of bed..help me... Help me get out of bed to go to toilet...and after I've come out the toilet.. to help me get in bed again.

(6:203-205)

(name)..lifts me out of bed...he puts arms round me...and lifts me up...lifts me up...sit up...sit up in bed..can't move...in PAIN (+)...AWFUL.

(6:213-215)

For others it seems based on the expectation that one will be Other-reliant. That this is 'normal' and to be expected.

I mean, I mean, I know I know you can't, you can't do nothing, I told Mrs S, I can't do... I can't do NOTHING for myself, wash meself, some days.

(8:43-45)

I mean I can't do nothing for meself, hardly..I mean, I can't do nothing for meself hardly.

(8:53-55)

This again is linked to 'models'. However, it is not as straightforward as following the 'model'.

Two participants described a theme about reliance/dependency between themselves and their mothers, which on some level seemed to have been 'created' or 'encouraged' by their mothers.

Participant 7 repeatedly used the pronoun 'we/us' when talking about her pain and control of it.

Errrr..when we come out of hospital when we had one done (hip replacement), me mum wouldn't let us..err do anything. (7:7-8)

Erm...we always try to do these exercises at home (7:26)

We've still got the scars where erm... they done it (7:66)

This may simply be a difficulty with language, or reflect a belief that pain control is a joint process with her mother. However, she later describes how her mother told her what to think, and what to say in the interview.

S - Mmmm. It is a lot better now but, mum says, we still have it and it's stiff, but I'm alright in myself.

I - Mmm. Your mum is obviously very important to you.

S - Me mum told me to say that to you. (7:165-168)

Participant 1 was 'made dependent' by her mother.

With me being Learning difficulties, duck...now.. me mum not here..I got to grow up, 'cos she never let me grow up. It's hard. (1:269-271)

Wouldn't let me do nothing, would she J? She treat me like a ...well...Mentally Handicapped. (1:275-276)

But she wouldn't let me grow up, duck. She'd treat like a mental wouldn't she duck? She was a good mother, but.. she would not let me grow up. (1:289-291)

Yet she still has expectations that she should be Self-reliant, and is distressed when she can not be.

And my life seems different, you know like I can't do nothing. I want to clean me windows, I try to, well I try to clean round, to keep this clean (pointing at carpet in living room), but it ends up with John doing the cooking and I do half of the cleaning and he do his, you know. (1:56-60)

Support may be a way of continuing to be as **Self-reliant** as possible in the face of continuing pain, a way of minimising the impact that pain has on one's life. Using others strength to continue with life and **Pull Through**.

Problems seem to arise with **Reliance** if:-

a)the situation does not fit with the individual's expectations.

eg Participant 1 believes that she should be **self-reliant** but needs support and therefore feels **guilty**.

..well I try to clean round, to keep this clean (pointing at carpet), but it ends up with J doing the cooking and I do half the cleaning.... (1:57-59)

b) either party of the **Reliance** holds different expectations or would choose to be less/more **reliant** on others. For example, Participant 7 appears happy with the level of dependency between herself and her mother. Whereas, Participant 8 wanted to be more **Other-reliant**, but others would not allow him to be so.

S - They said, they said ..you've got to do, you've got to try to. do a little bit yourself now.

I - What do they mean by that?

S - Sorry?

I - What do they mean by "you've got to do a bit for yourself"?

S - Well, I, I, I, I, I said I've got, I got..I told 'em I must..I must get someone to.. make sure if I'm alright, you know. I said it would be a good idea if somebody came in on Saturday for erm...5 or 10 minutes...to check I'm alright. (8:219-227)

c) the other on whom the participant is **reliant** has no **Ways Out** or ways of removing any **Blocks**, then the participant can feel **Desperate** (see later).

I - Do they help you with your pain? Do they try and help you feel better with your pain?

S - She (sister) tries to, but it's hopeless, you know 'cos it's very painful. (4:138-140)

EMOTIONAL EFFECTS.

The participants believed that the experience of pain Emotionally Effected their lives in a variety of ways. Although, they attributed various emotional states to the pain, these emotions were not always clearly distinct from each other.

They expressed feeling:-

Down/ Upset

Participants believed that the pain experience made them low in mood or unhappy. They frequently described this state by saying that they cried.

I used to go Leicester with J, come back laughing, and when I come in now I sit down CRYING with PAIN. (1:65-66)

If it weren't for you coming I could cry me eyes out (1:140-141)

... when I've done that and get up, I pull this leg back and it's painful you know. I stand up there and cry. (4:98-99)

Desperate.

Participants expressed beliefs that the pain experience made them Desperate - ie with little hope left, not able to carry on with life, in certain circumstances.

I just..I don't know how long I gotta wait. I can't wait to July, me duck (for operation). Surely. If people say you have to do I'll say well...I'll do meself in. I would.(1:189-191))

I - Can you tell me what it feels like today?

S - It feels bad today.

I - When you said that, you put your head in your hands.

S - Yeah I know, it's 'cos it's painful. (4:175-178)

Can't make it better. No matter what you try or rubs or anything like that..it's still the same. (4:343-344)

Participant 6 shows desperation behind his Pleading for help.

eg Please...suh... please.. seeing to it for me..PLEASE,...PLEASE.. PLEASE..
PLEASE..seeing to it for me. Please. I've got..I've got a..I've got a..lot of..pain. See to it
for me. (6:76-78)

Please..please.s..please.s.s.s.please seeing to it..For my sake. (8 secs) ..please seeing to
it. (6:291-292)

Frustrated/Fed-up

Belief that they have had too much of the pain, that they want it to be
different.

I am. I'm fed up. (1:140)

Yes.... You get fed up don't you.(5:158)

Anxious

Belief that pain makes one uneasy, concerned.

Since I've been here, I've been eating more you know. I think, eating eating 'cos it's been
worrying me..(1:32-34)

I - Does the pain frighten you sometimes?

S - Oh yes. Yes. Yes (heavy sigh)

I - What is it about it that frightens you?

S - I feel like I'm going to have a big...massive..mighty heart attack. That's how I feel
duck. You know. (1:229-233)

Angry

This participant was not angry at his pain itself but consequences of the
pain ie treatment in hospital.

The nurses used to come and see you every day, and in the afternoon. But they don't in
Leicester, 'cos they "ain't got time"(sarcastic voice)or "They're busy". They look like
they're busy, when they keep busy supping bloody tea.THAT'S NOT BLOODY BUSY.

(8:193-197)

Embarrassed

Participant believed that they were **Embarrassed**, felt awkward or ashamed because of their pain.

I do feel embarrassed when I'm.. limping. And people keep looking at me. (1:321-322)

Dimensions.

Participants expressed different **Emotional Effects**, with some participants tending to be more **Upset** and some more **Angry**. Some participants, in particular participant 1, expressed a wide spectrum of emotions, whilst some attributed few **Emotional Effects** to the pain at all.

These emotions also differed in degree (from extreme to none), at different times or in different conditions. For example, participants 1 and 4 believed they became **Upset**, as a result of the pain they experienced after activity (see above 4:98-99, 1:65-66).

These **Emotional Effects** both result from, and feed back into, other categories and subcategories of beliefs. They link to beliefs about pain **Intensity**, being **Blocked** in what one wants or expects, **Different** from others and how they want to be, not 'heard' or **Ridiculed**, and confusion and uncertainty due to lack of **Knowledge**.

Finally, the **Emotional Effects** are linked to expectations, as are many of the beliefs in this study. The participants have expectations that the emotions they were experiencing were **Different** to the ones they should be experiencing. For example that they should not be crying or upset, or embarrassed or frightened, but calm and happy (see participant 1:65-66 above). These are based on expectations of 'normality', of 'normal' moods. It is when experience differs from their expectations of normality that they become distressed.

In summary, categories of beliefs about the **Intensity** of pain, the **Effects** on one's life, the need to **Get Rid** and find **Ways Out** and examples of these in **Coping Strategies**, **Knowing** and **Reliance**, and the interconnections between all of these have been described.

OVERARCHING CATEGORIES.

The following four categories are linked to, and influence, all proceeding categories. They are higher level, more abstract categories that umbrella over the previous categories. Their links to having a LD will be considered in the discussion.

As examples from the previous categories will frequently be drawn upon to illustrate these four categories, the reader will regularly be referred back to the previous categories, so that quotes/points do not need to be repeated.

POWER.

The participants held beliefs that **Power**, strength, authority is needed to be in control of the pain, and especially to **Get Rid** of it, their priority.

LOCUS OF POWER

These are beliefs and expectations about who holds control/power over the pain sensations, it's causation, course, effects and control/ cure.

This category splits into four locuses for power.

1) INTERNAL/ SELF.

This subcategory consists of participants beliefs about the **Power** they themselves should, and/or do, hold over the pain, and could use to influence the pain experience.

Most participants (as already noted - **Way Out, Coping Strategies, Reliance**), believed that they did not have power to control, or produce change in, their pain experience.

There's nothing really, what ever I do, nothing to take it off. (1:211-212)

I - What are you thinking about?

S - Thinking about getting...getting me legs better.

I - And how are you going to do that?

S - Don't know. I've got no idea. (4:179-182)

I - What did you do when you felt like that?

S - Nothing. (7:198-199)

Participant 6 saw his only Power as financial.

I - What can YOU do.M,.. that makes the pain go away?

S - I'll pay... I'll pay. (6:252-253)

Participant 2 believed she did have some Power.

I cope well with mine. (2:76)

Some seemed to believe that it was not their place to hold the Power, or did not want it. For example participant 8, who was struggling to give the Power back to others whilst they kept returning it to him. (see under Reliance)

2) EXTERNAL/OTHER.

This subcategory consists of participants beliefs about the Power others should, and/or do, hold over the pain, and could use to influence the pain experience.

It splits further into:-

a) Close other.

Participants beliefs about the Power held by close others, usually family members.

Sometimes I talk to her (mother - deceased). She'd know what to do, she would. She'd go up the wall to see me like this.

I - What would she make different?

S - She'd get on the 'phone. "I want me daughter in now." She would. No messin'. If she were here today she'd go "she's really in a lot of pain, will you do something now?" She would.

S - Yes. She used to get doctor in and...she made me go to bed... (1:250-281)

Participant 1 sees her mother as a very Powerful figure. However, she is dead and no longer able to produce change for her. Most other participants believed that their families/ carers held little or no Power.

Many of these beliefs have been outlined in other categories (especially **Coping Strategies**).

Close others make suggestions on coping, act as models, and try to help. However, they are seen as having no/limited answers or **successful Coping Strategies**.

b)Distant other.

Participants beliefs about the **Power** held by distant others, usually health professionals.

See participant 6's **Pleadings** (in **Get Rid** and **Desperate** (**Emotional Effects**)). He had the belief that **Power** lies with interviewer, and not with him.

See participant 4's differentiation between the relative success of a **Coping Strategy** used by her sister or the physiotherapist, depending on where she saw the **Power** being. (see **Coping Strategies**).

'Distant others' tended to be seen as **Powerful** and **successful**.

However, when distant others, who are seen as **Powerful**, turn out to have no **Power**, then participants can 'give up' altogether.

I know S can't do much for me... I mean, I mean the doctor can't do a lot for you (+)
(8:89-90)

If it is **Withheld** it can result in **Anger** and **Frustration**. (see **Blocked** and **Emotional Effects**)

Participant 5 believed that the doctor held the **Power**, not herself, but that she was the one 'left to cope'.

I - So what do you do to try and make the pain go away?

S - Well NOTHING. THEY won't give me anything.

I - Is this the doctors?

S - He's the same. He don't give me NOTHING (5 Secs) I've got to try and cope on me own.
(5:40-44)

3)EXTERNAL/CHANCE

Participants also held beliefs about the Power being held by other 'forces', including the weather, chance, daily variation, medication.

But on some days it's.. in hot weather..it goes. (2:51)

.....that's how it goes, you see. Starts and..I'll be alright one day and then the next day it's worse. (4:91-92)

No, touch wood. Me hands have been alright. (4:223)

When the sun comes out, it makes it worse. (5:6)

I like it when it's cold. It stops the pain.(5:34-35)

YES, yes,yes...powerful..eh,eh,eh..strong tablets, powerful...tablets ...makes PAIN go..and arthritis go.. (6:246-247)

4) NONE.

Belief that noone or nothing has the Power. Noone is in control.
Control is impossible.

Can't make it better. No matter what you try or rubs or anything like that.. it's still the same. (4:343-344)

I mean, I mean you can't, you can't erm...you can't stop it (5 secs) you got to let it er..work off itself. (8:243-245)

Dimensions.

These range in all subcategories from none (no Power) to complete Power. As Power often involves 'others' another continuum is from whether Power is taken by others or given by the participants.

Finally, the continuum of being happy with the level of Power held by self or others, to being unhappy with the situation. For example, some participants were seemingly happy with having no Power themselves (not wanting any - eg participant 7), whilst others struggled and were unhappy with this (participants 1,5). Some were unhappy (eg participant 8) because

they believed they had too much Power. This continuum can differ between self and other.

Additional Links to other categories.

Effects:- All Emotional Effects are influenced by Power. For example, Desperate, or Anxious are linked to beliefs about either oneself not having any Power to change the pain experience, or noone having the Power. Angry, or Fed up/frustrated are linked to others having the Power but not using it in a way believed necessary by the participants.

Get Rid:- Need Power to do so. Power is given, or taken to Get Rid of the pain.

Try:- Belief that Power is needed to Try. It may be that if the person who is Trying, or expected to Try, is seen to have no Power, then it will be expected that they will not, or are less likely to, succeed in their attempts to cope or change the pain experience.

Blocked, withheld:- Power lies elsewhere, not with the participant or person who helps them day to day.

Coping Strategies:- Beliefs about where Locus of Power lies, influence beliefs about who should suggest/initiate Coping Strategies. Expectation of who should be in control, initiating Coping Strategies. This is usually 'others'. In this category the Power is knowing effective Coping Strategies, and therefore effecting change.

Power influences the belief that they or others can make Coping Strategies work effectively. (eg 4)

If one believes they have no Power or noone has Power, pain or having no ways of changing it, can be seen as inevitable.

Reliance:- Distinct from Power as it concerns what happens practically rather than beliefs regarding who should have Power. Also, participants expressed beliefs about being Reliant on others who they believed had no Power. This can lead to feelings of helplessness (see Reliant).

She (sister) tries to (help) but it's hopeless (4:140)

Knowledge:-

This category is about needing to **Know** and be **Known**. It may be that participants who believe that others should hold the **Power** (in this category - the 'answers'), are comparatively less distressed if they themselves do not, than those who believe that they should hold **Power** and **Know** what is occurring, but do not.

SERIOUSNESS.

The participants held beliefs about the **Seriousness** of the pain experience, and it's **Effects** on their lives. Due to the **Powerful** role played by others in their lives, they held beliefs about the importance of others also taking this **Seriously**. Again this category links with all categories previously described.

The participants believed that they need others to **Know** the **Seriousness** of the pain. They **Try** to **Tell** them (see **Know**) that they are not coping etc. Some believe that others need to **Know** the **Seriousness** to promote change.

... I mean, I mean, I know I know you can't, you can't do nothing, I told Mrs S, I can't do,... I can't do nothing for myself, wash meself, some days. She said you've got to take your time. Do a little bit and..not rush. I told her I only went and got myself a drink here, and something to eat. (8:43-47)

Participant 8 stresses the **Seriousness** of the effects of the pain on his life, and how he cannot cope with it alone.

However, some participants experience cures/controls seemingly **Withheld** (see **Blocked**) by others. Others experience **Ridicule** (see **Know**), or being given poor 'treatment'.

Dr S, before...another doctor before, before...before we went in, our own doctor err...Dr Q never examined us or anything . We went in and the nurses played up with..they played up with us. And they never examined us at all. (7:145-148)

But they don't in Leicester,'cos they "ain't got time" (sarcastic voice) or "They're busy". They look like they're busy, when they keep busy supping bloody tea. **THAT'S NOT BLOODY BUSY.** (referring to nurses in hospital 8:194-197)

Contrasted with the experience of 'treatment' where the participants condition is taken **Seriously**.

Dr R said if you have a lot more pain, we've got to see another... we've got to see a new doctor. 'Cos Dr R retired now. So he said, if you have any more pain ring up, don't hesitate to ring up and that. To see the new doctor. He said err...he'd let us know if I've got to go back again. (7:152-156)

Well, they said, if you're having pain or..you know... not very well, use the buzzer...on the, you know, on the side of the bed...Where they've got the light.. They said, just press that...I said, I said, I don't like to..upset you, me duck, while you're doing your writing. Oh no, she said that's what we're here for to, if you're not very well and noone can see you. (8:204-209)

This all contributes to beliefs about whether or not they, and/or their condition, are taken **Seriously** by others.

Some participants tried using **Concreting** (see **Know**) and **Everywhere** (see **Intense**)to 'prove' to others that their pain was real and **Serious**. Others tried **Pleading** to be taken **Seriously**.

They use extreme words to describe the **Intensity** of the pain to emphasis it's **Seriousness**. Beliefs about how **Serious** the pain experience is help motivate the desire to **Try to Get rid** of it.

DIFFERENT.

Again linked to all categories. Participants held beliefs about being **Different** to others and **Different** to how they want to be, in three areas. (Also see **Know**).

They held beliefs about being **Different** to those who are not in pain and similar to those in pain. This is complicated by being **Different** to those **Worse Off** than themselves, or those who seemingly get treatment which is **Withheld** from them.

Emotional Effects such as feeling **Down** or **Embarrassed** are linked to believing that they are in some way **Different** from others, or from being 'made' to feel that way.

Different to 'normal life'.

This is especially linked to the **Effects** of the pain experience. Participants held expectations that their moods should be **Different** eg not **Down**, **Fed-up** etc. Or that they should not be **Blocked** or have treatment/support **Withheld**, or be less/more **Reliant**. "It should be **Different**".

However, many had difficulty answering how they wanted life to be **Different**, when asked. Some came up with activities that they would not want to do even if they could! (eg run 5:334)

Participant 2 gave activities that she already engaged in, and said that the main difference would be that there would be no pain.

S - Yes, things would have been different.

I - How do you think things would have been different?

S - Well, I wouldn't have no pain, would I ! I'd do things an' that...Help me mam. I do that anyway.. Do shoppin'... which I can. (2:37-40)

This is also linked to **Getting Rid** of the pain, which is wanting **Difference** and **Trying** to find a **Way Out** which is searching for **Difference**.

These beliefs are based on expectations of how it 'should be'.

STRUGGLE.

The final and core category is one of physical, psychological and social **Struggle**. The participants express beliefs about **Struggling**; making determined efforts to get free from the pain, or to maintain their efforts in difficult and restricted circumstances. This ranges from **fighting** to **beaten**.

They **Struggle** with an **Intense** phenomenon which is **Everywhere**, appears to be **Spreading/ Attacking**, and has wide reaching **Effects**. Despite being **Desperate** for a **Way Out** they find this **Blocked** in some way, or they do not **Know** how to **Get Rid** of it. They and their close others are **Powerless** to do. They continually **Struggle** with feelings such as **Despair**, **Anxiety**, **Guilt**.

However they continue to **Struggle** to live as 'normal' lives as possible, often because of expectations of a **Different** life and beliefs about **Pulling Through**. They **Struggle** to **Try** and find successful **Coping Strategies** or to **Search** for **Answers**. Often within systems and with others that **Ridicule** them, do not take them **Seriously**, and seemingly leave them **Powerless**. The oscillation between the Stoicism of **Pulling Through** and the extreme **Desperation** expressed at other times in the interviews is remarkable.

This is an ongoing 'battle' which some continue to fight and some have **Given Up** on and seem more **Despairing** and **Reliant** than others, tending to 'flip-flop' between the two sides less, remaining only in **Despair**.

DISCUSSION.

Previous research within the adult and child pain literatures has produced lists of pain cognitions and coping strategies. Some of these have subsequently been found to correlate with poor outcomes and influence interventions for chronic pain (eg higher levels of pain report, disability - see Introduction). However, this previous work has not focused on the complex processes within, or links between, these cognitions.

This study has attempted to draw out and identify, both the specific pain cognitions and coping strategies, and the processes linking these. It has also made explicit the properties and dimensions of these beliefs and shown the importance of these, which is not often included in other studies. All this with a novel population; people with a Learning Disability (LD).

The first set of categories (see Analysis) describe the pain beliefs and the ways that beliefs link to and through other beliefs. Many of the cognitions and coping strategies described in this first section are similar to those identified for adults and children without LD. Some were to be expected, given that these informed the Interview guide.

However, some of these beliefs, and especially those in the four more abstract categories, have important differences which seem to be linked to, and heavily influenced by the participants' experiences of having a LD. These differences and the consequent issues and clinical implications will now be discussed. In addition, the research methodology will be evaluated and future directions of research in this area explored.

POINTS FROM THE CATEGORIES.

This section will explore the pain beliefs, coping strategies and processes identified for these participants through the analysis. It will focus on the similarities to, and differences from, existing literature, and examine the factors that play a part in any differences. Difficulties that could and do arise from certain beliefs and the processes identified, will also be discussed. These points are complex, reflecting the interactions between many factors.

Comparison to Previous Literature.

Similarities to Existing Literature.

As already stated, some of the beliefs expressed by participants in this study are similar to those identified in existing literature. For example, beliefs about pain being **Intense** and using such words as horrible, terrible, and suffering. These would commonly fall into categories of beliefs labelled 'Catastrophising' in the existing literature. This is defined as negative self-statements and overly negative thoughts about pain. Catastrophic beliefs have been found to correlate with poor emotional adjustment (Rosenstiel and Keefe 1983) and interfere with the effectiveness of coping strategies (Bennett-Branson and Craig 1993).

Beliefs about the importance of understanding the nature of pain, its timescale and who is to blame for the situation have also already been identified (in **Intense** and **Knowing**)(eg Williams et al 1994). Beliefs about one's **Power** and ability to change situations (labelled Self-efficacy), and the **Coping Strategies** described here are again not completely novel to this study (see Introduction)

This in itself is an important finding. The mediating role played by pain beliefs in the experience of pain is well established (see Introduction). As is their importance in interventions for managing chronic pain. However, there is a paucity of both research and clinical interventions for people with LD who are in pain. Some of this is attributable to the belief of others, that people with LD have very different experiences of pain to people without LD (ie are insensitive/indifferent to pain Biersdorff 1994). However, this current study suggests some close similarities.

Differences to existing Literature

In addition, there are pain beliefs expressed by participants in this study that have not been identified, or maybe not explicitly stated, in any previous work. Again identifying their dimensions and links to other categories is important.

For example, beliefs about **Getting Rid** and **Ways Out** have not been previously identified. This is not to say that these beliefs may not be inferred in previous work, or that the obviousness of people with chronic pain wanting to **Get Rid** and find a **Way Out** of it just presupposed.

However, this is not always the case, with some people finding it hard to change their experience of chronic pain because of secondary gains, or 'being used' to the situation.

As shown here, the dimensions of the **Way Out** beliefs include, believing that one exists, that one knows it, and has access to it. Identifying such dimensions is vital for a fuller understanding of the influence of these beliefs on the pain and any interventions, and to show how **Way Out** beliefs are not always straightforward and obvious beliefs. The links identified between beliefs about how **Intense** the pain experience is, how well one is **Coping**, beliefs about a possible **Way Out** or being **Blocked** in this, are also important for a fuller understanding of this complex process.

As shown in this study, beliefs about having no **Way Out** can lead to **desperation** and increased **reliance** on others (maybe even more than is necessary). Some participants have unrealistic expectations of **Complete Cures** which are unlikely with chronic pain, which is more likely to need 'managing'. Anger and depression are likely to result when or if one's hopes are not met, especially if they are willing to undergo what are drastic measures (**Rip it Out**) to be 'pain free.'

Way Out and **Get Rid** beliefs are also linked to beliefs about having **Power** to change the situation. For many this is not directly available, leading to **desperation**, helplessness and hopelessness. All of these are identified in existing literature. However, the complete powerlessness that these participants express is not generally mirrored within that literature or clinically.

The **Coping Strategies** that the participants described are rather limited. The range of **Coping Strategies** used, the emphasis on **Practical** rather than **Psychological Strategies** and the **Reliance** on others for suggestions reflects the child more than the adult literatures.

Again, important and novel points are drawn out in the dimensions, such as beliefs about who should suggest **Coping Strategies**, the importance of believing in the **Power** of the initiator of a **Coping Strategy**, and beliefs about whether and how one should be coping. All these interact to

produce a complex picture and will effect the success of any strategies tried, or interventions developed.

In addition, 'Coping' has been shown to be much wider than that captured within the specific category on **Coping Strategies**. The whole process, described through the categories and their connections, is one of attempting to 'cope' or not, **Struggling** to do so or passive acceptance of the experience. Previous research (ie Brown and Nicassio 1987) identified 'passive' and 'active' coping strategies in people with arthritis. Specific coping strategies were labelled 'active' or 'passive', with 'active' strategies correlated with lower reported levels of pain, depression, helplessness and functional impairment. This current analysis has identified strategies that have previously been labelled as 'passive' or 'active' (eg **Telling Others** compared to **Distraction**), but has in addition explored passive and active processes of coping with pain (shown as progression through the categories) that have 'led'/ resulted in participants taking very different directions and influenced other pain beliefs.

Even beliefs that have been identified in previous literature have some differences in this study. For example, the similarities between existing literature and beliefs in the **Intense** category have already been discussed (see above). However, the style of showing **Another Place** to illustrate **Everywhere** beliefs seems to be novel to this study, and has close links with being 'heard' and taken **Seriously** (discussed later).

This study has therefore identified themes or parts of beliefs that differ from other studies. Whilst this is due in part to the focus on the dimensions of, and interactions between beliefs, some of the differences identified can be shown to be influenced by factors relating to having a LD. These influences will now be highlighted as they have important clinical implications.

Influence of having a LD.

Beliefs about Knowing

In the **Knowing** category participants expressed beliefs about needing knowledge to be able to identify and understand their experience, and themselves. The former beliefs are not novel to this study, for example beliefs about blame, causation, the significance of the pain. However, the close links to beliefs about oneself are different.

The **Knowing** beliefs seemed to include beliefs about being less informed, less intelligent, and **Knowing** less than people without a LD per se, not just with regards pain, and that therefore others always know more than themselves. In some cases the participants assigned greater knowledge to others than they necessarily held (see **You Know**). It also led to some bewilderment from participants about why the interviewer needed to ask them about their pain. Almost that she should already **Know** about it.

These beliefs about others **Knowing** more and oneself **Knowing** little if anything, are unhelpful when levels of perceived self-efficacy are known to be so important in the management of chronic pain. If others are seen as so **Knowledgeable** this can only lead to further hopelessness, despair and anger when hopes are not met.

These beliefs about **Knowing** appear linked to various issues. These include wider societal views about 'intelligence', the strong desire to be **Known** as a person, and/or to having had poor learning experiences about pain. These will be now be explored.

Societal Views

Beliefs associated with being less intelligent/ less able are not solely held by the individual participants but are socially constructed views. Our society highly rates people with good intellectual abilities, and by implication sees the less intelligent as less important. This links in closely with ideas of being taken **Seriously** (see later).

Secondly, society sees intelligence and knowledge as powerful commodities. Beliefs that they have no knowledge are likely to contribute to beliefs about having no **Power** to change the pain. Although not necessarily happening in a conscious way, but rather through not

recognising the pain as 'real', keeping information from these people in pain is reducing their Power.

Finally, it is often believed that because people with a LD are less 'intelligent', they are not able to, or do not need to understand experiences. This is linked to two further points. Ideas/beliefs about people not being able to experience things that they do not know about and therefore, ideas about it being better not to have information or education about pain.

These issues are related to the small but growing literature about grief/bereavement with people with LD. This work suggests that the view still widely held is that most people with LD do not understand death and therefore do not need to grieve, despite much evidence to the contrary (Oswin 1991, Cathcart 1995, Cochrane 1995). As Oswin notes, there is no evidence to suggest that people with a LD do not go through the same grieving process as those without a LD, although some may experience particular problems with grief/loss and may require specific help in the process (Cochrane 1995).

Much of this applies to the area of pain in LD as shown in this study, where participants report that there is a denial of the existence of pain at a 'normal' level, and where the reality of pain has to be 'proven'. The difficulties of making oneself 'heard' by others as shown in this category will be discussed later (see Desire to be Known).

In contrast with the view that people with LD do not need to know, is the participants beliefs about needing to Search for Answers. To deny information because it is believed that they do not need it, is condescending and sends further negative messages about their worth and Power (or lack of). In the LD and sexuality literature, Craft (1987) notes that the 'let sleeping dogs lie' policy usually fails because the dogs were not asleep in the first place! These people are experiencing pain whether others acknowledge it or not and their 'ignorance is not bliss'. The participants' incomplete understanding about pain may not be solely due to their cognitive level, but also to the lack of support to achieve understanding.

People are not always aware of having beliefs such as the ones outlined above, but these can be communicated to the people with LD, inform the way they are treated and their services developed (Baxter 1994). These participants have 'heard' (covertly and overtly) the views of them being less intelligent and therefore less important, often through their experiences and inferior treatment (see **Ridicule** and **Seriousness**). To varying degrees they have integrated these beliefs into their own belief systems. These affect how the participants cope with their pain.

Learning Through Experience.

The IASP (1986 - see Introduction) definition of pain includes a statement about learning about pain through personal experience. These participants Try to make sense of what is occurring and has occurred to them. They are not always helped in this task by others who do not Know or do not accept that this is a real problem to these people who have a LD (not taken **Seriously**).

Learning can also occur by observing and listening to others. This informal learning is often limited for people with LD, due to their communication problems, access to a narrow range of people, and difficulties discerning and accurately interpreting information gained in subtle ways (Schwab 1992). As already stated they need support in this.

Desire to be Known.

There is a strong need/ desire to be Known, understood, to have a sense of belonging (see **Comparison with Others in Knowing**). Maybe this enables people to feel reassured and safe, when the experience of pain is far from that.

Being Known requires being 'heard'. Its importance is emphasised by the participants' use of techniques to increase the likelihood of being 'heard' (eg Concreting), and proving the reality of their pain (to themselves and others) by showing **Another Place**. There are strong beliefs about receiving **Ridicule** if one shows pain or cannot prove its existence visually. This can lead to people not speaking out about their pain when they so want to. As a result, Staff/ carers do not always know that people are in pain or the extent of that pain, and they struggle on alone. Reasons for this will be discussed under **Seriousness**.

The people interviewed in this study were verbally able, and even when they did not have the appropriate vocabulary they could still describe their pain experiences in ways identifiable to the interviewer. If these people are not being 'heard', then it is likely that those with fewer communication skills encounter even more problems.

The need to be known may be linked to living in an impersonal life in a system where one is not really Known as an individual. The Comparison to Others subcategory, including ideas of Group Identity, is interesting as often people with LD are not seen as individuals but as groups. Their similarity to each other and difference to others (ie their LD) are frequently emphasised, rather than their individual characteristics. Services are provided based on similarities (ie same problems). Participants seemed to find the idea of being similar to others comforting, which maybe to do with a sense of belonging or familiarity.

Expectations.

Of great importance amongst these Pain Beliefs are the expectations. These appear in most categories and have a major influence on other beliefs. For example, the expectation of Complete Cures, how to 'behave' when in pain, or the Power of distant others. Or that of Pulling Through despite the prospect and experience of little change. The expectation that one 'Keeps Going'.

There are great expectations of 'normality'. In the category Blocked, this is in terms of what they should be able to do, what they should receive etc, and heavily influences their beliefs about being Blocked in these areas, and the resultant emotions such as Anger and Despair.

Expectations of 'normal' levels of Reliance, and 'normal' emotions (see Emotional Effects) are also evident. It could be speculated that the beliefs about 'normal' emotions are linked to beliefs that one should be happy and content, a throwback to wider societal beliefs about 'happy, smiling people with a LD'.

The participants mentally Struggle with the difference between the positions in which they believe they should be and the one in which they

find themselves (eg needing to **Get Rid** and not having an available **Way Out**).

These expectations are always individualised and must be assessed whilst being aware of the messages that people with a LD receive about not being 'normal' or the same as others, but **Different**. This also relates to **Searching for Answers** and beliefs about who they are and who they are like (**Knowing**)

Reliance

Regarding levels of **Reliance**, it is difficult to untangle how much **Reliance** pre-existed the pain problem (although for some, pain has been a life long problem); what is related to needing help because of the pain, and help because of having a LD.

Reliance differs from **Power**, as shown by despair and hopelessness arising when the person upon whom one is **Reliant** is believed not to have any **Power**. This again stresses the importance of understanding the complex interactions and links between various pain beliefs.

Power.

This study has shown that it is vital to find out where the individual believes the **Power** to lie, as distinct from on whom they **Rely**. Given the position of people with LD in our society, it is hardly surprising that these participants believed that they have no/little **Power**. However, it is more surprising that many believed that their close carers have so little **Power**.

Beliefs about **Power** have massive implications for any interventions for pain, which in part aim to increase the individual's beliefs about being in control of or having power to control the pain.

However, **Power** is not necessarily available to these individuals. It is not simply a case of encouraging them to take more control of their pain experience and management, for the systems in which they live often only enable certain others to have **Power**. Participants see that this sometimes does not include close others as well as themselves.

Being 'given' **Power** will require a large systemic shift and not just an individual one. This requires some people to let go of **Power** so that participants and close others can have more. As will be discussed later, people will then need support to take more control over their lives, this will not happen automatically. These are complex issues that this project has only touched upon, and in which further research is urgently needed. One way to do this is to begin to 'hear' the views and beliefs of these people, as in this, and increasingly more studies with people with LD.

Seriousness.

Looking at their experiences (see **Ridicule**), finding themselves **Blocked**, **Powerless** etc and the wider messages about being 'less important' (see above), it can be easily seen where the themes and beliefs about being taken **Seriously** (or not) have developed. However, being taken **Seriously** is of immense psychological importance to these participants, in the sense of reducing their psychological distress and influencing beliefs about helping them to manage their **Intense** pain.

However, others can respond as if their experience is trivial and does not matter. Giving further messages that they do not matter. Although these beliefs are not unique to the participants in this study, or to people with a LD, these participants experienced more extreme examples of **Ridicule** and not being taken **Seriously** than would be expected. This has resulted in these beliefs being more influential and important to these participants.

The desire to be 'heard' and the difficulties ensuring this, have already been described (in **Knowing**). This reflects responses to any subject matter that is **Serious** and difficult to 'hear' (for example Sexual Abuse). It is easier not to acknowledge its existence, than face the issues. In addition it is hard to 'hear' and take the pain **Seriously** if one does not know what to do to change the situation. This is illustrated by close others repeatedly Trying the same ineffective **Coping Strategies** (see dimension - Trial and Error). They need to be doing something, but do not have any ideas for alternative strategies.

The grief and LD literature suggests further reasons for not being taken **Seriously**. With respect to grief, Oswin (1991) stated that the reactions of people with a LD are not always recognised as 'normal' either because of

staff misunderstanding or because staff always concentrate on the 'abnormalities' of people with a LD, and not the 'normalities'. Conboy-Hill (1992) argues that on some level, people without a LD need to 'ignore' the pain of those with a LD. She says this is because if we saw people with LDs as having effective or the same "emotional apparatus" as others, it would become increasingly difficult to justify their barren lifestyles. These points are also likely to be relevant for the experience of physical pain for people with LD.

Linked to this theme of 'seeing/hearing' pain, has to be the difficulty encountered trying to find participants for this study. Despite intensive and wide ranging contact with health and social professionals working within LD services, only a small number of participants could be identified. As many people with LD have contact with these services, and for many this would be ongoing given their chronic conditions causing the pain, one would expect to find participants readily. Contact with the LD register entailed trawling for participants with chronic conditions usually causing pain.

This leaves two possibilities. Either this study has identified a unique group of people with LD who experience chronic pain and their experiences do not reflect those of other people. That others are, as Biersdorff (1994) would suggest, 'indifferent' or 'insensitive' to the pain. Or, that other people have similar experiences but are being made 'invisible' either by not being 'heard' or attributed to different causes. These questions are vital for the evaluation of this study and the importance of it's findings.

Anecdotal information gathered during the research process can add to this discussion. One physician remarked that he "did not routinely ask people (with LD) whether they are in their pain" during physical examinations. As seen in the **Ridicule** category some participants have given up telling people they are in pain. It could be questioned how widespread this response is for people with LD - a form of Learned Helplessness - because close and distant others do not hear their distress. The mother of participant 5 concluded that her daughter was not in pain because she did not complain about it. However, as shown (see **Ridicule**) participant 5 has given up complaining due to **Ridicule**. This compares to the child pain literature,

where it used to be believed that children could not be in pain if they did not 'show' signs of it, for example continuing to play.

Other people attributed pain report/behaviours to reasons other than pain. For example, one contacted member of staff questioned how the interviewer could distinguish who had 'real' pain from those who were complaining to get 'attention'. This idea of 'attention-seeking' is unfortunately still widely used to explain some behaviours of people with LD. Attention seeking behaviour is generally ignored or punished by staff groups, the complete opposite of what is needed according to these participants. The use of behaviours to gain 'attention' does of course exist, but where it does exist one has to ask why people with the ability to do so, cannot address the problem more directly? Is it that a more direct approach would not be 'heard'?

It is often the case that people who use such approaches to get the attention they need, respond to being ignored by increasing the frequency/intensity of behaviours. It could therefore be the case that there are people who are unconsciously 'becoming' more disabled to be 'heard' or taken seriously. (ie the worse I am the more likely to be taken seriously). This over-emphasis on the negative aspects of the pain is called Catastrophising in the adult/child literature and is associated with poor outcomes.

Different

Throughout the categories there were expectations of **Difference**. The participants were extremely dissatisfied and wanted their lives and pain to change. However, they had difficulty describing what this **Difference** would entail. Any stated **Difference** was limited to one activity, something the participant did not want to do or something they already did.

There are various reasons why this may be the case. Maybe because they find it difficult to put themselves in a place other than where they are. For some this may be due to never having known anything **Different**, having had pain since childhood. May be this is because they have learnt to 'accept one's lot', not to think about how life could be different.

In this study, many beliefs emerged about there being 'no choice'. This is especially expressed in **Pulling Through**, where the message of 'getting on

with it' is very strong. This may also be linked to not being 'heard' by others (see **Seriousness**), not being seen as able enough to experience pain (see **Knowing**); you just 'get on with it'.

For many adults without LD it is the disruptive effects of pain on their lives that are especially difficult to cope with. Perhaps it isn't that people with LD have less pain, but that it effects them less due to their poorer quality of life. (ie few have jobs and many lead sedentary lifestyles). This is likely to be especially true for those who are less physically independent and have less movement. It may be that the person may be less 'effected' (in the usual sense of independence, movement and Quality of Life) although not necessarily experience less pain.

Again these beliefs are closely linked to beliefs about oneself as someone with a LD. One's **Difference** to others has been labelled (eg LD, Mentally Handicapped etc) and emphasised throughout one's life (eg segregation).

CLINICAL IMPLICATIONS.

There are numerous clinical implications arising from this study. They exist at a number of different levels, including direct service provision for people with LD in pain and their carers, and the implication of others' views about pain for people with LD.

Direct Interventions.

This study has identified that people with mild/moderate LD do experience chronic pain and that pain beliefs, coping strategies and interactions between these have a major influence in this experience. Given the effectiveness of psychological interventions for chronic pain (see Introduction), these should be available to people with a LD.

The categories and their interconnections (see diagram) suggest where problems can arise in the thought processes which mediate chronic pain, for these people. Identifying difficulties or 'weak links' could improve coping with chronic pain.

From the identified pain beliefs here, the importance of information and education can not be underestimated. People need to be supported in their **Search for Answers**. It is known that gross misconceptions (associated with poor understanding) can lead to increased distress (anxiety, despair), which in turn can lead to increased pain through increased tension (see Bush (1987) Introduction in Child section). This information sharing should not be limited to 'formal' education, as many 'informal' opportunities arise in everyday situations in which issues about pain could be discussed to aid understanding.

Of great importance will be to explore pain beliefs and their dimensions with individuals in pain, to reduce the negative effects that are known to be associated with certain beliefs. Expectations (eg of 'normality' 'complete cures') play a prominent role in this study, and these need to be realistic to avoid increased distress and increase feelings of control and predictability. It is vital however, that each individual's beliefs are assessed, and that people with a LD are not treated as a homogenous group.

There is a great need to increase the variety of **Coping Strategies** used, given the limited range expressed by these participants. It has been found that having many different strategies for flexibly coping with pain and accurate information at an appropriate level leads to more successful coping with chronic pain (Peterson and Toler 1986). Psychological interventions could easily provide more alternatives.

The participants' repeated efforts to Try to reduce the pain itself or it's impact on their lives have to be marvelled at, in the light of their experiences. This could be harnessed in interventions.

Issues effecting Interventions

Issues identified in this study are likely to have an impact on the success of direct work with people with LD in pain, and must therefore be carefully considered.

It will be controversial and foreign (including to themselves) to suggest that despite their difficulties, the participants are the experts on the pain that

they are experiencing. This will need to be addressed when beginning any interventions.

With regards developing new **Coping Strategies**, the dimensions of who should suggest these, expectations on how one should 'cope' and the level of success the person expects, and connecting beliefs such as belief in a **Way Out**, need to be explored.

Often work with people with LD involves their immediate carers as 'initiators' of interventions, and therefore the person's beliefs about the **Power** of close others needs to be considered. Beliefs that distant others are powerful may enable new suggestions to be accepted, but this is not necessarily helpful on a daily basis if close others are involved in supporting the person to implement interventions. Issues about 'moving' the locus of **Power** will be discussed later.

The importance of **group identity** and expectations of who can understand you, how one should behave, cope and what the experience will be like, as learnt from other people, cannot be underestimated. This will be especially relevant if interventions promote ideas that are significantly different to the person's 'models'. Any individual interventions must take account of the individuals or groups beliefs about the groups they belong to. This may enable fruitful group work.

Literature and clinical work on issues of sexuality and people with LD has found that discussing issues, being 'heard' and lifting restrictions on developing sexuality, only go part of the way to aiding development of less difficulties with sexuality (eg Craft and Brown 1994). Changing systems is not enough in itself to encourage people who have experiences and have been damaged by the past system to grasp new opportunities and benefits offered. People with LD need proactive support to move into previously inexperienced areas.

The same is likely to be true for being able to report pain and expect it to be taken **Seriously**, and for the issue of being giving more control and **Power** over their lives. As seen in the categories most participants did not expect to hold power themselves and making this available does not mean that they will embrace opportunities easily.

It is important to maintain a balance between treating people as individuals, whilst accounting for the role of the wider system and the restrictions this could place on any direct interventions.

For example, when **Power** is not seen as available by participants, one has to question how effective individual interventions can be, as this is vital for successful interventions (see Introduction). The problem is not as simple as enabling participants to 'take' **Power** (see above). There are complex issues including how to give **Power** back to people with a LD, and whether they would want it. This must be developed on an individual level according to the persons needs and wishes.

Similarly, interventions encouraging people to try new **Coping Strategies** and change some 'negative' pain beliefs are likely to be ineffective in systems not recognising pain as a serious problem and not supporting people to change their experience of pain.

Work with Staff/Carers and systems.

A very strong theme in this study is the importance of being 'heard' and taken **Seriously**, and that this does not happen. The situation for some of these participants is that if one does not complain one can not in pain, if one reports pain and can not 'prove' it, one will not be 'heard' or may even be ridiculed, and/or if you 'show' pain it may be reinterpreted as something else, or the difficulties brushed over. Reasons for this have been explored in depth. Links between **Knowledge**, **Seriousness** and **Power** have also been discussed.

Information and education will be needed for staff and carers to enable them to 'hear' that people with LD are in, and can experience pain, and that this needs to be treated **Seriously**. Understanding and accepting that one may be 'blinded/ deafened' to this by the factors discussed above, will be difficult, but is vital for the realisation that these have stopped us truly 'hearing' about the pain of people with LD. This alone is likely to reduce distress levels as being 'heard' is so important. However, 'allowing' people with LD to have pain, requires a shift in people's beliefs (as in grief and sexuality work) this is likely to be a slow process.

As described above, the change of systems and beliefs of others will not be enough to change some of the beliefs that these participants expressed here, that are associated with negative outcomes. This will require proactive work and continued support for people with LD and their carers.

EVALUATION OF THIS STUDY.

This section will include points about the reliability, generalisability and reproducibility/ replicability of this study. It will also consider the difficulties encountered with the methodology used both in this study and with people with a LD. The effects of various aspects of the research process on the quality of the data will be reflected upon.

As discussed in the Introduction, it is questionable whether research using Qualitative approaches can be evaluated in the same way as Quantitative research. However, this does not mean that issues of reliability, generalisability and replicability are any less important, just different.

For example, reliability in Qualitative work is not a deviation from an objective reality, but the true representation of the views and meanings of the participants.

Issues of Generalisability also differ for Grounded Theory approaches which specify conditions giving rise to a specific set of actions/interactions related to the phenomenon studied and which results in certain consequences. Therefore, they tend to generalise to these identified situations only. However, the more systematic the theoretical sampling (ie the more conditions and variations built into the theory) the greater the generalisability. Strauss and Corbin (1990) stated that any variations found in subsequent research can be added as amendments to the original formulations.

Issues of replicability/reproducibility are complex, reflecting the complex psycho-social phenomenon studied here. Although finding an exact match for this study would be difficult, the major conditions may be similar in another study. Given the same theoretical perspective of the original researcher, the same general type of data and analysis process, and a similar set of conditions, one should get the same explanations for a phenomenon (Strauss and Corbin 1990).

Strauss and Corbin (1990) suggest additional ways to produce a good Grounded Research study. These include generating conceptually dense categories, linking concepts and categories together systematically (in terms of the Paradigm Model - see Methodology); ensuring variations in the theory; building into the explanation the broader conditions affecting the phenomenon; and producing significant theoretical findings.

These criterion should be used to evaluate this study by the reader, but will also be considered here.

To achieve a reliable and true representation of the views and meanings of the participants in this study, the researcher repeatedly returned to the original data to check all developing themes and connections. Every effort was made to ensure that saturation (see Methodology) was achieved, and that therefore no concepts were missed. All concepts and categories (including dimensions, properties and connections) are clearly described and illustrated by appropriate quotations. These are systematically linked in terms of the Paradigm Model. The wider conditions affecting the phenomenon and variations are built into the theory.

At various stages in the research process, these were also rated for their 'goodness of fit' by the research supervisor. Pre-existing assumptions are stated so that the reader can judge the part played by the researchers own beliefs. All procedures are clearly described so that their thoroughness and appropriateness can be assessed.

Reflection on the Effects of the Research Process/Design.

There are various points from the research process and design which influence the evaluation of the quality and reliability of this study.

Interviewing people with a LD.

The flexibility of the interview style of this approach allowed participants responses to be followed up, either by asking further questions or questions being rephrased or prompted. This encouraged further description and therefore a more complete account, helped the interviewer check for consistency of responses, ensured that she understood what the participant meant, and that the participant had grasped the intended

meaning of the interviewer's questions. Every effort was taken to ensure that no assumptions were made, with all noted ambiguities followed up. However, when transcribing and analysing the data, ambiguities in meaning emerged that had not been noted during the interview. Data analysis procedures (some of which are described in the Methodology section) helped the interviewer to discover the participants meanings, wherever possible.

The flexibility of this approach was vital with this participant group, who frequently had some difficulty understanding questions, had numerous sensory problems (especially deafness) and/or difficulties with concentration. However, it was sometimes difficult to tell whether the participant had not understood the question, did not wish to answer it or had simply not heard it.

Difficulties were also encountered trying to balance the importance of a flexible discussion guided by the participants, with the short attention spans of, and novel experience of in-depth discussions for some participants. At times this led the interviewer to feel that she was too directive, as she tried to keep the participant on the topic under discussion. Or, that she had misjudged the pace at which the participants were thinking, despite aiming to appropriately pace discussions and avoid multi-part questions. This was shown, for example, when after a long pause the interviewer changed topic, but the participant continued to discuss the preceding topic about which she was still thinking. Leading to confusion on the interviewers part!

Participants had difficulties understanding some concepts in the questions asked. For example, many took the word 'How', when used in a sentence such as "How does the pain effect you?", to mean 'How much' and would respond "a lot". Awareness of these difficulties however, ensured that their influence could be considered during the analysis.

These difficulties were further complicated by the importance of having someone come specifically to visit them. The novelty of this event for many people with a LD should not be underestimated. Understandably, this resulted in some participants wanting to discuss many areas of their life with the interviewer (from holidays to housing problems). This is likely

to also be connected to having someone listen to them and take them Seriously. In addition, was the novelty of being asked directly about their experiences and about an abstract topic such as pain.

Some participants were confused about why they were being consulted, and, as noted in the Methodology section, there were issues about valid consent being attained despite significant efforts to do so. These centred around some participants seeing the researcher as a clinician who would help with the pain. Despite verbal statements about the distinction between these roles, made by both the researcher and earlier by the health/social care professional who initially discussed the study with the participants, the boundaries were obviously not clear to some of the participants. This is demonstrated in the pleadings of participant six.

Although these difficulties about role boundaries and the difference between clinician and researcher exists to some extent in most clinical research, it is worth noting that this seemed more pronounced with those people with a LD who have difficulty with role boundaries in more general terms. For example, between friends and staff at day centres or hostels.

Given these varied complications and the importance of truly representing the views and meanings of the participants an important suggestion for future research (with a longer time scale) would be to have repeated visits to the participants. This would serve a variety of purposes. It would enable the interviewer to better understand the person's language and frame of reference, and better judge their 'pace'. It would reduce the 'novelty' factor of a visitor, and give opportunity to discuss other important parts of the person's life, given the importance of being taken Seriously. A deeper relationship may enable the participant to tell the interviewer more. This may not be unique to people with a LD, but being Known has been shown as an important theme to these participants. Repeated visits may not help people with short spans of attention to focus for longer, but would give opportunity to do an interview in smaller chunks. It would also enable the purpose of the discussions to be more fully explored with the participants.

Some issues of generalisability and replicability (ie whether this study has identified a unique group of people with LD with chronic pain) have been

discussed above (see Seriously). The points raised there, and the prominence of beliefs about not being 'heard' or taken Seriously suggest that these people are not alone, and that these research findings would therefore be relevant for people in similar situations. As the theoretical sampling has been systematic in this study (clearly including wider conditions and variations) then the findings are likely to have good generalisability. However, this is an initial study in this area and further work is essential.

Other Reflections on the Research Process.

Many ways that quality data and analysis have been ensured have already been discussed. It is difficult to write up such a cyclical and complex research process and integrate all ideas succinctly. This has been achieved according to the Paradigm model, although the connections 'developed' and 'emerged' according to this model during the analysis, rather than the model shaping the categories and their connections. It has been difficult to develop one 'Core category', with the final four categories (Power, Seriousness, Difference and Struggle) relating to all previous categories. However, Struggle is the category that runs through this data most clearly (as described in the Account).

Issues about conducting this research are likely to have some bearing on the findings. Especially relevant is that this is a sensitive area, developing a new framework, in terms of asking people with LDs themselves for their views, the topic of pain with LD, and using a Qualitative approach. This forms part of the context for this study alongside details of the participants' situations and the researchers assumptions (already described). The implications of this are shown in the difficulties recruiting participants. It's influence is also shown in the interviewer's nervousness at feeding back the findings of the study to people with LD services. A feeling of breaking new ground.

Finally, an idea at the beginning of this project (following the example of previous research - see Introduction) was to develop a list of pain cognitions and coping strategies relevant for people with LD. However, it is deemed inappropriate to do so, as this would remove all the connections and processes between the beliefs, shown to be so important. In addition, it is questionable how much use such a measure would currently be,

when people are having difficulty accepting that some people with LD have pain.

FUTURE DIRECTIONS FOR RESEARCH.

The findings of this study suggest a need for further research on three different levels. Firstly, further study of the categories shown here to influence and shape the pain beliefs of these people (eg levels of dependency, issues of being taken Seriously, seen as Different (eg sense of self), but which are likely to also effect other areas of their lives and are linked to, and influenced by to having a LD. Therefore these areas need to be specifically studied with the LD population.

Secondly, further research to develop the pain beliefs (their dimensions, properties and connections) and coping strategies identified here. The generalisability of the findings of this study is discussed above. Further studies will be needed to deepen the theory developed here by adding further conditions and variations.

Finally, it is suggested here that direct interventions for pain should be available for people with LD. This study has shown how differences related to LD can change the pain beliefs and the experience of pain for these participants. Therefore, directly applying interventions developed for children/ adults without LDs, without modifications, is inappropriate and likely to be less effective. Further work will be needed to develop the clinical implications raised here, into more structured assessments and interventions for people with LD.

CONCLUSIONS

In the adult/child literatures, the importance of specific pain beliefs and coping strategies in the experience of chronic pain has been emphasised. A thorough understanding of which beliefs and coping strategies lead to maladjustment and distress, and how this occurs, is vital for effecting change.

There are some differences between the pain beliefs and coping strategies of children and adults, (which seems to be linked to wider issues, such as level of independence), and between people with different pain related illnesses. Differences between populations must therefore be established and recognised, in research into chronic pain.

This study aimed to identify the pain beliefs and coping strategies of people with mild/moderate LDs, to compare these with the existing literature, and discuss any differences and clinical implications.

The identification in this study of a variety of pain beliefs and coping strategies with these people with LD, is important in itself. Especially given the suggestion that people with LD have very different experiences of pain to people without LD (ie are insensitive/indifferent to pain Biersdorff 1994), and the paucity of both research and clinical interventions for people with LD who are in pain.

Some of the pain beliefs/coping strategies identified in this study are similar to those in the adult/child literatures. However, the wider context is very different for these participants and this has a major impact on the beliefs and any resulting interventions. The importance of the dimensions of the beliefs, the connections between these beliefs, and the impact of these on any interventions, has also been emphasised.

This study concludes with reflection on the research process and suggestions for the direction of future research.

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APPENDIX 1.

INTERVIEW GUIDE.

Encourage free description of the experience of pain from the participants.
Use questions as 'prompts' to gain a fuller picture or clarify answers.
Do not re-cover an area already fully discussed.
Adapt question wording to the participants' vocabulary and level of ability.

- Introductory questions to focus participants on to topic of pain.

eg

- Can you tell me what pain is ?
- Can you tell me what pain is like?
- Can you tell me what happens in your body when you have pain?

- CAUSATION/ IDENTITY.

Can you tell me what (you think) causes pain?

Why do you think you have pain?

What do you think caused/ causes your pain?

Why do you think this happened to you?

- BELIEFS ABOUT DURATION OF PAIN.

How long have you had pain?

Has it ever stopped?

Why do you think it stopped?

Do you think it will ever stop?

- EFFECTS.

How does the pain affect you/your life?

Can you tell me what the pain stops you from doing?

Are there things that you don't do if you feel pain?

Would you do that if you didn't feel pain?

What would/did you do if/when the pain stopped?

Can you tell me how the pain makes you feel (inside)?

Can you tell me what you think about/ what goes through you mind (when in pain)?

- COPING STRATEGIES.

Do you think that you can stop pain from happening?

Have you found ways to make the pain hurt less?

- Can you tell me about them?

CURRENT.

Do you do anything to try and make the pain better?

Do you do anything to try and make the pain go away?

Can you tell me what you do?

(If responses given ask) - Does that help the pain to go away?

What helps the most?

POTENTIAL.

What could you do to make the pain better/go away/stop?

What could/would make the pain better?

What would/ could make the pain go away?

OTHER PEOPLE.

Do other people do anything to make the pain better/go away/ stop?

Can you tell me what they do?

Would it have helped if they did do something?

What would you want them to do?

If participants have difficulty focusing on their experience of pain, or the topic seems to 'abstract', use:-

- 1) The 'Worst Pain Ever' - ie) ask them to remember their 'worst pain ever' and to remember details about this experience. Start discussions from here.
- And/or 2) Outline of human body to mark on location of pain, and start discussion from here (see Appendix 2)