FACTORS ASSOCIATED WITH CHANGE ON A COGNITIVE-BEHAVIOURAL CHRONIC PAIN MANAGEMENT PROGRAMME

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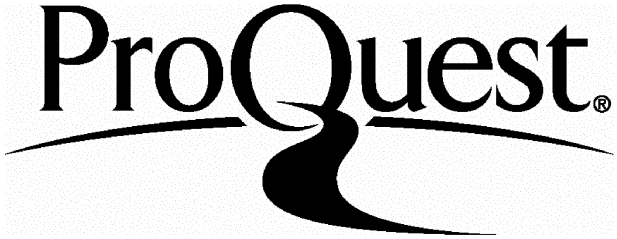

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ABSTRACT

A significant amount of research has been undertaken world-wide that demonstrates the efficacy of Pain Management Programmes in achieving their stated aims. There seems however to be a dearth of information about the processes by which beneficial change in pain management terms is achieved. This project aims to explore people's experience of change as the result of attending a Pain Management Programme.

A study will be presented which investigates outcomes from five consecutive groups of an established Pain Management Programme to determine mutative moments in the programme. Thirty patients were interviewed and data was analysed using a task analysis approach. Patients also completed standardised questionnaires as objective measures of change and these were compared with their personal reports. It was hypothesised that a relationship might exist between objective improvement as a result of participating in a Pain Management Programme and patients' capacity to reflect on and articulate "key moments" of change during the Programme. Evidence from the study supports this hypothesis.

It is suggested that findings from this study might enhance existing understanding about when and how change occurs within individuals during participation in a Pain Management Programme. These findings might be used to facilitate/enhance positive change for future groups of patients attending Pain Management Programmes.

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1. INTRODUCTION

Two major approaches to the assessment and treatment of chronic pain have evolved over the past 35 years. The behavioural approach (Fordyce, 1976) was based on operant-conditioning principles. The aim was to modify so-called "pain behaviours" which were considered maladaptive, for example, excessive dependence on rest, family members and/or medications. This was achieved by analysing and attempting to change the social and environmental contingencies considered to be reinforcing these behaviours. Recognition of the need to integrate a cognitive component into such programmes followed, based on contemporary theoretical developments in cognitive and behavioural therapies (Turk, Meichenbaum & Genest, 1983). Cognitive-behaviour therapy was designed to teach patients about the relationship between pain and cognitive, affective and physiological variables in order to help them re-conceptualise their ability to control pain. This approach also aims to teach patients skills in order to help them change the way they cope with their pain.

Cognitive and behavioural-based treatments for the management of chronic pain, including group pain management programmes (PMPs), have proliferated on a world - wide scale. An extensive international literature now exists demonstrating the efficacy of PMPs based on cognitive-behavioural principles with significant contributions from America, Canada, Australia, New Zealand and in Europe, particularly from the UK, the Netherlands and Sweden. Cognitive-Behavioural Pain Management Programmes have become an established method of attempting to help people with persistent pain for whom medical intervention has proved ineffective.

This introduction aims to explore:

1.What constitutes a "pain management programme"?
2. Components/elements of a pain management programme, including some empirical evidence.
3. Relevant research demonstrating efficacy of this approach and limitations of existing research with regard to understanding how change occurs on an individual basis.
4. Background to the current study.

A study will then be presented which investigates outcomes from five consecutive groups of an established PMP to determine mutative moments in the programme. Thirty patients were interviewed and data were analysed using a task analysis approach. These personal reports were compared with valid and reliable questionnaires as objective measures of change. It is suggested that findings from this study might enhance existing understanding about when and how change occurs within individuals during participation in a PMP and that these findings might be used to facilitate/enhance positive change for future group members.

1.1 **What constitutes a pain management programme (PMP)?**

Within the UK, there are currently 71 Pain Management Programmes (PMPs), (Johnson, 2002). Precise information is not available but a percentage of these programmes offer interventions for people with chronic pain provided by a multidisciplinary team and conducted within a group setting. The remaining programmes offer a range of treatment options on an individual basis. The Pain Management Programmes Special Interest Group within the Pain Society of Great Britain and Ireland has suggested that there are certain desirable criteria that constitute a Pain Management Programme (Seers, Williams, Richardson & Collett, 1997). In order to be correctly termed a Pain Management Programme, a mix of professionals providing input to the programme is required. The minimum combination requires a medical pain management specialist (usually a specialist anaesthetist or rheumatologist), a psychologist with experience of applying cognitive-behavioural techniques to the management of chronic health problems and a specialist physiotherapist. Larger teams usually incorporate nurse specialists and, frequently, specialist occupational therapists.

1.2 **Components/elements of a pain management programme (PMP)**

i) Assessment including readiness to change

In principle, people with chronic pain are only referred to PMPs once thorough medical investigation and treatment are considered complete. This is because participation in a PMP requires an acceptance on the part of the patient that further

medical intervention is not considered appropriate at the present time and may even be considered detrimental. Assessment for a PMP includes presenting the patient with an alternative model for thinking about their pain and introducing the concept of self-management, often the first time the patient will have contemplated this radical departure from their frequently prolonged "search for a cure". It has been widely hypothesised that chronic pain patients' readiness (Prochaska & DiClemente, 1983; Prochaska & DiClemente, 1984) for a self-management approach will impact on their successful engagement in cognitive-behavioural pain management treatment (e.g.Kerns et al, 1997). During assessment for a PMP,`a patient's readiness for change is explored carefully, by experienced questioning, by standardised questionnaire (e.g. Kerns et al, 1997) or both. The assessor will be attempting to determine whether the patient has any specific and realistic goals in relation to pain management and if they do, whether they have any ideas about how to achieve these. The process of change is likely to begin during the assessment interview.

ii) Psycho-education

The importance of educational aspects of a PMP cannot be over-emphasised since the mission of the PMP revolves around imparting information that will help initiate change. Other variables of the group experience are discussed below because of their significance in facilitating this process. Information is however central to the process, as is the way in which it is taught to patients. This is one of the ways in which psycho-educational groups such as PMPs differ significantly from psychotherapy groups. Information about the nature of chronic pain, about pain mechanisms, some basic anatomy and physiology, including muscles and joints, and about healing are absolutely essential for the patient with chronic pain. These would all be regarded as likely to facilitate the patient in beginning to make sense of pain that may previously have been seen as a mystery. Simple information may have been given in medical interviews but typically patients will not have grasped or retained much, if any, of this (Ley, 1988). Feedback from patients following such information-giving sessions is frequently along the lines of "if only I had known this before..." suggesting lack of adequate information has undoubtedly compounded an already difficult situation.

Information that helps patients to break the mental association between chronic pain and damage, usually responsible for the development of many problems, including fear, associated disuse and consequent de-conditioning, seems to be of particular significance. When patients can identify themselves with what is being presented (for example in discussions about "overdoing" and subsequent increases in pain), they begin to engage more fully in the process of change. Discussions about, for example the consequences of pain in practical terms, help them to identify the PMP as relevant to them. They also contribute to a sense of universality and group cohesiveness, as will be discussed more fully below.

Information about pain medication, including strategies for systematic reduction of pain medication would be involved within this remit. (Ralphs et al, 1994). Education about the cognitive and affective aspects of the experience of chronic pain aim to help patients understand their experience within the biopsychosocial context, preparing the way for specific sessions on cognitive restructuring. It seems likely that information may be the stimulus for change but that the process will not progress in the same way without the facilitating conditions which group membership seems to offer. Again, this will be elaborated below, especially in discussing the role of the group.

iii) Overcoming the effects of de-conditioning (loss of fitness) using a graded stretch and exercise programme. Overcoming pain-related fear and avoidance.

Patients on PMPs usually accept the rationale for incorporating the exercise and stretch component since they readily acknowledge an association between chronic pain and loss of fitness and flexibility. The degree to which they are fearful of movement is often underestimated however and this can significantly limit a patient's progress unless it is identified and tackled early on in the Programme. Kori, Miller and Todd (1990) introduced the term "kinisophobia" to describe the condition in which a patient experiences "an excessive, irrational and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or reinjury". These researchers developed the Tampa Scale of Kinisophobia (TSK) in order to quantify excessive fear of movement/(re)injury. Wynne and Newton-John (2002) administered the TSK to 100 patients following their referral for specialised chronic pain physiotherapy. They found that 56% scored 41 or above on

the scale, demonstrating extreme levels of fear associated with movement and exercise. This suggests that a chronic pain exercise programme is likely to prove threatening to at least half the patients referred for this approach and that specific fears need to be identified and tackled, using a combination of information/education (as above) and specific techniques (see below).

Using the TSK, Vlaeyen et al. (1995) observed that fear of movement/(re)injury was a better predictor for self-reported disability than biomedical signs/symptoms and pain severity. There are evidently many ways in which pain-related fear mediates disability (Vlaeyen et al.,1995; Crombez et al., 1998a). At its most straight forward, fear instigates avoidance behaviour by prompting an escape response from the threat. Hence avoidance of daily activities expected to produce pain leads to greater disability. Since avoidance occurs in anticipation of pain rather than in response to it, avoidance may persist because of reduced opportunities to correct the (wrongful) expectations and beliefs about pain as a function of physical activity (Crombez et al., 1999). Fear of pain also interferes with cognitive functioning. Several studies have demonstrated that fearful patients are more vigilant regarding possible signs of threat and are less easily distracted from pain-related information (Pearce and Morley, 1989; Asmundson et al., 1997; Eccleston et al., 1997;Crombez et al., 1998b). For the chronic pain patient therefore, anxious thoughts and avoidance result in anxious behaviour, ineffective behaviour, de-conditioning, a cycle of inactivity and depression.

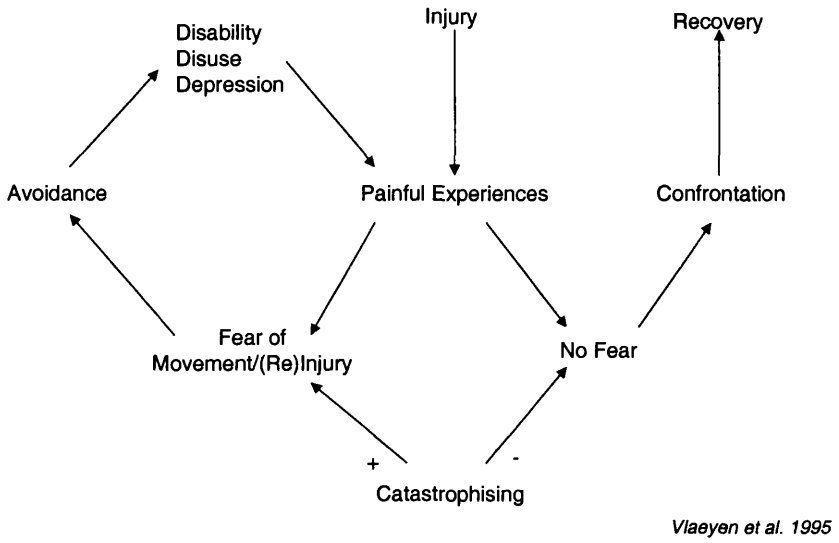
According to McCracken (2002), the avoidance response is not just about fear or pain or embarrassment in isolation but involves a complex web of relationships. Further the circumstances that put avoidant behaviour in place may not be what maintain it. The development and, possibly, maintenance of avoidance of chronic pain may be the direct result of conditioning, whereby a neutral stimulus can come to elicit fear. Social, verbal and emotional processes are also involved however and these may be occurring at a non-conscious level. McCracken (2002) has used the term "pseudo social phobia" to describe behaviour motivated by the wish to avoid embarrassment and potential criticism in social circumstances in the context of pain. Similarly, "pseudo agoraphobia" relates to an avoidant pain sufferer's behaviour when they have become sensitised to a situation where safety, help or escape are not readily available. McCracken suggests that much of the avoidance that pain patients show may function to prevent distressing emotional states that these

patients find threatening. He suggests that exposure therapy may be an appropriate treatment for avoidant behaviour.

Vlaeyen et al., (1995), have refined the cognitive behavioural model proposed by Lethem et al., (1983) to expand on the relationship between pain and disability. If pain (which may or may not be caused by an injury) is interpreted as threatening (pain catastrophising), pain-related fear develops. Negative affectivity and threatening illness information are assumed to contribute to this. Pain-related fear leads to avoidance behaviours, and hypervigilance to bodily sensations. Disability and disuse follow, together with depression that maintains the pain experience. The pain experience fuels the vicious circle of increasing fear and avoidance. If pain is not interpreted as threatening, fear and subsequent avoidance do not occur and patients are more likely to confront daily activities and resume normal functioning. This model may have a significant role to play in the transformation of an acute pain into the chronic pain syndrome (see figure 1).

Vlaeyen et al., (2001), examined the effectiveness of a graded exposure in vivo treatment with behavioural experiments, as compared to usual graded activity, in reducing pain-related fears, catastrophising and pain disability in patients with chronic low back pain who reported substantial fear of movement and (re)injury. The rationale for this was based on Bandura's (1977) supposition that "for a fearful patient, it is far more convincing to actually experience him/herself behaving differently than it is to be told that he/she is capable of behaving differently" (Vlaeyen and Linton, (2000), p.329). Graded exposure to the feared stimulus provides a unique way of challenging and correcting inaccurate predictions about the relationship between activities and damage/harm and, according to Davey, (1997), has been demonstrated to be the most effective treatment for individuals suffering from excessive fears and phobias.

Figure 1: Cognitive-Behavioural Model of Fear of Movement/(Re)Injury



Vlaeyen et al. 1995

Vlaeyen et al.,(2001) reported a replicated cross-over single-case design with four patients undergoing a behavioural rehabilitation programme. Two treatments were contrasted; a cognitive-behavioural graded exposure in vivo and a graded activity treatment. As part of their preliminary assessment, patients were shown the Photograph series of Daily Activities (PHODA; Kugler, Wijn, Geilen, de Jong & Vlaeyen, 1999) and asked to judge the threat value of each of 98 various physical movements from photographic representations of activities of daily life. A hierarchy of fear-eliciting movements and activities was thereby created for each individual. Patients were randomly assigned to one of two interventions: exposure followed by graded activity or the reverse order of treatments. Pain-related fear, pain catastrophising, pain control and pain disability were all recorded pre- and post-treatment. Pain-related cognitions and fears were recorded using visual analogue scales on a daily basis. Vlaeyen et al. used time series analysis on these daily measures and found that improvements only occurred during the graded exposure in vivo and not the graded activity, irrespective of treatment order. Comparison of the pre- and post-treatment differences revealed that decreases in pain-related fear corresponded with decreases in pain catastrophising and pain disability.

The findings of this study suggest that graded exposure has a considerable role to play in helping fearful and avoidant patients to overcome their fears through confrontation and reinterpretation of the threat associated with certain activities. They may hence be more readily able to resume their former levels of activity and escape the vicious circle of fear in which they have become enmeshed.

iv) Identification of patterns of behaviour and the development of pacing techniques in association with goal-setting.

Many people with chronic pain recognise an association between "over-activity" and increases in their experiences of pain. When this necessitates prolonged periods of rest in order to recover, the pattern is termed the "Overactivity/Underactivity Cycle". Patients are taught about the cycle as a rationale for adopting an alternative pattern of behaviour that is intended to limit pain "flare-ups". Some patients have deduced that they need to punctuate periods of activity with rest and/or changes of position if they are going to avoid significant increases in pain. Many people commencing a PMP do not however appreciate how low their tolerance to activity may have

become, due to overall loss of fitness, and hence that, for them, relatively short bursts of activity can constitute "overdoing". They are systematically taught to identify baseline tolerances to basic activities such as sitting, standing, walking and lying using a timer, thereby becoming increasingly aware of the need to change position more frequently than they are usually used to doing. They are also taught a method for systematic increase of these tolerances; the rationale given is that this becomes possible as a consequence of increased fitness.

A significant challenge for an individual in adopting pacing techniques frequently occurs at a cognitive level. Habits of thinking may need to be reviewed to permit the incorporation of what initially may be perceived as a "radical" approach. During a patient's initial psychological assessment it may be possible to identify some of their core beliefs (Blackburn & Davidson (1990); Teasdale & Barnard (1993)). Fairly typical examples of core beliefs might be variations on "I am only worthwhile if I complete all the tasks I set myself promptly" or "I am only tolerable if I put the needs of others before my own". A person with these kinds of core beliefs may struggle with the concept of pacing his/her activities for his/her personal benefit. They will need to develop alternative beliefs about self worth in the context of having a pain condition. This is discussed more fully in the next section.

Learning to pace activities systematically allows people to resume activities they may have considered impossible with chronic pain. Whilst perfecting pacing techniques, activities inevitably take longer to achieve and people need to tolerate a degree of frustration. However the experience of setting and achieving goals using pacing strategies contributes to increased self-efficacy, as measured by the Pain Self-Efficacy Questionnaire (Nicholas, 1990) and improved self-worth, (as measured by self-report).

v) Challenging unhelpful patterns of thinking and the significance of "the self"

According to Pincus & Morley (2001), "the cognitive-behavioural approach to chronic pain is based on several propositions (Keefe, Dunsmore & Burnett, 1992; Turk & Rudy, 1992), the central one being that an individual's emotions and behavioural activity in response to an event are influenced by the cognitive appraisal and interpretation of that event". Within the context of a PMP, cognitive appraisal and

interpretation are tackled both directly in sessions specifically devoted to cognitive restructuring and indirectly through a combination of informational input and as a consequence of behavioural experimentation.

An established body of empirical research has demonstrated significant associations between measures of pain beliefs and measures of functioning among patients with chronic pain (Jensen et al., 1991). In concurrent correlational studies, measures designed to assess pain-related beliefs have been shown to be associated with measures of psychological functioning (Boston et al., 1990;Vlaeyen et al., 1990), physical functioning (Flor et al., 1993; Vlaeyen et al., 1995), coping efforts (Jensen et al., 1987; Keefe & Williams, 1990), pain behaviour (Boston et al., 1990) and with pain treatment programme outcomes (Shutty and DeGood,1990).

A further area of interest for researchers has been in examining whether there is a relationship between changes in patients' beliefs and changes in their functioning. Flor et al., (1993), found that change in pain catastrophising scores was predictive of changes in activity level. Associations between reductions in pain-related catastrophic thinking, improved self efficacy, improved mood and improved physical functioning were reported by Williams et al, (1996). Changes in perceived ability to manage pain were found to be associated with changes in depression and pain for a group of arthritis patients (Stein et al., 1988). Changes in beliefs that pain signifies harm were associated with changes in depressive symptoms and physical functioning (Jensen et al., 1994). Jensen et al., (1999) recognised that a heavy reliance on patient self-report regarding patient beliefs was a limiting factor within this area of research. They set out to replicate and extend research on pain beliefs by examining their relationship to pain behaviours and functioning as measured not only by self-report but by spouse report and by assessment by trained observers. Within one study they first of all demonstrated a replication of previously found positive associations. These associations were between patient-reported physical and psychological dysfunction and pain behaviour and the beliefs that pain signals harm, that one is disabled and that solicitous responses from others are appropriate. (The latter had previously predicted the use of passive coping strategies such as rest (Jensen et al., 1987) and catastrophising (Strong et al., 1992)). They also showed an association between decreases in these three beliefs and decreases in patient physical and psychological dysfunction and pain behaviours over the course of a PMP. Interestingly, they found no consistent

evidence for the previously reported relationship (Jensen et al., 1994) between beliefs and function and level of intensity and/or duration of pain. Finally, they demonstrated that patient-rated beliefs were more strongly associated with patient-reported measures of functioning than with spouse-reported pain behaviours or with direct observational measures. Changes in the belief that pain signifies harm were however significantly associated with changes in observed pain behaviours over the period from pre-treatment to 6 months post-programme. Jensen et al. conclude that although their study cannot establish causal relationships, it may suggest some clinical applications for their findings. This is on the basis that interventions designed to modify maladaptive patient beliefs, for example that pain signals damage and that one is disabled, may lead to decreases in patient pain behaviour, physical disability and depression.

Specific sessions on PMPs are dedicated to teaching patients with chronic pain to identify and challenge unhelpful habits of thinking in relation to their experience of pain. Recognising in particular a tendency to "catastrophise" and learning ways of limiting this style of thinking is especially salient for this group of patients. Keefe, Brown, Wallston and Caldwell (1989) and Turner and Clancy (1986) amongst others have found that chronic pain patients with catastrophic thinking styles have been found to be more disabled and more depressed than other chronic pain patients. It is therefore extremely important for patients to learn to identify and tackle catastrophising and they need to be encouraged to continue to practice skills in challenging this potentially pernicious way of thinking. Coughlan, Ridout, Williams and Richardson (1995) demonstrated, with regard to inpatient treatment of chronic pain, that "frequency of catastrophic thoughts at one month follow-up was the best predictor of attrition from six month follow-up" (p.477).

The process of learning to challenge an internal dialogue of unhelpful thoughts and to limit catastrophising, inevitably occurs in conjunction with shifts in thinking prompted by other components of the programme. Particularly influential are educational sessions and those sessions focusing on enabling people with chronic pain to overcome pain-related fear and avoidance through behavioural experimentation, specifically exposure to feared movements and activities. Changing habits of thinking about pain and its consequences rely on the individual being able to acknowledge the existence of realistic alternatives. They are unlikely to make such changes until they have received information that is sufficiently

persuasive to make them do so. Sessions on PMPs are designed to complement each other in just such a way.

There is however a different way in which learning to identify unhelpful patterns of thinking can benefit a person who is attempting to make the shift towards self-management of their chronic pain. As above, individuals with core beliefs about strong relationships between self-worth and sustained goal achievement are quite likely to struggle with the concept of pacing their activities. People will need to learn to re-conceptualise themselves as having a pain condition that is manageable provided some behavioural changes are implemented but that this does not compromise their worth as a human being. By completing record sheets identifying thoughts and feelings in response to particular situations or events, individuals can begin to identify patterns in their responding. With help, they may be able to acknowledge problems with some of these, e.g. patterns of self-criticism, and with further help, possibly challenge some of these. Whilst core beliefs in particular are often difficult to modify, over time people are sometimes able to entertain alternative, realistic but more helpful beliefs which enable them to confront their pain problems more constructively.

Osbourne (2002) has highlighted the significance of "the self" in relation to the experience of chronic pain, describing chronic pain "as an assault on the self". "The self" has been variously described, for example, Bradley and Mathews, (1983): "an organised cognitive structure within long-term memory, which may incorporate both general trait-like information about the self, as well as specific behavioural episodes". Markus and Wurf, (1987) describe the self as "temporally dynamic, incorporating and shedding content across the life span". Pincus and Morley (2001) suggest that at the core of the self is an evaluative system, involving evaluation of thoughts, feelings and behaviour and thus generating a measure of what the self is worth. Osbourne (2002) suggests people with chronic pain may be living with an "unwanted self", a self that cannot be understood or controlled, or with a body separate from the self. This can lead to hostility and aggression and /or involve a huge effort on the part of the pain sufferer in order to keep experiences under control. As with other life events, it seems that pain has the capacity to disrupt aspects of the self at several levels. At its most problematic, where pain repeatedly interferes with an individual's major goals, this can impact on the self-schema and hence on the person's identity (Leventhal, Idler, and Leventhall, (1999). Pincus and

Morley (2001) note that persistent negative evaluation of the self, especially self-denigration, appears to be a central feature of cognitive theories of depression.

Pincus and Morley (2001) have developed the Schema Enmeshment Model of Pain that proposes the existence of three schemas, pain, illness and the self. Described very simply, some overlap between these three schemas is anticipated and regarded as healthy in coping terms. The particular aspects of a person's self-schema that are disrupted as a consequence of the experience of chronic pain will determine the focus of enmeshment and the cognitive and emotional consequences of it. A problem occurs where enmeshment exists between all three schemas, where pain and illness become incorporated into the self. Pincus and Morley make a distinction between negative affective distress and depression. Depression is characterised by a core sense of self-denigration and self-worthlessness and the belief that other people hold the same opinion of you that you do yourself (Beck, Rush, Shaw and Emery, 1979; Barton and Morley, 1999). Pincus and Morley suggest that the degree to which the chronically activated pain schema "traps" negative aspects of the self will determine whether the pain experience will be viewed more simply in terms of its sensory-intensity characteristics or, more problematically, in terms of its behavioural and affective implications for the self. These authors suggest that the degree to which the self-schema may be vulnerable may relate to whether or not individuals have experienced a depressive episode prior to the onset of pain, whether they are "cognitively vulnerable" prior to the onset of pain (Brown and Harris, 1978) though have never experienced a major depressive episode or, in a third subgroup of patients, no vulnerabilities have been established by prior adverse experiences. In this group, pain may still have the capacity to induce affective distress and may impact on the individual's identity, but does not significantly impact on the individual's sense of self-worth.

These distinctions have clinical significance in terms of how best to work with patients on the basis of the sub-group to which they might belong. Pincus and Morley (2001) suggest "it seems to be important to separate patients with chronic pain who are distressed about the situational constraints consequent to the pain from those who have the additional burden of believing that the negative consequences of pain mean that they are fundamentally flawed and worthless". It should be possible to make the necessary distinctions during a thorough psychological assessment involving taking a detailed personal history prior to

formulating a treatment plan. It seems likely that "distressed" patients may respond more rapidly to focused problem solving and hence be able to benefit from sessions focusing on challenging unhelpful patterns of thinking that relate specifically to the chronic pain experience (in either group or individual sessions). Depressed, self-denigratory patients will almost certainly require individual therapy sessions that may not, in the short-term at least, be focused on problem solving but on more in-depth cognitive therapy.

vi) Relaxation as an active pain management strategy

Relaxation techniques, breathing exercises and attention regulation methods have been taught to chronic pain patients to improve their ability to cope for the past twenty years or more (Turk and Meichenbaum, 1984; Benson, Pomeranz and Kutz, 1984). A variety of techniques are introduced to patients on the named PMP, ranging from diaphragmatic breathing (quick) to a self-hypnosis-type technique (slower to utilise but resulting in a deeper level of relaxation). On the PMP detailed here, an audio-taped recording of the latter technique is supplied for personal use once patients have experienced a session in vivo (up to three learning sessions). The emphasis here is not on pain reduction per se but on stress/tension reduction with possible pain reduction benefits. ("You can be relaxed and still in pain"). Patients are encouraged to practice on a regular basis and given the rationale that relaxation is a skill and that it is unlikely to help in a "crisis" unless one has previously mastered the technique. However, once learned, it can be incorporated into a structured plan for managing pain flare-ups to very good effect. The emphasis is therefore on using a relaxation technique as an active pain management strategy.

From the author's own experience, patients with chronic pain typically find it difficult to learn to relax fully (mentally as well as physically). Anecdotally, approximately two-thirds of the members of a given group report some benefit from in vivo sessions though this number is reduced when people attempt to practice relaxation at home.
Again anecdotally, approximately one third of patients report making sustained use of relaxation techniques post programme and obtaining benefit from them. It does not however seem possible at present to identify who is likely to benefit from this technique at the outset of a PMP and who is not.

vii) Medication reduction

Almost all of the medications taken by chronic pain patients fall into one of three categories: 1.) Analgesics; 2.) Antidepressants, and 3.) Hypnotics / tranquillisers (Benzodiazepines), (Williams et al,1993). On an outpatient PMP, reduction in medication is achieved by educating the patient, by providing advice on systematic reduction and by monitoring the patients' progress on a week by week basis. The main reasons proposed for reducing or stopping the above medications are the following (in no particular order):

1. Because of their contribution to cognitive impairment, which is reversible when medications are relinquished;
2. Because of other side effects, such as the development of gastric disorders linked to longer-term use of anti-inflammatory drugs;
3. The use of medication may encourage maladaptive behaviour such as over-activity or under-activity;
4. The use of medication may militate against the use of cognitive-behavioural pain management strategies;
5. Many patients do not want to rely on medication on a long-term basis and regard medication reduction/withdrawal as an important goal for them in pain management terms.

Systematic reduction of analgesic medication first of all requires that a regular dose of medication be taken at regular intervals throughout the day. Many patients admit to taking medication, especially analgesics, in excessive quantities, either too frequently, or else unpredictably, according to pain. The aim is to make analgesic medication "time contingent" as opposed to "pain contingent", e.g. taken four times a day at six hourly intervals. The amount of each dose can then be gradually reduced, ensuring that a reducing level of analgesia remains in the system until it is relinquished altogether.

Antidepressant medication may be given in order to improve sleep and mood but evidence from patients' own reports suggests frequent side effects of drowsiness and dizziness coupled with poor pain relief. Benzodiazepines are often prescribed as a sedative or for "muscle spasm", for which evidence of efficacy is lacking. Most patients are willing to consider other strategies for sleeplessness, such as relaxation strategies.

On an outpatient PMP, medication reduction is seldom an issue of huge proportions. However ensuring that patients understand the rationale for linking CBT to medication reduction should ensure that medication no longer substitutes for effective pain management strategies.

viii) Education for family and friends

Assessment for a cognitive-behavioural group pain management programme typically involves obtaining information about a patient's family and "significant others". As part of the functional analysis of the pain problem, the role that an individual's pain experience plays within the family context is explored. Turk, Meichenbaum and Genest (1983) have described many of the consequences that pain has on family members, including financial loss, decreased opportunities for families to enjoy activities together, shifted burdens of responsibility, disrupted sexual relationships and a range of problematic emotional reactions. Individuals are asked if, for example, their partners know when they are in pain and, if they do, how they know. The aim is to elicit information on the way in which couples communicate about pain; whether the pain sufferer communicates their pain verbally or behaviourally and whether they believe either means is an effective form of communication for them. Frequently, people with pain believe they are bravely "keeping their pain to themselves" by not discussing it. In reality, they are often causing consternation to a partner who observes a range of pain behaviours (limping, grimacing and the taking of pain medication) but receives no information, especially with regards to what they might be able to do to help. Partners of pain patients often report feeling confused by "mixed messages" ("I'm fine", when the patient blatantly isn't) and helpless.

If a partner attends an initial assessment appointment for a PMP, they are usually invited into the interview when an explanation of the programme is to be made. This can serve as a useful opportunity to explain the rationale of a self-management approach to both partners together so they can discuss this subsequently. It may also be an opportunity for the interviewer to observe interactions between the pair and identify where additional help in intercommunications may be appropriate. This is however the ideal rather than usual scenario. Typically, patients attend the

assessment alone, regarding pain as the problem of the individual. They are, however, often able to acknowledge that pain is affecting their partners and families and are keen to explore ways in which this might be addressed.

The idea of incorporating a day during the programme when friends and family members might accompany the patient has developed as a means of attempting to satisfy this aspect of pain management. This has good face validity although empirical support is not clear-cut. Fordyce (1976) recommended that in some cases, patients should not be admitted to treatment if their partner were unwilling or unable to participate in treatment. His rationale for this was that family members were frequently reinforcing pain behaviours. They needed to be "trained to withhold pain-contingent attention and sympathy, to refrain from performing aversive tasks that would normally be the patient's responsibility were it not for his/her pain, and to reinforce successive approximations of well behaviour" (Moore and Chaney, 1985, p.327).

Moore and Chaney (1985) looked at the effects of spouse involvement in an outpatient group treatment programme for chronic pain. Forty-three chronic pain patients were randomly assigned to couples group treatment, patient-only group treatment or waiting list control. Moore and Chaney (1985) demonstrated treatment gains in both treatment groups for a range of variables including pain reduction, marital satisfaction and utilisation of health care resources. They concluded that spouse involvement did not facilitate response as patient-only group treatment was apparently as efficacious as couples group treatment. It is worth noting however that the treatment programmes were relatively brief (8 x 2hourly sessions) and the report suggests that the couples group treatment did not particularly target couples' interactions and was probably very similar to an individual treatment (with partner as an observer).

Saarijarvi (1991) looked at the effects of couple therapy in chronic low back pain patients and demonstrated improvements in marital satisfaction and health attitudes and reductions in psychological distress. Saarijarvi et al (1992) subsequently published a controlled five-year follow-up study suggesting the benefits of couple therapy for mental wellbeing for patients with chronic low back pain.

King and Snow (1989) and Basler and Rehfisch (1990) investigated reasons for attrition from pain management programmes and both found that compared to completers, non-completers reported feeling less supported by their families. Richmond and Carmody (1999) found that higher levels of observable pain behaviour coupled with living alone seemed to be associated with dropout from the pretreatment phase of a PMP. On the assumption that living alone might imply lack of immediate family or social support, they suggested that PMPs should look at ways of addressing this. On the basis that family stress and conflicts might be contributing to, or "dynamically motivating factors of "(p.55) the pain itself, Richmond and Carmody (1999) proposed that family stress and conflicts become a specific focus of treatment.

In the PMP reported here, partners and friends (who attend for one day out of nine) receive education about chronic pain and the self-management approach together with patients and are then offered some separate time as a group. They are then invited to share some of the difficulties they experience as a partner/friend and to "brainstorm" what pain patients could do to allow partners/friends to help them more effectively. Meanwhile, patients are separately invited to consider what might be difficult for partners/friends and to identify the kind of help they might find most useful (e.g. planning a joint strategy for dealing with a pain flare-up). The groups then come together to look at similarities, and often differences, in partner/friends experiences of pain patients compared with how pain patients feel they are perceived. Typically, patients suggest partners may feel fed up and frustrated with them and their pain. Partners more often identify feeling helpless and left out. This can form a fertile basis for constructive discussion about how both sides can improve communications and help each other more effectively. Sometimes this involves the partner stepping back, in order to allow the person with pain the opportunity to experiment with their pain management strategies in everyday situations. Typical feedback from a day when partners or friends attend the programme suggests that the occasion can stimulate discussion about aspects of the experience of pain which have previously been avoided. Patients often report that they recognise they need to communicate their needs more clearly and not rely on the capacity of others to "mind read". From what they say, it seems likely that patients who are already gaining benefit from the programme will get most from this day for themselves and their partners. Quite often, patients who did not have a partner attend the day, report that they benefited from listening to the partners or

friends of other patients.

ix) The Role of the Group

Yalom (1985) suggests that therapeutic change in a group setting "is an enormously complex process and occurs through an intricate interplay of various guided human experiences". These are referred to as eleven "therapeutic factors". With regard to PMPs, the ones of particular relevance here are:

1. Instillation of hope (provision of optimism that things can change)
2. Universality (your experience of chronic pain is shared by significant numbers of other people)
3. Group cohesiveness
4. Altruism (your contribution to the group can benefit other group members)
5. Imparting of information (often better received when initiated or backed up by the experience of group members as opposed to didactic teaching from therapists in the group). Since educational aspects of the PMP have been covered elsewhere, they will not be reiterated here.

Whilst a PMP is different to a psychotherapeutic group in many of its aims and methods, it is not possible to discount the significance of some of the effects of the group, as identified by Yalom, on the individual participating in a cognitive-behavioural group self-management programme. These are explored further below.

1. Instillation of hope

Yalom (1985), among others, recognises that instillation and maintenance of hope is crucial to the success of all psychotherapies. Hope is required to engage a patient into therapy and keep them there whilst other therapeutic factors can take effect. Faith in a method of treatment can itself be therapeutically effective. Within the pain literature, Williams et al. (1996) has demonstrated a positive relationship between high expectations of help prior to treatment and positive outcome following participation in a PMP. In the author's experience, patients at one time were given the explicit message that their pain intensity would not change as a consequence of PMP participation. This is no longer stated overtly. People are encouraged not to raise their expectations unrealistically but are given information based on patient

feedback that some people report "changes" in pain intensity as they become fitter and more flexible. The other reason they are no longer given the explicit message is that even when patients recognise that change in pain intensity seems unlikely for them, they have reported finding it unhelpful to be told so.

Yalom (1985) suggests that within a given group, different individuals are functioning at different points along a "coping-collapse continuum". Patients are in constant contact with other group members who may have had very similar problems to their own and are demonstrating effective ways of coping with them. This form of "modelling" can prove very efficacious. Some PMPs utilise patients from previous programmes to help instil hope in the approach for current group members. The aim is to provide an optimistic appraisal whilst remaining realistic about the challenges involved.

2.Universality

Discovering that the experience of pain an individual thought unique to themselves is actually shared by others is frequently a revelation and a huge relief for patients entering PMPs. The nature of chronic pain means that people have invariably become socially isolated and the opportunity for consensual validation of the experience of pain has often not been available to them. Many programmes begin with exercises designed to emphasise universality. Patients may be asked to brainstorm a range of consequences of the chronic pain experience (both practical and emotional) within the group and these are recorded (e.g. on a whiteboard) for the group to see. Ostensibly, this is done to get people thinking about areas of their lives where unhelpful change has occurred and then to introduce ways in which different aspects of the programme might, in principle, be usefully employed to address these problems. One effect of such an exercise is however to enable people to see how their own experience of the devastation caused by chronic pain is frequently shared by others in the group. This would seem to have a variety of possible benefits for patients. For example, hearing other people acknowledge distress and anger may be particularly helpful for patients who have previously felt inhibited about sharing difficult feelings about pain. Experiencing universality appears to be closely linked to the development of group cohesiveness. The latter is generally considered to be a therapeutic factor and this is discussed further below. It has been demonstrated that feeling different from other group members (e.g. site of

pain, years of pain, associated difficulties) puts people at higher risk of attrition from a PMP (Coughlan et al, 1995).

3. Group Cohesiveness

Yalom (1985) defines cohesiveness as the attraction that members have for their group and for the other members and suggests that within a cohesive group, people are more accepting of one another and more supportive of one another. He also suggests that there are various pathways through which group cohesiveness exerts a therapeutic influence. Of particular interest with regard to PMPs, members of a cohesive group will apparently try harder to influence other group members, be more open to influence by other group members and be more willing to listen to others and more accepting of others. Some forty years ago, Dickoff and Lakin (1963), transcribed and categorised patients' explanations of the therapeutic factors in their group experience. Mutual support was cited as being of primary importance and patients who reported themselves as improved were more likely to have:

i. Felt accepted by the other members;
ii. Perceived similarity of some kind among other group patients;
iii. Made specific references to particular individuals when queried about their group experience.

Allen, Glover and Williams (2001) questioned patients about the influence of non-technical aspects of a residential PMP on the changes they made. 13 patients were interviewed on two separate occasions during the four-week programme and their answers were analysed using Interpretative Phenomenological Analysis (Smith et al, 1997) in order to try to identify emerging themes. Three themes relating to group cohesiveness were identified as significant in influencing change:

a. A mutually supportive group environment
b. Group Identity, as patients with chronic pain, and as patients participating in the programme, and
c. Acceptance of the patient's pain by staff and fellow patients.

The significance of the concept of the self is probably relevant here. As discussed above, Pincus and Morley (2001) have suggested that at the core of the self is an

evaluative system, involving evaluation of thoughts, feelings and behaviour and thus generating a measure of what the self is worth. As already highlighted in a previous section, Osbourne (2002) suggests people with chronic pain may be living with an "unwanted self", a self that cannot be understood or controlled, or with a body separate from the self. Leventhal, Idler and Leventhall, (1999), have suggested that where pain repeatedly interferes with an individual's major goals, this can impact on the self-schema and hence on the person's identity. Many patients entering assessment for a PMP acknowledge diminished self-confidence and self-esteem as a consequence of living with chronic pain. Some go so far as to say that they have changed significantly as people and they do not like the people they have become.

According to Osbourne (2002) how an individual feels they live in the minds of others appears to be central. If they assume that they are perceived negatively (as an object of contempt or ridicule, e.g. "a waster") this can lead to social withdrawal and isolation, together with a significantly diminished sense of self-worth. Membership of a group where individuals can challenge such assumptions could therefore be highly beneficial. In a cohesive group, individuals may be able to share feelings that they may not previously have felt able to own. When they find that others have similar feelings, they can often feel enormous relief as they experience validation by other group members and this in turn builds on group cohesiveness. Further, and perhaps even more importantly, where group members show that they value the individual for their courage in speaking out, this can have important benefits for the individual's sense of self-worth. In addition, group membership may also provide the individual with the experience of hearing others describe what they assumed were their personal "stories". Finding that they feel respect rather than contempt for that person and their "story" may result in them beginning to feel differently, and more positively, about themselves.

4. Altruism

Altruism is demonstrated in the setting of the PMP at different levels. Group members show altruism by agreeing to be part of a group whose purpose is to support all its members in developing self-management skills. This assumes people will be prepared to take turns within the group and to listen to others and show respect for their views. In practice, group members are typically enormously helpful

to one another in a variety of additional ways. They offer each other support, reassurance, suggestions for problem solving, often based on their own experience, and provide the medium through which others may gain insight into their own particular difficulties. Often patients find that discussions outside of sessions help to clarify and consolidate information they have learned within those sessions. Coping strategies may be more readily assimilated and applied with the advice and support of other group members. Yalom (1985) comments that professional team members remain separate from the group in important respects. Group members who are "living the experience" of chronic pain can usually be counted upon for the most valuable feedback in respect to problem solving.

It seems clear that people gain to varying degrees by this experience of helping others. Sometimes they report that they have continued with the programme in the face of considerable difficulties because dropping out "would let the others down". Many patients continue to contact each other after the cessation of the group for mutual support. Some offer their services to the programme, for example, by offering to talk to future group members about their experiences.

Other significant aspects of the group experience

Several researchers have recognised that therapeutic change cannot be accounted for simply on the basis of adherence to techniques described in a treatment manual (for example, Castonguay et al (1996)). The therapeutic alliance is clearly an important factor in outcome, as demonstrated in a meta-analysis of seventy-nine studies (fifty-eight published and 21 unpublished) relating alliance to outcome (Martin, Garske & Davis, 2000). Therapeutic alliance refers to the quality of the relationship between the client/patient and the therapist. This has been recognised as an important element contributing to change in psychodynamic, humanistic and cognitive-behavioural treatments (Goldfried and Padawer, 1982). Castonguay et al (1996) explored factors associated with predicting the effect of cognitive therapy for depression and found that the quality of the working alliance predicted improvement on all of the outcome measures collected at the post treatment review. The results of the meta-analysis conducted by Martin, Garske and Davis (2000) indicate that the overall relation of therapeutic alliance with outcome is moderate but consistent and does not appear to be influenced by other moderator variables.

Within the setting of a group PMP, therapeutic alliance between the patient and one or more but not all the professional team may be important but has yet to be examined. It seems quite likely that group cohesiveness, for example, together with the perceived quality and usefulness of the information provided may be equally or more significant in relation to change on a group PMP.

Researchers of different orientations have recognised that psychotherapeutic change implies significant affective processing and learning (for example, Greenberg & Safran, 1987; Teasdale, 1993). Castonguay er al (1996) identified the client or patient's emotional involvement as a further important factor in outcome. Part of the client's emotional involvement is their capacity for "experiencing", taken here to mean the client or patient's capacity to focus on and accept their affective reactions". At the highest levels, this means people gain awareness of previously implicit feelings and meanings and become involved in an "ongoing process of in-depth self-understanding, which provides new perspectives to solve significant problems" (Castonguay et al, 1996). Practically, they become increasingly skilled at exploring and understanding, for example, the relationship between their thoughts and feelings and utilise this in an on-going way to develop enhanced problem-solving skills. This process may be therapist-inspired. Within a psycho-educational group such as a PMP however, insight may also be stimulated as a consequence of the reported experiences of other group members and/or observation of behavioural changes they are achieving.

3. Relevant research demonstrating the efficacy of this approach

There is now a wealth of published literature reporting the efficacy of cognitive-behavioural therapy (CBT) in helping people with chronic pain to manage the problem more effectively. The emphasis for assessing improvement generally focuses on the restoration of function, on overcoming the effects of de-conditioning and on improving mood and pain-related self-efficacy. Reductions in pain and disability-related behaviour are also cited as successful outcomes from a pain management perspective.

Research into efficacy

Four meta-analyses of CBT for chronic pain have been reported in the literature to date, the most recent published in 1999 (Morley, Eccleston & Williams, 1999). This has been especially well-received because it focuses on Randomised Controlled Trials (RCTs) whereas its three predecessors (Malone & Strube,1988; Flor et al., 1992; Turner,1996) were less selective in terms of studies that they incorporated within their respective meta-analyses. Within their systematic review and meta-analysis of randomised controlled trials, Morley et al identified 25 controlled studies for analysis, 21 of which compared more than one treatment with a control (cognitive behaviour therapy (CBT), behaviour therapy (BT), biofeedback (BFB) and relaxation training). These studies involved patients treated in both in- and out-patient settings with a variety of chronic pain- related conditions (e.g. low back pain, mixed chronic pain, rheumatoid arthritis and osteoarthritis, upper limb pain (work related) and fibromyalgia. Morley et al also identified 221 outcome measures for which effect sizes were computable and these clustered into eight domains, five of which they eventually utilised. These domains were pain experience, mood/affect, cognitive coping and appraisal, pain behaviour and social role functioning.

In terms of effect sizes, three of the domains were subdivided on the basis of the measures in them (e.g. in the mood/affect domain, there was a clear division between measures of depression and measures of other affective states, specifically anxiety). Effect sizes for treatments versus waiting list controls were calculated for each domain. The mean effect size was found to be significantly greater than zero for all measurement domains and hence the null hypothesis that treatment is no more beneficial than the waiting list control condition could be confidently rejected. Three types of treatment (CBT, BT and BFB) were found to be effective in changing pain experience (i.e. in reducing pain intensity), improving social role functioning and in reducing negative appraisal and negative coping (predominantly catastrophising).

To summarise the findings of Morley et al., (1999), active psychological treatments based on the principles of cognitive-behavioural therapy (including behaviour therapy and biofeedback) are effective relative to waiting list controls. Overall, CBT produced demonstrable changes in measures of pain experience, mood/affect,

cognitive coping and appraisal (reduction of negative coping and increase in positive coping) pain behaviour and activity level and social role functioning.

Morley et al.'s systematic review and meta-analysis has been widely cited as providing definitive evidence for the efficacy of cognitive-behavioural pain management programmes. Randomised comparisons and controlled studies of inpatient and outpatient treatment (e.g. Williams et al., 1996) demonstrate that both methods of delivery of pain management are effective and reasonably well-maintained. The question "Do Pain Management Programmes Work?" seems to have been answered satisfactorily for the most part. A new focus of research is emerging now however, focusing on *how* they work. Williams et al., (1996) identified a particular problem with existing studies. " Much conventional outcome research....cannot give clear insights into the detailed processes whereby change occurred..". Developing a better understanding of these detailed processes might have two advantages. By identifying some key variables linked to change, it might be possible to give those who struggle to take on board a self-management approach for their chronic pain a greater chance of success. In addition, on the proposition that change might be achieved by a discrete, and identifiable, set of variables, the process of learning to self-manage pain might be simplified. Attempts to "deconstruct" the components of a PMP have so far failed to yield particularly useful information with respect to simplifying the process however (Williams, personal communication, 2003). One explanation for this may be that change probably occurs at multiple levels, the complexities of which vary from individual to individual. The process may therefore defy simplification.

4. Background to Current Study

The study to be reported here was developed in order to gain a greater understanding of the processes associated with change for people taking part in a PMP. This was considered to be of particular interest on the basis that information obtained might be used to enhance the efficacy of the approach, especially for participants who might be struggling with it. There currently seems to be a dearth of information in the existing literature about the processes involved in achieving beneficial change in pain management.

The author, and others colleagues with pain management experience, have become increasingly aware that patients reporting success with the approach at the end of a programme (and who would seem to be improved according to objective measures) tend to make certain statements associated with their progress. Examples of this are as follows:

i) "I don't feel frightened now I understand more about chronic pain",

ii) "Its OK now I know I can't damage myself",

iii) "Pacing (activities) allows me to do more of the things I want to do",

iv) "I've recognised my tendency to "catastrophise" and I've learned ways to reduce this".

People doing less well objectively do not typically make these statements. If they comment on progress, it is not usually linked to specific programme content but to more general aspects of group participation, for example, "It was nice to meet other people with pain". It was therefore decided to explore this systematically in the first instance in order to establish whether people who seemed to be making the greatest changes on the PMP were indeed those who could reflect on specific aspects of their experience.

An area of research pertinent to this question involves work looking at client/patient perceptions of significant events in treatment. This area has previously been explored on the assumption that such events will contain the sought-for effective ingredients in therapy (Elliott, James, Reimschuessel, Cislo and Sack, 1985; Greenberg, 1986). Several studies have attempted to explore the client's viewpoint in individual psychotherapy by asking them to identify the most crucial or helpful events occurring in therapy for them (e.g. Elliott, 1985; Elliott et al., 1985; Llewelyn, 1985; Lllewelyn et al, 1988). These studies involved the collection of retrospective perceptions of significant events taking place, either in a given session or else over the course of therapy. These descriptions were then classified into categories of therapeutic impact that permitted subsequent quantitative analysis. Helpful and unhelpful events in therapy have thus been categorised (e.g. Elliott et al, 1985). The same authors developed a system that can be applied to events identified by either client or therapist and which allows comparisons to be made between impacts at different stages of therapy and between different treatments (the Therapeutic Impact Content Analysis System (TICAS)).

The current study involved attempting to obtain similar information from patients involved in a PMP. Patients would be asked to identify helpful (or unhelpful) events in treatment in terms of significant events or "key moments" of change. It was hypothesised that the capacity to reflect on the programme and identify "key moments" would be interesting at two levels. As above, the capacity to identify "key moments" of change might distinguish those patients who had made significant, and possibly enduring, improvements from those for whom little or no real change had occurred. Secondly, if certain aspects of the programme were frequently identified as "key moments", particularly by patients who had made objective improvements during the programme, these aspects might suggest themselves as significant in promoting change. Such information could be utilised for future groups of patients. Perceptions of clients in particular have been demonstrated to serve as pointers to the effective ingredients of therapy. Llewelyn (1985), for example, analysed significant events identified by 40 clients over an average of 10 sessions each and contrasted these with events that their therapists identified as significant. The therapists came from a variety of theoretical backgrounds and used a range of theoretical techniques. The findings suggested that therapists considered the most helpful impact of therapy for clients was the gaining of insight. Clients however reported the most helpful impact of therapy was the reassurance and relief they gained, together with help in solving their problems. Similar findings have been reported by Murphy, Cramer and Lillie (1984) and Lietaer (1983) also reported that clients consider interpersonal aspects of the experience of therapy as more significant than do therapists. These studies suggest that the significant ingredients of treatment may not be obvious and that obtaining the client or patient's viewpoint is hugely important if the process is to be better understood.

With regard to group treatment, and group PMPs in particular, relatively little information has so far been obtained. Allen, Glover and Williams (2001), as above, asked group members about non-technical aspects of a 4-week in-patient PMP in terms of what they believed might have helped them make changes. The findings are reported in terms of themes influencing change rather than significant events. The themes identified as significant relate to group cohesiveness. Hine (2002) investigated the relationship between group cohesiveness and outcome on a residential PMP. He was unable to demonstrate a correlation between the two. One possible reason for this may be that the questionnaire used to assess group cohesiveness was adapted for PMP groups from psychotherapy research and may

not have been valid for this purpose. Alternatively, group cohesiveness may be significant for some but not necessary for all group members to make progress. A third possibility is that in certain cases, change may be facilitated by active non-identification with other group members whilst still identifying with what's being presented on the PMP. This may occur as the result of a decision "not to end up like them" which can be a constructive response to dealing with one or more fellow participants who are tending to present obstacles to change. This will be discussed further below.

In the current study, patients were asked to identify personal "key moments" of change during the course of the PMP. By examining patients' reports and comparing them with individual objective measures, it was hypothesised that more would be learned about triggers for change and the processes underlying the change that is subsequently observed. The method chosen for the analysis of this qualitative data was determined by the fact that experience with pain management patients suggested an existing framework for understanding the material they provided. Specific themes had already been identified on the basis of the researchers' (and others') experience. Task Analysis (TA) was the chosen method, therefore, and this will be discussed further below.

An alternative method of analysis frequently used in qualitative research is Interpretative Phenomenological Analysis (IPA) (for example, Smith, 1996). In IPA, the experimenter attempts to be as neutral as possible and approach the data from a hypothesis-free position. The aim is that themes emerge from the material and are not influenced by the experimenter's preconceptions. In this case, it was not possible to be neutral, since the researcher had a number of hypotheses regarding themes that were expected to emerge from the data. Task Analysis therefore suggested itself as a more appropriate method for the current study. Greenberg (1986), looking at processes of change within individual psychotherapy patients, suggests that it is the occurrence of a particular pattern of variables rather than just their presence or frequency that indicates their therapeutic significance. The analysis of pattern has become one significant area of interest in process research and task analysis, in which a human observer identifies the pattern (Rice & Greenberg, 1984), one of the main approaches to this analysis. The goal of task analysis is to identify and understand those internal operations engaged in by a patient that are essential for successful problem resolution.

The technique used here is an approximation of Task Analysis, adapted for this study. Conventionally in TA, a hypothetical model of patient change is developed with the help of an "expert" clinician. This idealised client performance is compared with descriptions of actual client resolution performances. According to Greenberg (1984b) "this is done in an iterative manner, moving back and forth between idealised and actual performances until a refined proposed model of resolution performance is built. This postdictive, discovery-oriented aspect of the approach involves a process of moving from clinical and theoretical expectations to observation and back again until the investigator is satisfied that the phenomena at hand have been described"(p.7). Greenberg suggests that the model constructed by this method can then be subjected to some sorts of verification procedures, for example relating these performances to outcome.

In the present case, the process was not an iterative one and hence the method used is an approximation of Task Analysis. The hypothetical model of patient change was developed and data was then examined to establish whether it contained examples of the hypothesised shifts. For example, it was hypothesised that prior to involvement in a PMP, the patient might experience a reliance on medical management of their chronic pain. Following participation in a PMP, it was hypothesised that the same patient may have acquired self-management skills and the confidence to utilise them such that, for example, they no longer depend on analgesic medication on a regular basis. The data of each patient were examined in order to identify the presence or absence of a series of similar examples (seven in this model) and thereby test the "expert" model. A further hypothesis was developed regarding the data of individual patients. The more examples of the various shifts that could be identified from the qualitative data of each individual, the more improved that individual patient would be, according to objective, quantitative data.

Data collected by a participant-researcher

In this study, the researcher was a member of the clinical team running the PMP and this had potentially both positive and negative implications. The researcher had a detailed insight into the content of the PMP and was able to interview study participants from a well-informed position. The use of feedback to make potential improvements on the programme was also made explicit to participants in the study.

Interview by a participant-researcher might be anticipated to reduce patients' willingness to be critical of the programme and this was also discussed with patients prior to recruitment into the study.

2. METHOD

2.1 Overview of Design

This study involved the analysis of both qualitative data obtained from semi-structured interview and quantitative data obtained from standardised psychological and behavioural measures. Patients were invited to participate in the study at the completion of their eight-session PMP, with a further interview scheduled to coincide with their three-month programme review.

Quantitative data were collected as part of the standard evaluation of the PMP. Three sets of data were collected in the study, at the pre-treatment assessment, on the last day of the programme and at the three-month review respectively. Qualitative data were collected at the end of the programme and at the three-month review. Quantitative data from pre- and post-treatment assessment and qualitative data collected immediately post-treatment were utilised in the current study.

Qualitative data were examined using Task Analytic techniques. Quantitative data were examined in order to explore potential relationships between objective measures of change and people's own reports of the experience of change in relation to self-management and its on-going challenges.

2.2 Ethics

Ethics Committee Approval was sought and obtained from the local Joint Research Ethics Committee. As part of that process, information sheets about the study, together with patient consent forms were developed. All patients were given information sheets and signed consent forms. Those patients whose interviews were recorded also gave formal consent for the recordings to be made (see appendix).

2.3 Procedure

2.3.1 Subjects and Subject Recruitment

a) Sample: All patients attending quarterly pain management groups run at the centre between February 2001 and April 2002 were approached. Since each group is typically composed of between 6 and 8 patients, this resulted in a potential cohort of 35 patients, of whom 32 completed the programme and 30 agreed to take part in the study. Of the two who declined to take part, one had developed non-pain related health problems requiring outpatient investigation immediately post-programme. The other was experiencing a marital break-up. The subjects were aged between 21 and 68 years, the majority being female (n=27). Whilst PMPs are typically composed of more women than men, the ratio of female to male patients was particularly high in this sample. Two groups were exclusively female. This may have had some influence on the findings of this study and will be discussed below. Details of subjects are included with their objective measures in the Appendix.

b) Recruitment Procedure: During the penultimate session of the PMP, the study was introduced to potential participants and described as an opportunity for the researcher, as part of the clinical team, to learn more about how patients experience the programme. The rationale given was that this would inform current practice and provide scope for planning future developments. Patients were assured that constructive criticism would be welcomed alongside any positive comments since this might be important in terms of developing the service. The study had apparently good face validity for patients and there was therefore minimal difficulty in recruiting subjects.

Patients were given information sheets to read and those who were willing to participate signed consent forms agreeing that they understood what was involved. They were each given questionnaires and asked to complete them during the last week of the Programme (see appendix). Appointments were made in order to interview individuals to expand on the questionnaires, or else to complete them with them if they felt more comfortable to do this. The aim was to interview all participants, either on the day of completion of their respective Programme, or within one week of completion.

As far as the researcher could judge, patients felt comfortable about expressing concerns and/or dissatisfactions where they occurred (although these were relatively rare). This may have been because patients felt they could influence the process by speaking directly to a member of the "team" and because the researcher's insight into the specifics of a particular group made it possible to encourage patients to elaborate more fully on some of their responses. Several of the subjects reported finding the process of reflecting systematically on their experiences of the programme useful.

2.3.2 Measures

a) Measuring the Subjective Experience of Change

Subjective experience was elicited by using a detailed questionnaire that was given to patients; the questionnaire was then used to structure a subsequent interview. In order to develop the questionnaire and interview, a pilot questionnaire was constructed (see appendix).

Pilot Questionnaire

The aim of the pilot was to try to identify the most effective way of obtaining information from patients about their personal experiences of change. This involved a series of open-ended questions looking at every aspect of the programme and focusing on the perceived helpfulness or otherwise of the respective components. Patients were then asked a specific question about "key moments" of change, described as a point when "something clicked for you, you understood things better or felt you were suddenly making progress". Responses to this question were elicited in as neutral a manner as possible.

The pilot questionnaire also included questions about the following:

i) Patients' perceived readiness and preparation for the programme,

ii) Patients' overall satisfaction with the programme.

iii) Patients were asked to comment on anything they felt was missing from the programme and

iv) Anything that occurred either within or outside of the group that they felt may have interfered with their progress.

Prior to administration, the pilot questionnaire was reviewed by an experienced researcher in Pain Management Programmes * who screened it for neutrality and pertinence.

This pilot questionnaire was administered in the form of a semi-structured interview to a group of seven patients returning for review one month after completion of a programme.

On the basis of the pilot, the questionnaire was revised. Two versions of the questionnaire were developed. (see appendix). Version 1 fairly closely resembled the pilot questionnaire with one or two minor modifications. There was increased emphasis on asking patients to identify how techniques may or may not have been helpful for them. They were also asked to comment on potentially beneficial factors, both within and beyond the group setting, that may have helped them to progress. The previous emphasis had been on factors interfering with change. Finally the layout of the questionnaire was altered in order to make it easier to understand and complete.

Patients were asked, as before, to identify any specific "key moments" during the programme ("when something clicked for you, you realised that you understood things better or felt you were making some progress"). Version 1 of the questionnaire was administered immediately post-programme (within one week of completion of the programme). Patients were asked to complete the questionnaire themselves initially and were then interviewed in order to elaborate on their written responses. Where patients felt less confident to complete the questionnaire on their own, the researcher conducted the interview straight away and recorded the patients' responses verbatim. This occurred in six cases, where patients had difficulties with literacy or because English was not their first language.

* Dr Amanda Williams

Version 2 of the questionnaire was designed for administration three months post-programme. In version 2, patients were asked to review their experience of the programme three months on by responding to questions about specific components of the programme and whether or not they were still utilising these techniques. The emphasis was on identifying when and how change occurred, continuing to focus on the helpfulness of various programme components. They were asked to identify what currently seem to have been the "key moments" of the programme for them, as opposed to trying to remember those that they reported in version 1 of the questionnaire. Two weeks prior to their review appointments, patients were sent questionnaires by post and they were asked to bring completed versions with them to their review appointments. At around the same time, they were also contacted by telephone to arrange interviews with the researcher, either on the day of review or within the same week

Initially, a number of interviews were recorded on audio-tape and one was video-taped for teaching purposes. However, taping was stopped when it became clear that several interviews exceeded one-and-a-half hours and the salient information could be summarised more effectively in writing by the interviewer.

b) Standardised Quantitative Measures

All patients at the centre are routinely asked to complete a battery of psychological and physical measures before commencing the PMP, on the last day of the programme, and at their 1,3,6 and 12 months post-programme review. Those measures utilised by the centre have been chosen using the shortlist from a consensus meeting of the Pain Management Programmes Special Interest Group of the UK Pain Society (unpublished). Although not yet operational, a national database would permit large-scale studies to be conducted and this might be particularly beneficial for programmes without the resources to conduct research in-house. The measures chosen assess pain; mood; beliefs and thoughts about pain, including pain self-efficacy; pain-related disability and function, including some physical measures.

A subset of the larger battery of measures was selected for analysis within this study. The measures utilised are as follows and some background will be given about each in terms of their utility for the current study.

(i) Assessing pain

Pain is typically assessed using either simple numerical or visual analogue scales and in this study, pain intensity and pain distress were measured separately using numerical rating scales (0-10). Zero is labelled "no pain at all" and ten, " pain as bad as it could be" for pain intensity, and "not distressing at all", "pain as distressing as it could be" for pain distress. Jensen, Karoly and Braver (1986) looked at a number of measures of subjective pain intensity and concluded that the numerical rating scale has several advantages over other measures. It is extremely easy to administer and score and can be given in either written or verbal form. Difficulties with completing the scale do not appear to be associated with age, as appears to be the case with visual analogue scales. Ratings are taken for "current" pain intensity and pain distress in order to anchor them. Of more interest from both a clinical and research point of view is a second measure of "average" pain intensity or distress, the time-scale for assessment being the past 7 days.

Graceley (1992) has suggested that pain sensation (in terms of intensity) and pain-related affect (pain distress) can vary together or separately and that the relationship between the two can be of particular interest. In a pain management programme context, it is predicted that ratings of pain distress may vary, and hopefully reduce, independent of ratings of pain intensity, which may not reduce. An important aspect of the pain management approach is to encourage patients to pursue their goals more independently of pain levels. Reduction in pain intensity may or may not occur and is not a pain management goal. Williams et al (1996) have however reported significant reductions in both pain intensity and pain distress for patients undergoing a 4-week in-patient PMP.

Both pain intensity and pain-related distress were measured for all patients participating in the study. Pain-related distress scores only were incorporated in to the analysis as they are more closely associated with patients' function than are pain intensity ratings (Price, 1999)

(ii) Pain Self-Efficacy

The Pain Self-Efficacy Questionnaire (PSEQ) (Nicholas, 1990) has become a widely used tool internationally. Nicholas chose Bandura's (1977) construct of self-efficacy as a basis for the PSEQ, since it referred to an individual's belief that he or she could or could not perform a particular activity. This was expanded to ask about a person's belief that they could perform a given activity, **despite being in pain**. The PSEQ consists of ten items selected as representative of the sorts of activities and tasks that patients with chronic pain report as being problematic. Items include statements such as: "I can still do most of the household chores (e.g. tidying up, washing dishes), despite the pain", "I can gradually become more active, despite the pain" and "I can cope with my pain without medication". Each item is rated by selecting a number on a 7-point scale, where 0 equals "not at all confident" and 6 equals "completely confident". Patients are asked to rate how confident they are that they can do each of the ten activities or tasks at present, despite the pain and a score is obtained by summing each of the ten items (maximum possible score = 60). The mean score on the PSEQ at assessment = 24.7 (s.d. 11.7) for inpatients and 25.4 (s.d. 9.1) for outpatients in the randomized controlled trial reported by Williams et al, (1996).

The Pain Self-Efficacy Questionnaire (Nicholas, 1990) has now been utilised on large samples of people with chronic pain (e.g. Williams et al, 1996) and improvement in PSEQ scores recognised to be a clinically meaningful indicator of change. The PSEQ possesses very good internal consistency (Cronbach's coefficient alpha = 0.92) and stability across time. 114 patients were administered the PSEQ at an initial screening interview and then again before admission to a programme (between 2 and 40 weeks later (mean 11 weeks). The test-retest correlation was .79, demonstrating stability across time despite various medical interventions. In terms of validity, the PSEQ has been correlated with other pain-related measures and demonstrates significant negative relationships with measures of medication use, depression, anxiety, catastrophising and functional disability and significant positive relationships with coping self-statements. This provides good support for its construct validity. Importantly, however, none of these significant correlations were so high as to make the PSEQ redundant, demonstrating that the PSEQ is measuring something different to these other instruments. The PSEQ also predicted dropout in a study of patients entering pain management programmes (Coughlan et al., 1995).

Finally, personal familiarity with the questionnaire also made it an obvious choice of measure for inclusion in this study.

(iii) Pain-Related Catastrophising

Understanding chronic pain frequently proves challenging for both patients and clinicians, not least because it contradicts prevailing ideas within Western medicine that pain is a diagnostic sign of bodily damage that requires repair (Morris, 1991). Patients with chronic pain commonly struggle with attempts to understand this pain and themselves in relation to it and can develop a variety of self-denigrating and self-destructive thoughts as a consequence (Aldrich, Ecclestone & Crombez, 2000). Such patterns of negative thinking are considered responsible for maintaining maladaptive ways of coping with pain. The tendency to catastrophise about pain and its consequences has been particularly well investigated. As a result of multidisciplinary pain treatment, decreases in catastrophising, together with increases in perceived control over pain and decreases in the belief that one is disabled have been found to be associated with decreases in self-reported patient disability, pain intensity and depression (Jensen, Turner & Romano, 2001).

The Coping Strategies Questionnaire (CSQ) (Rosensteil & Keefe, 1983) has been widely used as a measure of catastrophising. In this study, an adapted short version of the catastrophising subscale of the CSQ, The Pain Catastrophising Scale (PCS) (Sullivan, 1995) has been used. People are asked to indicate the degree to which they can identify the specified thoughts and feelings when they are experiencing pain. Questions such as "I worry all the time about whether the pain will end" and "It's awful and I feel that it overwhelms me" are rated on a scale of 0 – 4, with zero taken to mean "not at all" and four, "all the time". There are 13 items on the questionnaire, yielding a maximum possible score of 52. The mean score for outpatients at assessment = 22.25 (1 SD below = 12.09; 1 SD above = 32.41 (Williams, personal communication, as above).

Sullivan, Bishop & Pivik (1995) examined the PCS for reliability and validity. The PCS has good internal consistency (Cronbach's coefficent alpha = 0.87). Test-retest correlations on the PCS indicate a high degree of stability across a six-week period ($r=.75$, $p<.01$). In terms of validity, the PCS was shown to be significantly correlated with depression ($r=0.26$, $p=<0.05$), trait anxiety ($r=.32$,$p<0.05$), negative

affectivity (r=0.32,p,.05), and fear of pain (r=0.80,p<0.001). Further, participants' ratings on a range of measures during ice water immersion (Sullivan, Bishop & Pivik, 1995) showed significant correlations (r=0.33,p<0.01) between participants' pain ratings and PCS scores obtained 10 weeks prior to taking part in the experiment. This supports the predictive validity of the PCS.

(iv) Pain-Related Disability

The Pain Disability Index (PDI) (Pollard, 1984) was chosen as a behavioural/physical measure for this study. It involves patients rating each of seven categories relating to everyday physical activities, in terms of the degree to which their pain disables them with respect to that particular area of their lives. People are asked to respond using a numerical scale of 0 and 10, where zero is labelled as "no disability" and ten, "total disability". Examples would be "Family/home responsibilities" or "Social activities" with explanations of what is involved within each category. Although less widely used in published research, The Pain Disability Index was selected because it provides a quick and easy method of obtaining an objective measure of function to complement physical measures (see below). The maximum score that can be obtained on the PDI is 70.

Tait, Chibnall & Krause (1990) reported on the psychometric properties of the PDI. The measure has good internal consistency (Cronbach's coefficient alpha = 0.86). Test-retest reliability was assessed by comparing PDI scores for 46 patients tested at pre-admission and again on admission to a chronic PMP. The delay between the two time points was two months. The Pearson product-moment correlation between the two sets of resulting scores was r=0.44 (p<0.001). The test-retest reliability of the PDI is disappointing given that disability status generally is considered to be a stable construct.

The same study provided evidence for concurrent validity of the PDI in that measures on the PDI were significantly related to patient reports of psychological distress, pain severity and other items measuring pain-related disability. Multiple regression analysis provided support for the construct validity of the PDI and nine variables were found to predict PDI scores (R = 0.74) These were: number of hours in the day spent in bed, frequency and intensity of symptoms, times of the day when

activities were stopped because of pain, work status, pain duration, usual levels of pain, quality of life, pain extent and level of education.

Whilst the study cited supports the reliability and validity of the PDI, it suggests some methodological considerations. In summary, the PDI is considered to represent a valid and brief measure of the construct of disability providing that disability is defined as "interference in the performance of routine activities". It is therefore considered to be useful as an assessment and research tool in most chronic pain treatment facilities where pain-related interference is frequently the focus of intervention. The authors of the study suggest that additional attention should be given to the test-retest properties of the PDI in order to assess its utility for outcome research. The relationship between the PDI and other behavioural measures of disability is also considered to be in need of further exploration.

(v) Walk Test

Self-report measures provide the opportunity of assessing patients on a fairly wide range of different activities, often asking them to average their behaviour over a period of several days. A disadvantage of this is that self-report measures of behaviour are subject to mismatch between how subjects believe they perform and how they actually perform (Fordyce et al, 1984). Sanders (1983) for example, reported poor compatibility between self-report measures of "up-time" (periods of activity) and objective monitoring obtained using mechanical recording devices attached to the patient. Whilst an ideal way of assessing patients' day to day functioning would be through direct observation in their everyday environment, this is clearly impractical under most circumstances. A practical alternative that has been utilised in this study is the direct sampling of behaviour under controlled conditions.

Harding et al (1994) evaluated a range of physical measures using a heterogeneous chronic pain population. She demonstrated reliability, validity and clinical utility of many of these measures whilst acknowledging that measurement of actual physical performance might be considered to be a necessary, but not sufficient measure of general function. According to Harding (1994) both 10 and 5-minute walk-tests offer excellent reliability (test-retest reliability for 10-minute walk was shown to be 0.944 using Pearson product moment correlation coefficient). Since the 5-minute walk test

was highly correlated with the 10-minute walk test, the 5-minute version was selected for this study. Although the shorter time carries a risk of producing a ceiling effect with fitter patients, it is probably more useful as a clinical tool since patients can use it to monitor their own progress more easily later on. Since physical measures are all direct samplings of physical performance, measures such as the walk test obviously have excellent face-validity. It is recognised however, as above, that samples of walk only approximate an individual's everyday level of performance, for which repeated measurement in appropriate settings would be required.

The 5-minute walk test was chosen as a physical measure for this study because of the ease with which it can be measured. Patients were asked to walk an indoor marked distance of 20 metres as many times as possible within the 5 minute period. They were not allowed to use walking aids but instructed to rest/stop and lean against the wall/sit down whenever they felt the need. They were informed of elapsed time on each lap or each minute if laps were very slow. Distance walked in 5 minutes was then calculated according to the number of laps recorded for each patient.

(vi) Measure not included

A measure of mood was **not** included in the subset of measures selected for this study. It has become increasingly recognised that existing measures of the severity of anxiety and depression are often confounded for chronic pain patients by the inclusion of somatic items (Williams & Richardson, 1993). These scales have typically been standardised on physically well psychiatric patients or normal populations. Patients with chronic pain (whether depressed or not) are likely to score heavily on these somatic items since they reflect problems that are as likely to occur as a consequence of pain as of depressed mood such as sleep disturbance and reduced activity. For the purpose of this study, the decision was made to sample pain-related distress directly (see above) rather than to use a possibly misleading total mood score.

2.3.3 Data Analysis

The aim of the analysis was to be able to examine the qualitative data in combination with the quantitative data. There were therefore three stages involved in the data analysis:

a) Examining the quantitative measures for clinical significance;
b) Exploring the qualitative data for "Key Moments"; and
c) Combining qualitative and quantitative data in order to test the hypotheses.

a) Establishing criteria for clinically significant change on quantitative measures

The first stage of the analysis was to establish which members of the group had made clinically significant improvements as identified by the standardised quantitative measures. The aim was to set clinically meaningful thresholds which would allow the sample to be stratified into a) those who had made clinically significant change and b) those who did not improve as a consequence of treatment.

Traditionally, psychological studies have depended on the use of statistical significance as a means of determining differences between groups. From a clinical viewpoint, however, this inferential method of statistical analysis does not describe treatment effects and the results are dependent on sample size. Small change, for example on the walk test as described above, might be statistically insignificant but clinically meaningful in terms of patient function and reduced interference of pain with life goals. Establishing clinical significance may be a way of overcoming these difficulties in order to provide information that is useful to clinicians and it is for this reason that measures of clinical significance were developed for the purposes of this study.

Morley and Williams (2002) have identified one of the main questions regarding clinical significance as relating to who is in a position to determine what amount of change or threshold achieved might be considered "clinically significant". Turk (2000) has suggested that this should be the party with most at stake in the outcome. For example, the patient might determine the threshold for clinical significance for pain relief whereas for the clinician prescribing medication, it might be the threshold at which a clinically significant reduction of opioids is achieved.

Establishing criteria for clinically significant change is a complex business therefore and one which has not to date been widely reported in the literature. It was however considered the method of choice for this study for reasons that will be explained below.

An alternative method for defining clinically significant change is the Reliable Change Index (RCI) as described by Jacobson and his colleagues (Jacobson, Roberts, Burns & McGlinchey, 1999, and Jacobson and Truax, 1991) The RCI is a statistical technique with two separate functions. According to Morley and Williams, "it takes into account the reliability properties of a measure to test the hypothesis that the observed change is not merely attributed to the unreliability of the measure". Its second and related function is to determine whether change might be regarded as clinically significant. This however depends on having normative data for the measure and this is where the RCI becomes problematic in respect to a chronic pain population. The RCI assumes first of all that scores for a healthy population and an untreated population approximate to normal distributions and do not overlap greatly. Significant clinical change is considered to have occurred if a post-treatment score falls within one of the following three bands:

(i) Within two standard deviations of the healthy mean,

(ii) Beyond two standard deviations from the untreated mean towards the healthy mean, or

(iii) On the healthy side of the intersection of the two distributions.

These do not necessarily coincide.

For the measures used in this study, healthy norms were unavailable or inapplicable so the RCI was not an option for establishing clinical significance. In preference, it was decided to set criteria to establish a categorical system for clinical significance. This was done as follows:

i) Each measure chosen for the study was reviewed to establish benchmarks for clinically significant improvement taken in the context of psychometric properties and their clinical meaning. For the latter, reference was made to: (a) a broad range of outcome measures from comparable although more intensive pain management programmes, reported in published research of

a UK randomised controlled trial of inpatient and outpatient pain management (Williams et al., 1996).
(b) A grant report of a cumulative sample of 2000 patients treated in the same unit as the RCT (Williams et al., 2002), and
(c) In consultation with the author of this research (Dr. Amanda Williams).
Pain-related distress, pain self-efficacy and pain-related catastrophising constitute the three psychological variables, pain-related disability and the walk test the two physical variables.

ii) The baseline scores were checked to ensure that none started in the "healthy" range defined: on this basis, one subject was excluded from analysis of catastrophising.

iii) A percentage change score was created for each of these psychological and physical variables as follows:

1. Pain Distress

A 30% reduction was selected as the threshold for determining improvement on a score of pain distress. This figure exceeds that reported for outpatients by Williams et al (1996). It more closely approximates reductions observed by Williams et al. (2002) and has therefore been chosen on the basis of benchmarking data in this study against that sample. Further, Farrar et al (2000) found in cancer pain that a 30% reduction was sufficient for patients not to request additional analgesia. Since the expectation in chronic pain management is not to abolish pain, a 30% criterion for pain reduction may be considered to be fairly ambitious.

2. PSEQ

The RCT reported by Williams et al (1996,) demonstrated a 37% improvement in pain self-efficacy for their inpatient cohort. On the basis of benchmarking data collected for this study against data already published, 40% was the figure that was chosen as the threshold for determining improvement on the Pain Self-Efficacy Questionnaire. A 40% criterion for clinically meaningful change is strict.

3. Pain Catastrophising Scale (PCS)

Scores on the PCS range from 0 – 52 ("not at all" to "all the time").

A 30% reduction was considered to be a reasonable threshold for improvement for this study. This was determined on the basis of clinical experience and with reference to Williams et al (1996). Williams et al (1996) utilised the catastrophising sub-scale of the Coping Strategies Questionnaire (Rosensteil & Keefe, 1983) (an earlier version of the PCS) and obtained a 33% reduction for their outpatient cohort.

4. Pain Disability Index (PDI)

Scores on the PDI range from 0 – 70 ("does not interfere" to "interferes completely"). A 30% reduction in interference ratings was considered reasonable on the basis of combined clinical experience. Williams et al (2002) used the Sickness Impact Profile (SIP) (ref) as opposed to the PDI but these questionnaires have similar content so the former was used as a guide in setting thresholds for clinical significance in the current study. Williams et al (2002) reported a 46% reduction on the SIP for inpatients and a 26% reduction for outpatients.

5. Walk

Data published by Williams et al (1996) reporting the results of a randomised controlled trial of inpatient versus outpatient pain management found that a comparable walk test demonstrated an average improvement post-treatment of 17% for the outpatient cohort and 35% for the inpatient cohort. Using this RCT as a benchmark, it was decided to set the threshold for improvement in this study of an outpatient PMP at 25% or above.

Two groups for each variable were thus created :

1. insignificant change or "non-improved" (0);

2. significant change or "improved"(1)).

The thresholds were as follows: see Table 1

Each of the five variables were then examined for each patient and coded as either improved or non-improved according to whether or not they reached the threshold designated to indicate improvement. (see Table 2)

Table 1: Thresholds

	Range	Group
PSEQ	0–39%	Non-improved (0)
	> 40%	Improved (1)
Pain Distress	0–29%	Non-improved (0)
	> 30%	Improved (1)
PAIN CATASTROPHISING	0–29%	Non-improved (0)
	> 30%	Improved (1)
PAIN-RELATED DISABILITY	0–29%	Non-improved (0)
	> 30%	Improved (1)
WALK	0–24%	Non-improved (0)
	>25%	Improved (1)

Table 2 : Patient change scores on individual variables

1 = Improved 0 = No change 99 = missing

Patient No.	P D	PSEQ	PCAT	PRD	WALK
01	0	1	1	1	1
02	0	0	1	1	1
03	0	1	0	1	0
04	1	1	0	99	0
05	1	1	0	1	1
06	0	1	1	0	0
07	1	1	0	1	0
08	0	1	0	1	0
09	0	1	1	0	0
10	0	0	0	0	0
11	0	1	1	1	0
12	1	0	1	1	1
13	1	1	0	0	0
14	0	1	0	0	0
15	0	0	1	1	1
16	0	0	0	0	0
17	1	0	1	0	0
18	1	1	1	0	1
19	1	1	1	1	1
20	1	1	1	1	1
21	0	1	1	0	1
22	0	1	1	0	1
23	0	1	1	1	0
24	0	0	1	1	0
25	0	0	0	0	0
26	0	0	0	0	0
27	1	1	1	1	0
28	1	1	1	1	0
29	1	1	1	1	0
30	1	1	1	1	1

v) The data was then inspected to identify who had improved on each measure and thresholds were set to reflect change as follows:

0 = not improved on either psychological or physical measures
1 = improved on one psychological and no physical measures
2 = improved on one psychological and one physical measure
3 = improved on no psychological and one physical measure
4 = improved on two psychological and no physical measures
6 = improved on two psychological and one physical measure

On this basis, patients were identified as having made clinically meaningful changes in both psychological and physical measures, in psychological measures only, in physical measures only or in neither.

The final categorisation scheme was as follows:

Improved: Patients who scored 6 (at or above the approved threshold on two psychological and one physical measure)

Part-Improved: Patients who scored 4 or 2 (improved on two psychological measures and no physical measures or one psychological and one physical measure)

Non-improved: Patients who scored 3,1,or 0. One patient scored 1 (improved on one psychological and no physical measure). This patient made a statistical improvement on the measure of pain self-efficacy but this improved score remained within the range considered to be associated with dropout at assessment (Coughlin et al (1995). This score was not therefore deemed an improvement and it was decided to categorise this patient as non-improved. No patient scored 3 (improved on no psychological and one physical measure). Categories 1 and 3 were therefore re-coded as zero.

See appendix for individual patient data.

b) Analysis of interview and qualitative data

i) Background to Task Analytic Approach used in this study

The first stage of the Task-Analytic approach (Greenberg, 1984b), involves generating a hypothetical "expert" model of change independent of, and blind to, any data which has been collected. The hypothetical model is based on the expert-clinician's best understanding of how change takes place. The accuracy of this model can then be tested against the data that has been collected.

In this study, two experts in pain management treatment and research (see footnote*) met to generate a hypothetical model of key moments presumed to underpin change in a PMP. The "expert model" is shown in table 3.

*Dr. Amanda Williams, renowned as an expert in psychological and statistical approaches to chronic pain management and Dr. Toby Newton-John, with considerable experience in both.

Figure 2 : The Expert Model

Necessary Psychological Shifts

Starting Point	End Point
Helplessness and loss of control	Sense of what is required to achieve change (hence self-efficacy)
Helplessness and loss of control	Sense of potential empowerment
Personal attribution and self-blame/guilt/ shame	Attribution to external non-personal cause/chance
Sense of being isolated/unusual	Communal experience
Devalued	Valued
Fearful inhibition	Experimentation and learning
Pain as a mystery	Achievement of an articulated working model of pain (creation of a narrative)

For example, prior to joining a PMP, a person with chronic pain might be hypothesised to feel helpless and lacking in control. They might blame themselves, both for the pain and for the way they are currently managing it and feel both isolated and devalued. Mechanisms involved in the experience of pain would probably be a mystery to them and they would be unlikely to be able to explain them. By the end of participation in a PMP, various psychological shifts would be hypothesised to have occurred for those reporting positive change. For example, in place of feeling helpless and out of control, the same person would be hypothesised to have developed both a sense of potential empowerment and a good idea of what is required to achieve change (hence enhanced self-efficacy). Rather than blame themselves, they would be more likely to attribute their pain and associated difficulties to an external, non-personal cause or else to chance. They would no longer feel isolated, due to the validating, communal experience of membership of a group with other people with similar problems. They would begin to feel more valued as a consequence of all the above. Finally, as a result of the PMP process, pain would no longer be a mystery and group participants would have developed an articulated working model of pain for themselves (creation of a narrative).

In order to test the expert model against the data, "key moments" (as identified by patients completing the PMP) were examined in order to establish whether they contained reference to, or evidence of, one or more of the hypothesised psychological shifts.

ii) Hypotheses

It was hypothesised that:

a) Patients who experienced and articulated "key moments" as identified in the expert model would be those identified as having improved on the basis of quantitative measures.

b) Greater levels of change would be associated with the articulation of a larger number of these key moments.

Further, by examining "key moments" articulated by patients who did well on the programme, it might be possible to identify components of the programme that seem to be associated with positive changes. It might also be possible to identify other potentially important psychological shifts that were not included in the expert model.

iii) Method of Analysis

The researcher and a colleague with experience of working on PMPs each examined the "Key Moments" section of each patient's post-therapy questionnaire independently. The "expert" model (which describes seven possible categories of psychological shift) was used to code the raw data.

Each rater coded independently. Both coders were blind to each patient's outcome in terms of their performance on quantitative measures (though it should be noted that the researcher was (inevitably) aware of the identity of the patients).

They each examined every case and independently identified and recorded any examples of the seven constructs they could find for each patient. Inter-rater agreement at this stage was found to be low (kappa = .392, percentage agreement = 48.6%). Discussion between raters indicated that this was attributable to ambiguity in three of the categories, leading to overlap in ratings. On this basis the data were re-examined jointly, reaching consensus on the category assigned to each example of a hypothetical shift. The limitations associated with this method of analysis will be discussed below.

The following problems were identified in the process of coding key moments:

1. The expert model implied a start point and end point for the each of the "necessary psychological shifts". From the data, end points could be deduced

from what was recorded but it was not always clear that the predicted start points were valid. An example of this is the construct with the start point: "fearful inhibition", and end point: "experimentation and learning". "Experimentation and learning" was frequently coded as an end point but there were few examples where it was clear that "fearful inhibition" was the start point. The data suggested that a more frequent start point might be "frustration". It was therefore decided that coding would be determined by end points unless both start and end points were explicit.

2. Three of the constructs appeared to be closely related. These were the end points "empowerment", "sense of what is required to achieve change (hence self-efficacy)" and "achievement of an articulated working model of pain (creation of a narrative)". These were identified by both researchers but coded differently. Consensus was achieved by discussion leading to agreement to code as one construct or another.

3. Some participants described complex shifts in their thinking that simultaneously referred to more than one of the key moments in the expert model. For example:

   (The session on the) "overactivity/underactivity cycle on the first day hit the spot. Made me think about plans and routines and also how I got here in the first place (loss of strength etc.)"

   In examples such as this, "hit the spot" was coded as "1" – "empowerment" and "made me think about plans and routines" was coded a "2" – "sense of what is required to achieve change". The above example was scored as containing two key moments.

   In order to demonstrate the extent to which the hypothetical model accounted for the data, the researcher was interested in the range of constructs within each patient's data. A single subject could, in theory, score up to 7 in total, reflecting the total number of necessary psychological shifts in the expert model. A score of 7 would demonstrate that examples of all seven constructs were identified and coded in the individual's interview. In practice, the maximum number identified for any patient totalled five.

Several examples of the same construct, such as "experimentation and learning", might be coded in an individual patient's data. These examples would collectively be scored as "1" because they all represent a single construct.

(See Appendix for Example of Method Used for Coding Key Moments and Summary of Key Moments by Subject Area)

c) Combining qualitative and quantitative data in order to test the hypothesis

The above will be reported in the Results Section.

3. **RESULTS**

3.1 Clinical significance of change on quantitative measures

Table 3 shows the overall rating of change for patients post-treatment and their outcome category (improved, partially improved or not improved).

Table 4 shows the frequency of number of patients in each category.

Table 3

Patient No	Overall Rating	Outcome Category
1	6	Improved
2	2	Partially improved (1)
3	2	Partially improved (1)
4	4	Partially improved (2)
5	6	Improved
6	4	Partially improved (2)
7	6	Improved
8	2	Partially improved (1)
9	4	Partially improved (2)
10	0	Not improved
11	6	Improved
12	6	Improved
13	4	Partially improved (2)
14	0	Not improved
15	2	Partially improved (1)
16	0	Not improved
17	4	Partially improved (2)
16	6	Improved
19	6	Improved
20	6	Improved
21	6	Improved
22	5	Improved
23	6	Improved
24	2	Partially improved (1)
25	0	Not improved
26	0	Not improved
27	6	Improved
28	4	Partially improved (2)
29	6	Improved
30	6	Improved

Footnote - Improved: Improved on at least two psychological and one physical measures
Part-improved(1): patients improved on one psychological and one physical measures
Part-Improved(2): patients improved on at least two psychological and no physical measures
Not improved

Table 4: Frequency of number of patients in each category

IMPROVEMENT CATEGORY	NO. OF SUBJECTS IN EACH CATEGORY
0 - (Not improved)	5
2 - (Partially improved (1))	5
4 - (Partially improved (2)	6
6 - (Improved)	14
	Total = 30

See appendix for individual scores given ratings of either 0,2,4 or 6, overall ratings and outcome categories.

3.2 Qualitative measures of change

This section describes key moments described by each patient both immediately after treatment and at 3 month-review.

Key Moments for each subject are presented as recorded verbatim from interviews post-treatment and at three-month review.

Quotes in the text are accompanied by numbers in brackets. These relate to the numbered psychological shifts in the "expert model" (See appendix (xi), Example of Method Used for Coding Key Moments).

Footnote - For the purpose of the current analysis, post treatment key moments only were analysed in order for them to be compared with standardised measures obtained post treatment. Key Moments collected at the three-month programme review are included here for interest. (Further analysis of three-month data may be informative in order to establish, for example, whether there is a relationship between those who identify the same key moments post-treatment and at three months and more stable change, comparing post-treatment and three-month data from standardised measures. This constitutes a second aspect of this study however and will not be reported here.)

PATIENT 1 - A 57 YEAR-OLD, MEDICALLY RETIRED WOMAN WITH AN 11 YEAR HISTORY OF PAIN.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 1

After the "healing processes session", I was left thinking how can this be. What is causing the continuing pain? The doctor's visit (AR- Pain Mechanisms) this was my Key Moment. **(7)**

Key Moments identified at 3-month review:

I'm not sure if there has been one key moment, but by the end of the first few days, I was much more confident/less anxious to travel on the train on my own. The knowledge that I could not damage myself (make worse) by doing activities despite the pain has helped a great deal. (Linked to educational session (medical) and this was helped also by physio session on education).

There are times when I wonder if over-activity, extreme weather and anxiety (alone) aggravate my symptoms. "How can there not be damage?" Fortunately this thought soon goes away.

PATIENT 2 - A 55 YEAR-OLD MEDICALLY RETIRED MAN WITH A 4-YEAR HISTORY OF PAIN. ATTENDING PSYCHIATRIC DAY HOSPITAL FOR DEPRESSED MOOD PRIOR TO ATTENDING PROGRAMME.

Overall rating = 2
Outcome category = Partially improved
Number of Key Moments identified post-therapy: 2

Lots of key moments - can't remember.

When first try pacing – doing it –think not getting anywhere. After 2 weeks, start to see things happening e.g. hoovering, cooking. This was Key Moment. **(1)**

Footnote - 1= Post-treatment data, 2= data recorded at the three-month review.
Initials refer to staff in the PMP Team. K/M refers to "Key Moment".

Discovered can do anything "know when to stop". If you put the practise in – understand it. Now don't think "I've got to get this done by..." **(6)**
Flare-ups – don't get as many as I used to. Having a flare-up, mind goes back to "lesson" automatically.

Key moments identified at 3-month review:
Missing due to distressing family bereavement. Subsequent multiple family problems.
Remained in contact. Positive feedback to Team after 20 months – "back on track" and reporting good progress.

PATIENT 3 - A 32 YEAR-OLD FEMALE PSYCHOLOGY UNDERGRADUATE WITH A 5-YEAR HISTORY OF PAIN.

Overall rating = 2
Outcome category = Partially improved
Number of Key Moments identified post-therapy: 5

My pre-treatment assessment: CD showed me I might be being too harsh on myself and this was a revelation! I felt that my pain problem was being taken seriously for the first time (although AR, who referred me, was unusually attentive in this respect). **(4)**

Realising that relaxation is necessary – a necessary pleasure! Periods of calm are good. **(2)**

Learning the differences in the physical treatment for chronic and acute pain. Coming to terms with the benefits of pacing and that although it is irritating at first – that is the nature of training.**(7,6)**

Realising that I can affect my experience of pain, even if only to some extent, and that's great! **(1)**

Key Moments identified at 3-month review:

Very first session with CD – initial assessment – so hard to believe how cruel, critical I was being to myself – how unreasonable it seems now. CD pointed it out.

Being taught exercises, patience of physio teaching – felt like I was really learning something good, useful and convincing. (K/M) - in early exercise session doing stretch and circuits (not first session).

Reading manual about muscles and physical mechanisms of pain. Missing from most other medical-type consultations. Explanations. (K/M) – early on, reading at home.

PATIENT 4 - A 33 YEAR-OLD FEMALE TRAINED COUNSELLOR WITH A 30-YEAR HISTORY OF PAIN (SINCE CHILDHOOD).

Overall rating =4
Outcome category = Partially improved
Number of Key Moments identified post-therapy: 3

Over-activity/under-activity cycle on first day hit the spot. Made me think about plans and routines and also how I got here in the first place (loss of strength etc.) **(1,2)**
Healing (session) – made me feel that my body still "worked" and that things could improve. **(1,7)**
Sleep (session) – made me think about developing a routine to include exercise, relaxation and a regular morning regime. **(2)**

Key Moments identified at 3-month review:

Session 1 or 2 – to do with exercise. (Recognition that) responsibility remains with me – I'm my only hope of improving – with help. Commitment required. Overactivity / underactivity cycle made perfect sense.
Pain mechanisms session (physios) realised (I'm) "not going to break" – felt great.
For pacing – NOT sessions themselves but session on sleep. Talking about routine and how you can help set up helpful routines in your life. (I) needed routine – key for pacing and planning.

Still not had gear change with relationship with others. Boyfriend has (attended FF day).

PATIENT 5 - A 54-YEAR OLD MEDICALLY RETIRED WOMAN WITH A 16-YEAR HISTORY OF PAIN.

Overall rating =6
Outcome category = Improved
Number of Key Moments identified post-therapy: 3

"Pain does NOT equal damage" – message from AR session (Pain Mechanisms). (Hearing about) causes of pain and that most pain cannot be seen on X-rays and that doesn't mean (you're) not in pain, made me feel that I have something real. Had felt disbelieved before. IMPORTANT THAT THIS CAME FROM A (MEDICAL) DOCTOR. **(7,5)**
Listening to (observing) fellow patient "X"– good model of improvement. Also pacing etc. **(4)**

Key Moments identified at 3-month review:
Missing but attended subsequent follow-up review.

PATIENT 6 - A 49-YEAR OLD FEMALE HOMEMAKER. HISTORY OF GROUP AND INDIVIDUAL THERAPY IN PAST.

Overall rating =4
Outcome category = Partially improved
Number of Key Moments identified post-therapy: 4

Session with physios (Healing) gave me confidence to do things, knowing "I'm not going to make my condition worse". I was so scared of (doing) damage, not now. **(1,6)**

Psychology sessions (thoughts & feelings). Suddenly realised state of mind can make pain worse. K/M occurred in week 5 in thoughts and feelings sessions with TNJ. Hadn't seen (until then) how much own frame of mind was contributing to how I was feeling- "circular relationship". **(7,2)**
Practising exercises. I knew my muscles were wasting away, producing their own pain – different to pain up my spine. Doing it slowly (exercising) slowly was the key. Could only do 1-2 of each exercise at the beginning – physios so good at encouraging us. Gave me a bit extra to go home and keep going. **(6)**
I'm shocked – I'm so much more flexible. Each bit connects. K/M at about Day 4 – got hands below knees in flexion – effort made – now worthwhile. Definitely see improvement if do everyday. **(1)**
Getting muscle tone back – daughter says it.

Key Moments identified at 3-month review:
Before starting programme, still looking for a cure (scans etc.) – hoping for a miracle, never came. Programme made me accept the "now" – here and now- no cure. Can use medication when have to, rest of time, don't need it.
Accepting pain, relates to thoughts and feelings sessions, acceptance happened on the programme. "Accept in pain now and can help self. Who knows what's in the future but not waiting for it/getting depressed etc." not so afraid that e.g. will end up in a wheelchair – not thinking that so much now.
"By session 4, whatever was happening was doing us good, we all felt this".

PATIENT 7 - A 48-YEAR OLD STUDENT DISABILITY ADVISOR WITH A 9-YEAR HISTORY OF PAIN. ALSO LONG-TERM PARTICIPANT IN PSYCHOTHERAPY GROUP.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy:5

PN and AR (talks on Medication and Pain Mechanisms) – content and doctors' input. **(7)**

Relatives Day – session without relatives – us put in position of carer, not person with pain. Something "clicked" about being on "other side" (I've been a carer, partner with MS). Good reminder of what have to tell boss/partner, how helpless one can feel (as a carer). **(1,2)**

Session with TNJ (?scenarios). "C" and I discussed "The Wedding" scenario. Really good to recognise that we had different perspectives when discussing a real situation. **(4)**

Difficult encounter with counselling group members (separate from PM group). (Was related to her use of timer in that group and the group's ambivalence about it. Impeded her capacity to discuss fears about her mother's health on that occasion). Raised this as example in thoughts/feelings session. K/M for her – working through the effects of this difficult encounter. Work in terms of what it meant for her "moved things along". **(6)**

Visit by former group member- "Life After..." session – very useful. **(1)**

Key Moments identified at 3-month review:

Two visits from external specialists (PN and AR).

Pre-treatment day. Lay down foundations – very important ? not given enough importance.

PATIENT 8 - A 31-YEAR OLD UNEMPLOYED WOMAN WITH A 5-YEAR HISTORY OF PAIN.

Overall rating = 2
Outcome category = Partialiy improved
Number of Key Moments identified post-therapy: 3

Being told you are not causing any more damage to yourself (by activity and exercise) AND BELIEVING IT. K/M - did not happen straight away. **(7)**

"B" (other member of group) said it took her a long time to come to terms with. Now, if I have an increase in pain, can say "My pain has increased but I have not damaged myself" so I'm not afraid to try things. **(6)**

Thoughts and feelings, realising links between the two was a K/M. **(1)** Not really challenged feelings before. Let them get me down. This occurred during thoughts and feelings sessions plus individual sessions with CD (psychologist). **(1)**
Outside of group, someone mentioned that I seemed happier. K/M – someone recognising this.
TNJ – talk on communication about pain. It was what he said, tell people about how you're feeling. Putting skills into action, "you can only learn by doing". This was a K/M. **(1,6)**

Key Moments identified at 3-month review:
Missing – moved to Ireland. Wrote that continuing to make progress.

PATIENT 9 - A 47-YEAR OLD UNEMPLOYED WOMAN WITH A 4-YEAR HISTORY OF PAIN

Overall rating = 4
Outcome category =Partially improved
Number of Key Moments identified post-therapy: 5

Introduction to Chronic Pain. TNJ explaining that the aim of the programme was to make you functional, not to get rid of the pain. This changed my perspective considerably. **(1)**
Physios saying "is there another way of doing this?" has encouraged me to be more imaginative and flexible in my approach to movement – fitted with Alexander technique – made me think how I could do (a particular movement). **(2)**
Goal-setting session and other "management" aspects of the programme made me focus on what I could realistically do – breaking things into manageable chunks has been very helpful. When you're in severe pain its often impossible to focus on the wider picture, but attempting unrealistic tasks can make you feel like giving up altogether when you inevitably can't manage them. **(6)**
Medication review (PN) - very important. PN and AR (medical consultants) both non-hierarchical – very holistic – very important (to have this kind of approach). Felt for the first time, being treated like an equal (have been treated appallingly by some other hospital doctors). Given information here which I knew which other health

professionals treated me like a maniac for suggesting. (Effectiveness of these sessions) depends on level of knowledge of person doing it. NEEDS TO BE A MEDICAL DOCTOR. **(5)** Programme relatively non-hierarchical and non-judgemental – very important. "Feel I've been given information in order to make up my own mind" **(7)**

Key Moments identified at 3-month review:

Being amongst people who did not question (my) being in pain (in group). Degree of acceptance by other people, therefore not having to explain things. Have been stressed trying to explain this to people.

TNJ Chronic Pain session. Explaining aim of programme is to make you more functional and not pain free.

Lectures, e.g. medical sessions, thoughts and feelings sessions, very empowering, felt being treated like a grown-up. (NHS very bad at giving information).

Thoughts and feelings sessions, triggered things I knew intellectually but had drifted away from, space here to (think about) again.

Holistic experience. I felt a large degree of empathy with the group and the people running it. First group of people within the NHS for whom I've felt this.

Women only group – was good for me.

PATIENT 10 - A 36-YEAR OLD WOMAN, EMPLOYED PART-TIME, WITH A 30-YEAR HISTORY OF PAIN (SINCE CHILDHOOD). DID NOT FEEL HER NEEDS WERE MET BY PROGRAMME.

Overall rating = 0
Outcome category = Not improved
Number of Key Moments identified post-therapy: 0

Sadly, I did not experience many of these. Anything that did "click" was towards, or at the end of the programme. I would not say any of these have really helped me manage pain, but may help in future with my approach to things.

Exercise, practising techniques etc. needs to become second nature to be a success. I picked this up from the physio and "B" (group member), who also talked about getting into a routine. I have realised that my problem is that these things are

not becoming second nature to me, and are not likely to whilst my life is in such a mess and I cannot keep on top of it. I therefore worked out for myself that I need to get things back on course, by trying to establish some kind of routine that I can achieve and then add in the exercise/techniques around this.
A K/M was realising motivation (lack of) and my personal problems were getting in the way. I thought trying to do more, establishing routines, setting goals, etc. might help me to get my life back on track and feel a sense of achievement. Having done this means that I can then hopefully progress additional things, like the pain management programme techniques.
Psychological – realising that I catastrophise and that this is a problem. However I can't get out of this and don't feel the programme offers anything to help me with this.TNJ said "Perhaps I was asking questions that couldn't be answered". I agree to an extent, but still strongly feel that those I ask the questions to have a responsibility to at least listen to my concerns, look at my situation, and then honestly tell me whether or not there is something that can be done or an answer that can be given, rather than ignoring my questions or dismissing them. I do not know if this will have any impact, as I am still chewing it over and trying to find a way of acting on it.
In general, I think that I have learned that I was not ready for the programme, given the lack of support to help me through it successfully, and that there are other issues I need to resolve before I can gain anything from it. I knew I had these issues before I started the programme, but did not realise the impact they would have on my progress on it.

Key Moments identified at 3-month review:
Missing

PATIENT 11 - A 48-YEAR OLD FEMALE HOMEMAKER WITH A 20-YEAR HISTORY OF PAIN AND ADDITIONAL, NON-RELATED MEDICAL PROBLEMS.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 4

Generally, it was everything as a whole. Early on ? session 3, another group member said she felt that she had no life. I thought "I know exactly how you feel, I have thought that, felt that, said that". **(4)** But when I heard her say that I thought, no you mustn't think that, there is still so much you can do. Then I realised that if I could think that for her, then I must also think it for MYSELF. **(1)**

K/M – can't forget September 11th – happened that day, been discussing a problem with parking at school – built up as huge problem. Got home feeling quite worked up – TNJ said try to find way out – what have I done to deserve it – then came home and heard the news. Thought – "my problems are nothing in comparison. People went to work that day, healthy, never went home again. How can I think not being able to park somewhere is important". Then I thought "If I can do it today, should be able to remind myself "September 11th" – can do it again. Would not have thought that way if I had not been on the programme. **(1,2)** ? Learning techniques would not have made so much impact but ? would have come to same conclusion that could change things myself. Got caught for speeding, had very positive thought, "made me slow down, might prevent me from having an accident in future". **(6)**

Key Moments identified at 3-month review: (completed close to 6-month review). Diagnosed with additional medical problems

K/M – September 11th –New York. This did change the way I felt about myself and many other things. It has helped me to retrain my thought and feelings and I have been able to continue with this on the whole. Perspective still remains – others get so tied up with what's not important. Sheer fact that "victims" ordinary people, not in a war situation, not ill, just on their way to work ... no understandable reasons. They shouldn't be dead. Makes me feel that although my life only half a life, I've got a life and got to make the most of it. Before, I'd be thinking, can't do this, that and the other...Profound shift since September 11th, so used to approach (challenging unhelpful thoughts) now.

PATIENT 12 - A 28-YEAR OLD EMPLOYED WOMAN WITH YOUNG CHILDREN. FIFTEEN SESSIONS OF INDIVIDUAL PSYCHOLOGY PRIOR TO PROGRAMME.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 4

Group – outside sessions talking at lunchtime about how people reacted to us. **(4)**
Around session 2 or 3, recognising that although we have different pains, (we are) experiencing similar reactions from other people and having similar experiences. (Several of us have had a few bad experiences with doctors. I was right to demand an apology from a doctor – and I received it.) **(4)**

Around session 5, finding exercises getting easier. Not so tired, not so exhausted afterwards. Thinking "must be getting something right". Growing recognition that getting fitter. **(2,6,)**

Session 8 – last day – feedback. Pleased with results – made it worthwhile. **(1)**

Key Moments identified at 3-month review:

Session 4 – being able to sit longer without fidgeting – first noticed it. Doing things on my own e.g. going for bike ride on own because confidence beginning to grow. (No longer having to wait for husband if wanting to go out etc).

Talking as a group (without staff) – realisation that I was not the only one having problems getting diagnosed or problems with doctors. Then really wanted the programme to work.

Beginning to feel fitter and to sit longer.

PATIENT 13 - A 33-YEAR OLD EMPLOYED WOMAN WITH A 7-YEAR HISTORY OF PAIN.

Overall rating = 4
Outcome category = Partial improvement
Number of Key Moments identified post-therapy: 4

(K/M occurred)?Session 2-3/early on. Discussion with TNJ about goals. Had stopped using computer- made it a goal. Got very excited, could suddenly see big possibilities. Felt I could get back to where I was before, could suddenly see big possibilities. Beginning to see what I could achieve using building blocks. **(2,1)**

Session 7. Pacing at work. 2 set-backs, writing time low (1 minute) making it very difficult to work. KW (physio) spent lot of time on pacing. K/M when she said "You can't do anything meaningful in that time but need to keep practising". Very important for me because I had felt " I can't function". What she said made me feel its quite normal. This was an incentive to keep going, being more realistic. I was pretending my tolerances were higher before that. **(1)**

Talking to TNJ with husband. Ideas about husband not doing everything for me e.g. not carrying the shopping all the time. Very helpful to look at idea that I might get weaker through not carrying. **(7)**

Initial session – consequences of pain – session 1.

Sessions 7 and 8 – circuit training – been pacing up circuits this week (doubled). Now feeling that its hard exercise (out of breath) – feel I'm really working at it and its falling into place. Stretches were painful – now only 1 or 2 of them are. Key is that this (progression) is spread over time. **(1,6)**

Key Moments identified at 3-month review:

TNJ – computer work (identified) as difficult for me. Suggested "maybe increasing computer work could be one of your goals". ? start to do things that frighten me most.

Talking with P. (husband) about him doing less and me doing more.

On holiday. Using relaxation and getting through holiday O.K. (using relaxation to manage flare-ups).

PATIENT 14 - A 45-YEAR OLD WOMAN WITH CHILDREN AND A 10-YEAR HISTORY OF PAIN. CURRENTLY UNEMPLOYED FOLLOWING INJURY AT WORK. INDUSTRIAL CLAIM PENDING DURING PROGRAMME (NOT DISCLOSED AT ASSESSMENT).

Overall rating =0
Outcome category = Not improved
Number of Key Moments identified post-therapy: 3

Physio (KW) saying: "We have a different way of looking at pain" (here), thought that was good.
Sense of being understood "and this is what we're going to do about it". **(5)**
First session with physio (SH) –realised that there were individual aspects to programme as well as group (though group very important).
Introductory talk (TNJ) differences between acute and chronic pain. "First time Id heard it explained like that". Very important. **(7)**
"Muscles grow round joints to replace wear and tear" – interesting – reinforced need to exercise to keep it all going. **(2)**

Key Moments identified at 3-month review:
missing

PATIENT 15 - A 67-YEAR OLD MAN, WORKING PART-TIME AS A MUSICIAN. HISTORY OF MULTIPLE SURGERY AND 2-YEAR HISTORY OF CHRONIC PAIN. HAD FURTHER INVESTIGATIONS DURING PROGRAMME AND FURTHER TREATMENT WAS OFFERED.

Overall rating = 2
Outcome category = Partial improver
Number of Key Moments identified post-therapy: 4

Discussion groups – collective message – Thoughts and Feelings (TNJ). I was really impressed by being asked how I feel about things. **(5)** Led to rapport. Weren't necessarily my thoughts – broad section of people's views.**(4)** In first

thoughts/feelings session (aware) something changing. So can say to people, got to tell them how you feel – i.e. using elements of the programme (applied to others). **(2)**

With KW (physio). Attitude helped a lot. Rather than being sympathetic, implying there are ways of exercising you out of situation e.g. "M" (group member) could not sit still on first day of programme. Riding bike by end of course. KW suggesting "Do it, try it". This is about "having a go". On last day of programme, "M" and her husband rode home, what an example to follow. **(2)**

A few months ago, I would not have tried walking from the car on rough ground. Now got there. Thoughts and feelings - very significant. **(6)**

(Had MRI scan during programme, further surgery proposed). If pain management consultant and neurosurgeon had said changes (on scan) were not radical, would have greater motivation to do PMP things.

Key Moments identified at 3-month review:

K/M thoughts and feelings session with TNJ.

Seeing how the "camaraderie" and staff support and enthusiasm assist the (group with a) feeling of well-being and hope for the future.

Watched people improve e.g. "L", more flexible with each session. Struck me as very significant. "M" cycling impressed me. Suddenly changed, was miserable, then "I'm getting a bike". Cumulative effect of other peoples' achievements.

PATIENT 16 - A 36-YEAR OLD WOMAN WITH AN 8-YEAR HISTORY OF PAIN. HAD NOT WORKED SINCE PAIN BEGAN.

Overall rating = 0
Outcome category = not improved
Number of Key Moments identified post-therapy: 3

About week 5 – Something happened personally. Got very upset. If had stopped (attending) might not have come back. HAD to come here to break pattern of hiding under covers. Came a) "only thing left for me (programme); b) couldn't let others

down on course; c) "S"'s experiences (traumatic bereavement) – no excuse for me. Got to get on with it. Something began to change then. d) saw progress of everyone else – worse than me (at outset). Telling self "Get it together, Y...) **(4)** Penny dropped with pacing 2-3 weeks ago (about session 5-6). Overdid it, paid price, dealt with it without phoning G.P. Won't do it again. Dealt with it. **(6)** Sick of people (outside programme) saying "Take tablets". Know they can't do anything – up to me now. All happened at this time. Quite a major shift. If I had had information (before), perhaps I would not have got depressed/lost weight. Never thought getting there but given motivation on programme – all positive vibes – "got to pursue things". **(1)** Knew it in my head, but very difficult to put into action. Negative stuff does not disappear but able to think more positively (now). Speaking to people who've been through same things – programme gave them hope. Had nothing before, still don't know if it will work but hope. No reason why I shouldn't manage to make transition but I need more push.

Key Moments identified at 3-month review:

When had first set-back, realising exercise helps, I had a choice to either lie there or EXERCISE. I tried it and it worked – period of bad days decreased. (? About session 3-4). Do exercise religiously, more on bad days. Pacing – discovered can do more. "Not worrying that people call me crazy". Always used pacing from the beginning of the programme (not using timer).

PATIENT 17 - A 58-YEAR OLD WOMAN WITH A 7-YEAR HISTORY OF PAIN, WORKING PART-TIME. INDIVIDUAL PSYCHOLOGY SESSIONS PRIOR TO STARTING PMP.

Overall rating = 4
Outcome category = Partially improved
Number of Key Moments identified post-therapy: 3

About session 5, recognising benefit of physical stretch prior to doing an activity. **(1)** Realising should have been doing this all along. e.g. Taking tiles off the wall at

home. "If I stretch exercise first, I will be O.K. afterwards. Next time I will do the same". **(2,6)**

Catastrophising. When TNJ gave example, I thought "Yes, that's me". Had this recognition early on in programme. Had already covered in some individual sessions in preparation for the programme.

Session 1 – combination of things good – knew this is what I want. Knew this is for me – needed help to get "happy medium". **(1)**

Key Moments identified at 3-month review:

Combination of things. Started exercising – body – thinking about it all. Thoughts and feelings – all together – all this makes sense together. Loosen self up – get exercise – then thoughts and feelings, recognising the role of negativity. Happened early on ? session 2-3. Had spoken to CD before (programme) – was so ready for it. Once got the ins and outs – things clicked. Exercise would be wasted without (using) thoughts and feelings (techniques). "ONE COULD NOT WORK WITHOUT THE OTHER".

PATIENT 18 - A 55-YEAR OLD WOMAN, CURRENTLY UNEMPLOYED, WITH A 30-YEAR HISTORY OF PAIN. EXPERIENCED TRAUMATIC BEREAVEMENT DURING PROGRAMME BUT CONTINUED TO ATTEND.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 4

Got friends stretching with me. Showing them what the programme is about. Even if you're not in pain (now), (exercising) may delay pain. **(1)** Educating people to think about themselves —has a knock on effect for me. One friend, very sceptical about most things, but very enthusiastic when she started exercising (with me). Powerful effect on my own experience.

Thoughts and feelings. When started to apply techniques, finding that negative thoughts don't last long (but can't do anything about despondency). Able to take these techniques deeper because of recent emotionally painful experience. **(6)**

Physio : Squatting – when joints did not squeak.

holding leg up – behavioural signs

"feeling comfortable doing most of exercises" **(6)**

Pain Mechanisms talk – doctor – AR – showed they are taking problem seriously. Believe that unseen pain is real. Shows they believe – never had any explanation before. **(5,7)** Told (pain) due to amount of children I've had – muscles getting slack. Told "got to learn to live with it". Yes (this talk) meant we aren't imagining it. I stopped taking pills because I thought I was imagining it (the pain). **(7)** Sometimes willed myself not to have pain but had I known there were things you could do to help....looking for something to hold onto.

Key Moments identified at 3-month review:

Missing, but seen individually due to multiple personal stressors. Making progress with PMP skills in spite of these (she says these issues have made her more determined to succeed with self-management of her pain.

PATIENT 19 - A 57-YEAR OLD WOMAN WORKING PART-TIME WITH A 30-YEAR HISTORY OF PAIN.

Overall rating = 6
Outcome category = improved
Number of Key Moments identified post-therapy: 5

KW saying that regular gentle stretching will make me more flexible and not increase my pain level **(2,6).** Actually practising under guidance – DOING IT. KW said something (in relation to) my question about my knees. I thought "I didn't know that". Felt I got something out of this. **(1,7)**

CD "Challenging thoughts changes mood". Thoughts/feelings session, "L" (group member) got up, moaning about her mum, felling guilty (about her). I said "Is she cold, hungry etc?" "L" replied "No". I said "So she's fine". Then I thought "this applies to me". (Own worries/difficult relationship with own mother. Aware that needing to challenge feelings of guilt about her own mother). **(4)**

AR explaining that a man can have his leg amputated and still feel pain **(2,7)**

Something about relationship with Team and with other group members, e. – really stuck in my mind – cutting off leg wouldn't help. Also, lady with hand in fixed position. I thought, "I don't want that to be me so I'm going to get on with it".(g. can relate to KR). K/M – "J" (group member) saying I'm lovely". (? acceptance by group, being valued by group).

Medication – coming off it.**(2)**

Key Moments identified at 3-month review:

Giving up the sleeping pills and pain killers. CD said something one day about sleeping tablets. Didn't say I had to (come off them) but that it would be a good idea - ? Sleep session (session 4-5).(It was) "the way CD put it". "Confidence in CD. Also stopped pain killers towards end of programme? Session 7-8.

"My attitude has gradually changed, using pacing to achieve things".

PATIENT 20 - A 60-YEAR OLD WOMAN WITH A 4-YEAR HISTORY OF PAIN POST-STROKE. NOT WORKING FOR 4 YEARS BECAUSE OF PAIN BUT RECOMMENCED WORK AFTER PMP.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 3

When TNJ talked about First Aid Plans and Setback plans, I really couldn't see how they would be of any help. BUT having a Flare-Up and setback for 2 weeks, I

realised I was wrong. Afterwards, I found that I'd actually done a lot more than would have happened in the past. **(2,6,1)** Then I would have done only what "had" to be done and spent long days just sitting – I didn't know how else to cope with it. That, of course, made me feel much more confident about setbacks etc. in the future. Still don't like it happening but life can be better during them. **(6)**

Key Moments identified at 3-month review:

I think probably after about 4 weeks (sessions 4-5) I realised that I was able to do that little bit more.

The day in early December we went Christmas shopping and it was a whole lot better than the years before.

I remember when KW gave us the circuit training and I thought "now that really is pushing it!" but a week later feeling that they were helping.

The thoughts and feelings sessions with CD for me were very good. To be able to talk openly about those and to find that it was possible to turn those around and that it actually helped.

The Friends and Family day (although no one with me) I realised that I tried to cover up, with friends and family, how I really felt, and that being that way didn't help me or them.

PATIENT 21 - A 39-YEAR OLD EMPLOYED WOMAN (BIOLOGY GRADUATE) WITH A 10-YEAR HISTORY OF PAIN. HISTORY OF DEPRESSION – HAS HAD LONG-TERM PSYCHOTHERAPY.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 5

K/M KW- Main factor was finding out that over/underactivity was a commmon phenomenon in chronic pain and that this is what exacerbated the situation.**(7)**

Surprised WE ALL SAID IT – how is it I can do loads some days… knowing this is what happens and its detrimental, can be depressing.**(4)**

Realisation that a flare-up can be dealt with efficiently and doesn't have to be a major worry. **(2)** Its partly the KNOWLEDGE knowing the difference between a flare-up and a setback – don't always know. If "nip it in the bud" don't always have to have a setback. I'm not just going to lie about. I did not have a "flare-up plan" before, think this is very good. **(2,6)**

Lecture on why still feel pain by rheumatologist (AR) helped me understand how the pain is there even though no new damage. Receptors **(knew a lot, degree in Biology)** – phantom limb stuff – he really explained very well - physiological thing – nerve pain.**(7)** Tended to catastrophise before, now reassuring, know that conscientious exercise will help it lessen. **(1,2)** Reassures you that you are not imagining it. Can have pain without damage. (I'm) always reading things in the paper – needs clarification and we've had it here. (Good) when it relates to you. All diagrams of joints and information re: shrinkage of muscles – all the physiology – so helpful.**(7)** I hadn't noticed lost stamina, not too late to improve it. **(2)** Emphasis on importance of exercise – very comforting. **(6)**

Key Moments identified at 3-month review:

Combination of AR and physios – educational aspect about pain mechanisms and potential to improve physical health by doing even small amounts of regular exercises – dispelling of fears of causing more damage.

Theory of pacing, breaking things up into very small stages rather than all – or-nothing method we ALL used to do. This was a revelation!

Generally just hearing other people voice EXACTLY SAME THINGS about how pain made them feel and how it interfered with their relationships/moods/frustrations. DIDN'T FEEL SO ISOLATED.

PATIENT 22 - A 32-YEAR OLD SINGLE MOTHER (DIVORCED) WITH TWO YOUNG CHILDREN. CURRENTLY HOMEMAKER. 7-YEAR HISTORY OF PAIN.

Overall rating = 6

Outcome category = Improved

Number of Key Moments identified post-therapy: 4

K/M - Day 1- KW explaining the overactivity/underactivity cycle. Realising I did it said to me I was going to learn something here.**(7)** "Something in this for me". "How can I stop the OA/UA cycle from happening? **(1)**

Learning about chronic pain and medication and healing. INFORMATION. Things can go wrong in the body and its nobody's fault and it can't be fixed. First time I'd heard this. Reassurance reduces anxiety. Its O.K. to do things. There's a reason for the pain, it won't get worse, "penny dropping". **(7,1)** Doctors don't tell you, give time, you get very worried, lack of education.

Talking with the group. They say something about themselves and you identify – "I do/don't get that!" I'm not alone. Knowing others are there in the same situation as you –felt very isolated before. Now know "not the only one". Having something in common, support, gel together "BE THERE FOR THEM". **(4)**

Seeing the difference pacing makes if you keep it up. Aware of this by half way through the programme (? Session 4-5, cumulative effect). Seeing times written down. Increasing times from 1 –10 minutes for sitting, walking – "something's really improved". **(6)**

Key Moments identified at 3-month review:

When the time increased from 2 minutes to about 10 minutes. Instead of silly times – a more realistic time.

Realising that the stiffness was reducing. Could not see benefits of exercise really until session 8. Did not notice so much at the time.

PATIENT 23 - A 53-YEAR OLD UNEMPLOYED WOMAN WITH A 13-YEAR HISTORY OF PAIN PLUS MIGRAINE.

Overall rating = 6

Outcome category = Improved
Number of Key Moments identified post-therapy: 3

Physio input – realising we're like a machine – can stretch nerves. **(7)** "I'm a convert now" – good time pacing and stretching. **(2)** In last 3 weeks of programme, have tried and had some success. **(6)** Overdid writing which led to flare-up, not for any length of time. Spasms last year – much better now.

? Friends & Family Day or individual (K/W) sessions: KR's help in "packaging my response to people who ask why I'm not working i.e. "I have a Pain Problem" and also making me aware of the extent to which I feel I must justify myself to all and sundry. **(2)**

Thoughts and Feelings: CD's talk on our "internal dialogue".

Key Moments identified at 3-month review:

Pacing ironing on one particular occasion.

Understanding movement - cumulative.

Awareness of thoughts and feelings – sorry I didn't get help years ago. Guidance about when to show feelings etc....

When I do stand up for myself and say something.

PATIENT 24 - A 48-YEAR OLD UNEMPLOYED WOMAN WITH A 10-YEAR HISTORY OF PAIN. (Language issues in relation to the PMP (and cognitive sessions in particular) emerged during these interviews since English was not her first language. Although thought to have good use of English at time of assessment, she felt she would have benefited from being given handouts in her own language to back up sessions. Obtained medical treatment for pain during last week of the programme).

Overall rating = 2
Outcome category = Partially improved
Number of Key Moments identified post-therapy: 1

When starting exercises, session 3, starting to feel more flexible. Thought "something's working". **(6)**

Around session 4-5, exercises helped me to give up my crutches. **(6)**

Taking new dog for a walk (got him during programme but not because of programme). Could not have walked him before (not mobile enough). **(6)**

Key Moments identified at 3-month review:

KW explained how my knee was before – click – today explained my movement not right – still clicking. Helpful to do something different.

No real K/Ms.

PATIENT 25 - A 67-YEAR OLD RETIRED WOMAN WITH A 30 YEAR HISTORY OF PAIN. SOME GAINS, SOME DISSATISFACTIONS WITH THE PROGRAMME BUT AGREED TO COMPLETE QUESTIONNAIRES, PARTICULARLY IN ORDER TO VOICE SOME OF THE LATTER.

Overall rating = 0
Outcome category = Not improved
Number of Key Moments identified post-therapy:0

(under heading: Key Moments)

Why I get no relief from pain killers anymore.

The differences between acute and chronic pain.

Why I get sensations as well as pain.

Finding I could manage the exercises.

Key Moments identified at 3-month review:

Missing

PATIENT 26 - A 63-YEAR OLD RETIRED WOMAN WITH A 25-YEAR HISTORY OF PAiN. (LIVING WiTH HUSBAND WITH DEMENTIA, UNDER CONSIDERABLE STRAIN).

Overall rating = 0
Outcome category = Not improved
Number of Key Moments identified post-therapy: 1

Was still thinking it was hopeless when others were benefiting and was considering giving up and going to live with my daughter and sitting in an armchair all day. Realised on Monday 18th March (day before session 9, last session) that could turn head when crossing road, hooray something is loosening up at last which was proof to me that something was working so my attitude changed completely. **(1)** (Twenty years ago when neck pain was awful was locked into leather helmet with weights attached which hang over back of hospital bed and made to stay still for 10 days without moving (presumably to stretch my neck to relieve pain). Was wondering if would come out like giraffe woman – what awful treatment on looking back and almost medieval by your standards.

Key Moments identified at 3-month review:

Just before the end (7th session ?) when felt all was hopeless and my pain was much worse, suddenly realised could move neck after years of stiffness. I now test myself by that to see how rest of body is! Some exercises cause increased pain so I have learned not to do them all as pain doesn't improve – the opposite after a time.

PATIENT 27 - A 45-YEAR OLD WOMAN WITH A 13-YEAR HISTORY OF PAIN. WORKING IN SETTING WHERE HAS HAD PREVIOUS EXPERIENCE OF FACILITATING AND PARTICIPATING IN GROUPS. MOTHER OF YOUNG CHILD.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 4

One K/M was during AR session where I faced the likelihood that to some degree or another I would live with my back pain hereafter. That there was little use in my hoping for a miracle (though of course there are exceptions). **(7)**

If I'm not injured, why is this pain going on – not entirely within my control – wondered if I was perpetuating pain somehow.

I started to feel less blaming of myself too once I began to feel that in effect I was learning life management with pain rather than pain management through life. **(2)**

Minor K/M – to do with experiencing other people. Very shocked by comment made by group member to a disabled observer (trainee in wheelchair). Had preconception that people would not be that insensitive. Realisation about other people. **(4)**

CD – very interesting ideas in relation to thoughts and feelings. (Recognised) all members of the group have different experiences of pain and (differences) in the way we interact with pain and how it makes us. (Had pain for 13 years, constant for 2 years). **(4)**

Group – not homogeneous. When I heard that other people (in the group) had had 30-40 years of pain, (I was) shocked to begin with...also interested to know how it had influenced what they had become. Thought – "not going to let it get to me like this" i.e. like it seems to have influenced some of the other group members. **(1)**

Key Moments identified at 3-month review:

One of the K/Ms was realising that my pain was not going to respond to treatment by disappearing altogether. This belief had been kind of "Holy Grail" which had led me to physios, chiropractors etc.

Also realising that I wanted someone to say that living my life was not going to damage me physically i.e. that physical exercise would not damage me. I had tended to avoid things believing that I might cause myself injury. (K/M when got that reassurance implied here). Although I still have some fear to overcome in this

regard, I am more confident that I am less subject to an overactivity/underactivity cycle.

PATIENT 28 - A 66-YEAR OLD WOMAN WITH A 40-YEAR HISTORY OF PAIN. HELPING HUSBAND WITH BUSINESS ON OCCASIONAL BASIS. ? SUBTLE COGNITIVE IMPAIRMENT NOT DETECTED AT ASSESSMENT ? RELATES TO CORONARY ARTERY BYPASS GRAFT SURGERY OR OTHER.

Overall rating = 4
Outcome category = Partially improved
Number of Key Moments identified post-therapy: 0

No real key moment

Felt a lot of pressure on me from physiotherapy side of things. Psychology felt very valuable. Did not feel pressure from psychology. Spoke to TNJ after two lots of exercises (one new) – could not cope – thought I can't go on. When phoned to speak to TNJ about this – he made me feel that I did not need to feel under stress. "Still feel its worth pursuing pain management programme".

"Can't think at present". (? felt pressured by cognitive demands of this question).

Key Moments identified at 3-month review:

Data missing. "Too busy to return form and/or make appointment".

PATIENT 29 - A 46-YEAR OLD EMPLOYED MAN WITH A 25-YEAR HISTORY OF PAIN.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 3

K/Ms – Seeing the positive effects of pacing. "Two Saturdays ago" (session 6-7), leaning over the production desk for 35 minutes without experiencing any discomforts gross enough to make me have to leave the situation. (I was previously struggling on 5 minutes / checking clock etc.) Realising that doing something for a lot longer without use of timer. **(6,1)**

One-to-one with TNJ re: psychology of the course. Removed anxiety about being on the course – session 2 or 3 – felt it would be O.K./much more aware of everything.

One-to-one with KW re: muscles and joints. Knowing about information – THOUGHT HAD NEVER HEARD THIS FROM DOCTORS BEFORE. Knowing more about physical self. **(7)**

Key Moments identified at 3-month review:

K.M. "Switch" occurred when I came on course but can't put finger on point. Hearing other people's views as we were proceeding on the programme helped this to happen, especially FH talking about dancing around at bus stop and CF saying that she was no longer bothered about what people thought in the office. (? wish I'd never thought like this (as I did before) – e.g. social services – real problem with official expectations – can't accept explanation because can't see it.) Hearing people talking in that way was very influential, especially during last couple of sessions (sessions 8-9).

"You don't really know who you are until you see your reflection in other people".

"Something in the way I think about my condition has changed" – cumulative.

Time in the course where I realised that through instruction and exercises I could make a difference.

During one-to ones with KW and TNJ - Visual impression of what I look like inside – (mechanics, body structure).

Part of session -? coping in "real life" or setback plan – (significant).

Can't highlight one particular thing – spontaneous effect.

PATIENT 30 - A 25-YEAR OLD EMPLOYED WOMAN WITH A 12-YEAR HISTORY OF PAIN.

Overall rating = 6
Outcome category = Improved
Number of Key Moments identified post-therapy: 3

First individual (key work) session with CD helped me to address the extra "baggage" that I'd added on to having chronic pain – especially the restriction of my social life and fears about talking to people about the pain. From then on, I have made plans and (mostly) kept to them. **(2)**

Within days (within first week of programme), experience of PAIN REDUCTION. Outside the group it was when I realised – despite my sitting tolerance being only 3 minutes and thus exhausting over a day in the office – that my back pain was less than it would normally have been at the end of a day. That gave me reason to stick to it. **(1,6)**

Session 5 – before "Friends and Family Day" – instant effect as partner read file. His recognition that things in the file related to things in our lives.... Will help once programme is finished. Had done stretches together before that.

Key Moments identified at 3-month review:

Realising that exercise and getting fitter was going to be the key thing in CONTROLLING my pain – it has helped me stick to a fitness regime.

3.3 Combining standardised measures and subjective measures of change.

3.3.1 Two sets of data for each patient were entered into the SPSS statistical software package. These were:

i) The quantitative category of improvement for each patient. It was decided to combine the two groups making partial improvement into one, hence four categories became three. These were represented by numbers 0, 1, or 2 where

0 = not improved on either psychological or physical variables
1 = improved on either one psychological and one physical variable
or two psychological and no physical variables
2 = improved on at least two psychological and one physical variable

ii) The number of "Key Moments" as described above (0, 1, 2, 3, 4 or 5).

Table 5 shows the frequency of Key Moments for patients within the three groups (not improved, n=5; partially improved, n=11 and improved, n=14 (see table 5).

TABLE 5

RESULT 1 : FREQUENCY TABLE

Key Moments	Not Imp (n=5)	Part Imp (n=11)	Improve (n=14)	
0	2	1	0	
1	1	1	1	
2	0	1	0	
3	2	3	5	
4	0	3	5	
5	0	2	3	
6	0	0	0	
7	0	0	0	
Totals	5	11	14	

3.3.2 RESULT 2: NON-PARAMETRIC CORRELATIONS COMPARING PATIENT CATEGORY OF IMPROVEMENT WITH NUMBER OF KEY MOMENTS IDENTIFIED PER PATIENT WITHIN EACH CATEGORY

The aim of the analysis was to establish whether:

(i) a relationship existed between categories of patient improvement and the number of key moments identified for each of the thirty patients in the study, and

(ii) whether this relationship was statistically significant.

The analysis involved examining two sets of variables, neither of which was identified as either a dependent or an independent variable. It was not therefore a case of trying to establish whether improvement as a result of participating in the PMP (and measured objectively) would predict who would report most key moments or whether the number of key moments reported would predict who did best on objective measures of change. The aim was simply to establish whether or not a relationship existed between the two. A correlational method of analysis was chosen to analyse this relationship. Correlation does not identify direction of causation and takes into account the possibility that a third variable could explain the relationship between the measured variables.

The data consisted of both rows and columns containing ordered values but since the improvement categories were not measured on an interval scale, a parametric statistical test could not be utilised. A non-parametric test was therefore required and Kendall's tau_b was the chosen method of analysis. **Kendalls' tau_b found a significant positive correlation between degree of improvement following participation in a PMP and the number of "key moments" reported (Kendall's tau_b = .019, n=30, p=.05 (2-tailed) .This anaiysis demonstrated the main findings of this study.**

This correlation identifies a positive relationship between category of improvement and number of key moments per patient within each category. The outcome suggests that the more improved the patient, the more examples of "key moments" they will have identified, the less improved they are, the fewer number of "key moments" identified. The significant result (.019) suggests that there is less than a 5% probability of this association occurring by chance. This relationship supports

the hypotheses both that such a relationship might exist and that the greater the individual's change on objective measures, the more categories of key moments they would have identified, according to the "expert model".

4. DISCUSSION

The discussion will be presented in five sections:

4.1 Support for the hypothesis

4.2 Issues associated with the collection of data

4.3 Issues associated with the analysis of data

4.4 Findings and their implications

4.5 Methodological critique and future directions

4.1 Support for the hypotheses

The main hypothesis of this study was that patients who experienced and could articulate specific "key moments" of change whilst participating in a PMP might be those who could also be demonstrated to have made the greatest changes on standardised measures. A further hypothesis was that there might be a relationship between number of factors present and magnitude of change. These hypotheses are both supported by analysis that suggests a statistically significant relationship between number of "key moments" and magnitude of change according to standardised measures.

One of the main aims of the study was to attempt to establish a preliminary understanding of the processes involved in change on a PMP. This involved combining qualitative and quantitative research methods. Pope & Mays (1995) have argued that whilst qualitative and quantitative approaches tend to be portrayed as antithetical, qualitative techniques can provide substantial breadth to quantitative research. This study could not have proceeded without both types of approach; qualitative data is being used to try to obtain answers to process questions which quantitative measures cannot access. Equally, a quantitative measure of improvement is required to validate qualitative findings. This study could not have proceeded if one type of method had been rejected in favour of the other and

supports the thesis of Pope & Mays (1995) that" we need a range of methods at our fingertips if we are to understand the complexities of modern health care".

4.2 Issues associated with the collection of data

(i) The role of the participant researcher.

As already identified above, some issues exist around the collection of data by a member of the clinical team who also participated in the PMP. On the positive side, the researcher was known to the patients and had detailed insight into both the programme content and the dynamics of each group. Patients were encouraged to identify aspects of the programme that they found helpful but also to make constructive criticism where they felt this to be appropriate. This was promoted on the basis that one of the aims of the research was to identify areas for improvement in the programme.

As stated above, the researcher believed patients felt comfortable with the interview process and several reported finding the process useful, both in terms of consolidation of, and reflection upon, what they had learned. Some recognition needs to be made, however, that interview by a participant researcher as opposed to a researcher unknown to patients may have had some influence on the nature of the data obtained. It is possible that patients felt under some pressure to report "key moments" of change as somehow more significant than they really were to them. They may have reported certain things simply because they remembered them occurring, possibly in order to "please" the participant researcher. On the basis of the way in which key moments were reported however, particularly in the way that information was backed up with other relevant material, the researcher felt confident that events reported as "key moments" were genuinely meaningful to patients.

(ii) The ratio of women to men in the sample

The sample of women attending PMPs typically outnumbers men on a ratio of 2:1. (based on unpublished sample of 5000 patients who attended INPUT at St Thomas' Hospital; Williams, personal communication). The sample of thirty in this study included only three men and it was felt that this could have had some implications

for the reported findings if men and women were found to respond differently to the question of "key moments" in some way. The bias towards women in the sample might therefore obscure some aspect of the findings. However, on surveying the data from the three male programme-participants (patients 2, 15 and 29), there do not appear to be any obvious differences between the data obtained from male and female participants in terms of number or type of key moments and their relationship with objective measures. For example, the men identify the achievement of an articulated working model of pain, reflecting on their own experience of change, including thoughts and feelings, and on the communal experience of participating in a PMP. One man improved and two partially improved on objective measures. Additional male participants in the group might have resulted in different types of "key moments" being accessed but on the basis of existing data, there is little evidence to suggest a difference between the male and the female experience of PMP participation. The sample would therefore seem to be reasonably representative.

(iii) The relationship between the experience of "key moments" and the capacity to identify and articulate them.

A method which relies on people's capacity to articulate what they have learned may have some limitations. Patients were interviewed for up to one-and-a-half hours and in most cases, large amounts of information were obtained. The "key moments" section constituted the culmination of the interview for the purposes of the current research but was actually a relatively small part of the whole interview. On reviewing the raw data, two possible concerns emerge:

1) There are examples of patients who improved well on objective measures but were not particularly articulate in terms of "key moments" (2-3 identified, as opposed to 5 or more). It would be anticipated that some patients may be less able to articulate their thoughts than others, or that for some, change may be occurring at a level that they cannot readily access. This suggests that the "key moments" measure has some limitations in terms of its association with the objective measures recorded by patients who have done well on the programme.

2) There are also examples of one or two patients who have made only partial change on the basis of objective measures but scored highly in terms of "key

moments". Some of these patients might be recognised as being able to articulate the "right" answers but without having "internalised" the material. This is a further example of some of the limitations in the "key moment" methodology.

(iv) Timing of the data collection.

During the course of the data collection phase, a hugely significant world event occurred (the terrorist attacks on the World Trade Centre on September 11th, 2001). The cohort of patients involved in the programme at the time provided a variety of insights into their personal experiences of that event in conjunction with participating on the PMP during their post-treatment interviews. The event impacted on several patients in a way that may have influenced their progress in learning pain management strategies, particularly with respect to cognitive restructuring. Some of the key moments cited relate to individual's reflections on "September 11th" (see section 3.2).

Although not directly relevant to the current study, one or two taped interviews include some fascinating material regarding patients' experience of this event. For example, one patient had a son working in the World Trade Centre and did not know his whereabouts for 24 hours after the attacks. She relates her experience of waiting for news and how she employed cognitive techniques learned on the PMP to help her.

4.3 Issues associated with the analysis of data

(i) Quantitative data

1) Creating thresholds for improvement

The method of setting thresholds for determining change in the quantitative measures has been described above. This was done carefully on the basis of prior research (Williams et al, 1996) and in consultation with the first author of that research, Dr. Amanda Williams). The thresholds were therefore set on the basis of considerable clinical and research expertise. It might be argued that statistical significance should have been established using a Jacobsonian Model (Jacobson &

Truax, 1991). However, a data set of thirty patients may have been too small a number in order to establish statistical significance and the clinical significance of change would therefore be overlooked. The method utilised for determining clinical significance (as above) may become a more established and accepted way of appreciating change in relatively small groups of patients.

(ii) Qualitative Data

1) Difficulties in coding

The qualitative data proved difficult to code using the constructs defined by the expert model of 'necessary psychological shifts'. Although there was evidence of these constructs in the data, in practice it became apparent that overlap between constructs (as described above) accounted for much of this difficulty, and additional discussion was required to reach a consensus on ratings. Though a clear methodological concern, in some senses this difficulty is also helpful, in that it indicates a need for further iteration of the expert model.

It is possible that involving a third "rater" might have been useful in helping to clarify some ambiguities, though this option was not pursued on practical grounds. A more helpful approach might have been to re-code the data with two new and independent raters working from the next iteration of the expert model, which would also have the benefit of ensuring that both raters were blind to outcome and the patient's identity.

There were also certain inherent assumptions within the model that meant some potentially significant data were ignored (could not be categorised). For example, the model suggests that one necessary psychological shift starts with a sense of isolation and ends with communal experience. Communal experience is assumed to be a good thing. One member of the group found the communal experience a negative one, based on her perceptions of the behaviour of some of the other members of her group. She therefore considered that remaining "outside" of the group was a constructive response to this behaviour. She nonetheless improved on objective measures of change and identified several key moments as evidence of her capacity to reflect on her experience of PMP participation.

4.4 Findings and their implications

A secondary hypotheses to this study was that by examining the "key moments" of patients who improved, it might be possible to identify the aspects of the programme that may be most necessary in order to effect positive change. Referring to the summary of key moments (see appendix), it may be possible to identify aspects of the programme that seem to be most frequently identified as key moments. Quotes in the text are accompanied by numbers in brackets. These relate to the numbered psychological shifts in the "expert model" (See appendix (xi), Example of Method Used for Coding Key Moments).

(i) A combination of education from the medical pain specialist and from the physiotherapists demonstrates that the achievement of an articulated working model of pain **(7)** is a common key to change for this group of patients. This will be dealt with in two sections:

1) Medical "pain mechanisms" session.

With regard to the "pain mechanisms" session, several patients commented that it was really important for them that this came from a medical doctor. One patient also wrote "source matters, trust in the person (giving this information) is vital" **(5,7).** From the data, there seem to be several ways in which this session can be a "turning point". Some people talked specifically about the level of explanation they received in this session and how "this brought (them) new understanding" **(2,7)**. For others, the important point seemed to be that this was an acknowledgement (from a high status and apparently highly knowledgeable person) "that my pain is "real" " **(5,7)**. Others still were impressed by the doctor's capacity to acknowledge that "medicine does not have all the answers". This seems to have had a powerful effect in validating patients for not having the answers to these complex questions for themselves. Several patients recognised a shift relating to having felt devalued but now feeling valued as a consequence of a doctor taking time to explain their condition and doing so in an accessible manner. Someone commented that for the first time, as a consequence of this talk, they felt they were "being treated like an equal" **(5)**. Another patient elaborated that the session on pain mechanisms (coming as it did from a "specialist") made her realise that "no one has a "magic cure" and that learning pain management skills is my only realistic option" (**1,7**). Finally, a

patient who developed chronic pain as a consequence of a "surgical" accident, and who had never received either an explanation or an apology, reported finding this session went part-way to helping her resolve some of her very difficult feelings about the medical profession. (This was difficult to code and is not reported here verbatim. It was concluded however that this should be attributed codes **2,5, and 7).**

This session in its fully developed form has only comparatively recently been incorporated into this PMP. Although it cannot be quantified, it is assumed likely from the above that this session plays a central role in preparing the way for patients to embrace the pain management philosophy.

2) Expert physiotherapist input

Physiotherapists provide both an educational and a practical component to the programme. They facilitate the move from theory into practice, helping patients to overcome their fear of movement through education, teaching patients about the benefits of exercise and then helping them to do it. In terms of necessary psychological shift, their input, according to the data is closely identified with both developing a sense of what is required to achieve change **(1)** and experimentation and learning **(6)**. The achievement of an articulated working model of pain **(7)** is also facilitated by sessions with the physiotherapist and empowerment **(2)** is closely related.

The introductory session on underactivity/overactivity cycle is cited in the data as of key significance when people identify with the behaviour being presented and recognise, often for the first time, that there is a specific way of dealing with this. A number of key moments are identified associated with the link between the theoretical session on healing processes and the way in which this promotes experimentation. For example, one patient described one of her key moments as the effect brought about by the healing session. "It gave me the confidence to try things...I'm not going to make my condition worse. I was so scared of damage, before, not now **(1,2,6,7).**

Several patients reported some sorts of links between the medical session, the healing session and/or putting stretch and exercises into practice. One example of this: "My key moments...learning about pain mechanisms and medication and

healing. Learning that things go wrong in the body and its nobody's fault and it can't get fixed. First time I'd heard this...information reduces anxiety...there's a reason for the pain and it won't get worse... helpful to know this" **(2,7).** Another patient reported a key moment as follows: "Healing..told muscles grow around joints to replace "wear and tear" – interesting, reinforced need to exercise to keep it all going" **(1,6,7).**

From the findings is seems most likely that this aspect of the programme is enormously significant in promoting change in pain management terms.

(ii) The role of psychology in the PMP

It is interesting that although patients do acknowledge the significance of psychological techniques for promoting change, the data suggest that they may find it less easy to access examples of cognitive shift associated with key moments of change. One example that emerges from the data on a few occasions relates to the identification of catastrophic thinking. Generally people link the capacity to challenge catastrophic thoughts (usually about their conditions) with information they have learned from medical/physiotherapy sessions. (This is typically coded in the data in relation to developing a sense of potential empowerment **(2).**) Teaching people the skills to challenge unhelpful thoughts is unlikely to benefit them unless they have alternative more helpful thoughts with which to replace catastrophic ones. In this instance, new information can allow people to challenge old assumptions about their pain conditions with beneficial results.

On this basis, cognitive restructuring, particularly related to catastrophising, seems to be an important factor in effecting positive change.

(iii) Change occurring as a consequence of reflecting on one's own progress.

There are numerous examples in the data of key moments associated with the experience of people reflecting on their own progress. Examples of these include versions of the following: "I'm shocked, I'm so much more flexible. Key moment at about Day 4 – got hands below knees in flexion – effort made – now worthwhile. Definitely see improvement if do everyday". The "expert model" does not adequately account for the shift associated with this experience. Developing a sense of

potential empowerment **(2)** comes closest but still does not fully reflect the psychological shift that has occurred. This is discussed further below in the critique of the method.

Another area identified as significant for some people but not included in the model was the effect of other people noticing and commenting on the patient's improvement. Several examples of this in the data are typified by one person's key moment: "Outside the group, someone mentioned that I seemed happier. Someone noticing, this was a key moment for me".

From the data therefore it does seem to be possible to identify aspects of the programme that patients apparently find particularly salient and which are identified as key moments of change for them. These may be the aspects of the programme that are necessary in order to effect positive change and they are summarised below:

Summary of aspects of the programme that may be necessary in order to effect positive change.

1) Education session from medical pain management specialist, and all that that involves;
2) Education on healing processes and the facilitation by the physiotherapists of experimentation in order to improve physical fitness and flexibility;
3) Education on the Overactivity/Underactivity Cycle and its relationship with learning techniques for pacing activities and for avoiding pain flare-ups through "overdoing";
4) Education and implementation of cognitive techniques for identifying and challenging unhelpful thoughts, in particular in relation to managing catastrophising.
5) Any aspects of the programme that influence a patient's capacity to acknowledge and reflect on their own progress.

(iv) The complex nature of positive change

From an examination of the data however, there are a wide range of key moments and different combinations of key moments that emerge for different individuals. Some individuals, who have apparently improved on the PMP, may make little or no reference to the key moments summarised above. However, they identify other key moments that were significant for them. Examples of this include reduction in pain intensity and encouragement from others, both of which may occur as a by-product of the programme but not for all participants. On the basis that reported key moments reflect the most salient aspects of the programme for different individuals, it is clear that the experience of change does not occur in a uniform way. This has implications for the discussion surrounding attempts to deconstruct the model of pain management delivery. Positive change is a complex process and there are evidently different "paths to success". Attempts to deconstruct programmes in order to focus on a more limited range of material/techniques are likely to result in also limiting the opportunities for making positive change amongst PMP participants.

Whilst it emerges that some key moments reflect single events, more often they occur as a result of the "coming-together" of a combination of different aspects of the programme at one particular point. It is therefore not possible to identify any one or two discrete components of the programme as responsible for change without taking into account aspects that may have played a minor, but significant role in the process along the way. This is one reason why it is difficult to separate key moments by codes. Within the data, there is evidence of a variety of necessary psychological shifts, all of which can be identified. The data suggest that the process of change is however occurring at multiple levels. The wide range of key moments supports this and demonstrates that many facets of a PMP need to be in place to obtain comprehensive benefit.

(v) Implications for the programme

Findings from this research have proved encouraging for the participant researcher and other members of the clinical PMP team. The great majority of patients in this cohort improved or made partial improvements according to standardised measures. From the qualitative data, most of them reported experiencing positive change in relation to what they were learning on the programme and, although not directly reported here, they were, by and large, satisfied with their treatment and results.

On the basis of aspects identified above that may be necessary for effecting positive change, the following components of the programme are routinely included:

1. Pain Mechanisms session. The importance of this session has been identified. If the doctor normally responsible for this session is not available, negotiation is undertaken to ensure the session continues to be taught by a medical colleague. Care is taken to ensure that the person responsible for this session is very experienced in chronic pain management and "non-hierarchical".
2. Identification of, and explanation of the Overactivity/Underactivity Cycle. This seems to be a necessary precursor for patients to assimilate the theory of pacing techniques.
3. Theory/education is delivered alongside practice in sessions run by physiotherapists because of the pronounced benefits of information in reducing fear associated with movement and exercising.
4. Cognitive restructuring is taught by psychologists with a particular emphasis on learning to recognise and challenge catastrophic thinking. Frequently psychologists now join physiotherapists in exercise sessions to help patients challenge catastrophic thoughts in relation to movement at the same time as they exercise.

Temptation to "skip" sessions, such as relaxation techniques, in the absence of relevant staff is avoided. These sessions have sometimes been considered somewhat peripheral to the programme but data from this study suggests that they may constitute a key moment of change, or a component of a key moment for some individuals. On that basis, their contribution may be enormously significant.

Two patients who participated in the study expressed dissatisfaction with the programme. Both had suffered with a particular condition (Benign Joint Hypermobility Syndrome) since childhood and felt that the pain management approach in its usual form failed to take into account some of the particular challenges faced by this group of patients. They both reported experiencing no key moments on the programme.

This issue has been acknowledged and addressed as a consequence of this study. The programme has decided to run specialist groups for these patients. There is a particular emphasis on the specialist information they are given during the Pain Mechanisms session and on the types of exercises taught for people with this condition. The first specialist group of this sort has been run and was greeted with considerable enthusiasm by its participants.

Finally, the process of undertaking this research highlighted the importance of group processes in a way that had not previously been fully appreciated by the researcher and others. Within some of the key moment material, evidence emerged of patient discovery/insight gained through participation in the group. The clinical team felt that they were insufficiently trained to optimise this aspect of the change process and have subsequently obtained advice from a group therapy expert.

4.5 Methodological critique and future directions

This study utilises an approximate version of the qualitative analytic technique, Task Analysis (Greenberg, 1984). Greenberg (1986) suggests that initial attempts at explanation in process research looked for simple associations between single variables in isolation from their context and that this neglected the importance of patterns of associations. In this study, an "expert model" of hypothetical change is developed as a first stage to understanding the variables associated with change. Patient data is then compared with the expert model to establish the extent to which this data exemplifies the model. In "true" Task Analysis, a refined proposed model of resolution performance is built by comparing idealised and actual performance "in an iterative manner". Greenberg (1986) suggests that this represents a rigorous form of inductive clinical theorising that results in the construction of a model in terms that can be tested by process assessment.

What has been attempted in this study goes part-way with the task-analytic approach. There are at least two ways in which the current study could develop the approach further and gain additional information about the process of change involved in participation on a PMP:

(i) A more refined model of change in terms of problem resolution might be obtained if the process of iteration were to be repeated. Three of the

categories were closely overlapping and in some instances the same item was identified as exemplifying three different constructs. Further iteration might enable more discrete categories to be established. One category of the proposed "expert model" was, with one exception, absent from the interview data. This was the category "personal attribution and self-blame/guilt/shame" moving to "attribution to external, non-personal cause or chance". Further iteration might remove that category from the refined model. There were also examples of "key moments" of change which were not predicted by the "expert model". These include patients' reflections on their own increased flexibility or personal insight, patients' sense of the significance of others' noticing this change and patients' experience of reduction in pain intensity (not anticipated but nonetheless present in the existing data). Further iterations might confirm the significance of these examples for a refined expert model. Figure 3 shows a hypothetical second iteration of the model. This is designed to more closely resemble the data obtained from the interviews.

Figure 3

Hypothetical second iteration

Necessary Psychological Shifts

Starting Point	End Point
Helplessness	Sense of potential empowerment
No sense of what is	Sense of what is required to
Required to achieve change	Achieve change
Sense of coping alone with	Having a shared, common problem
a unique problem	with shared solutions
Devalued	Valued
Frustrated inactivity	Experimentation and learning
Fearful inhibition	Confident managing
Lots of disconnected	Achievement of an articulated working
Information (or none at all)	Model of pain
Pain as a mystery that cannot be explained	Creation of a narrative

(ii) The current study reports frequency data in terms of numbers of examples from the "expert model" that could be identified in the data. Greenberg (1986) suggests that the pattern of occurrence of particular variables (either in terms of combination, or of when they occur) is actually likely to be more informative in terms of therapeutic significance. It follows therefore that one combination of three "key moments" may have more clinical significance than a second combination of three but collecting data in terms of frequency only means that this pattern and its meaning are not available to the researcher. Given additional resources this method of analysis might be attempted although would probably require larger numbers of patients than were interviewed for the current study.

These points suggest that the method used could be elaborated in order to make fuller use of the data available. Both the above could be developed by further examination of the data and additional time spent doing this might well be a fruitful way of gaining additional insight into the processes of change under examination. In addition, this research might benefit from replication using a) different experts to formulate the "expert model" and b) different researchers to code the data. This might yield information about additional and/or alternative psychological shifts associated with change on a pain management programme.

Reviewing the data as it has been collected in written form suggests that a model of change might also have been developed in a different way to that employed in Task Analysis. One alternative methodology which might have been used in order to understand when and how change occurs is offered by the Assimilation Model (Stiles et al, 1990). In assimilation research, outcome is viewed as change in relation to an individual's particular "problematic experiences" rather than as change in the person as a whole. "Problematic experiences" might encompass memories, feelings, attitudes, behaviours or even wishes that are threatening or painful. Published research using the Assimilation Model describes change as derived mainly from a series of intensive case studies in which problematic experiences are identified in detailed transcripts or tapes of multiple sessions. Researchers then study how the expression of each problem changes over the course of therapy. Stiles (2002) suggests that "in successful psychotherapy, clients follow a regular developmental sequence of recognising, reformulating, understanding and

eventually resolving the problematic experiences that brought them into treatment". According to Stiles (2002) there are eight stages or levels of assimilation and clients may enter treatment at any stage. Any movement along the continuum might be considered as therapeutic progress. The eight stages, numbered 0 – 7 are: (0) Warded off/dissociated; (1) unwanted thoughts/active avoidance; (2) vague awareness/emergence; (3) problem statement/clarification; (4) understanding/insight; (5) application/working through; (6) resourcefulness/problem solution and (7) integration/mastery. Stiles (2002) describes how observation of records from successive sessions makes it possible to identify how problematic experiences change from being feared/unwanted in early sessions to being understood, resolved and integrated by the end of successful treatments. He suggests that the problematic experience is assimilated into a "schema", a way of thinking and acting that is developed or modified within the therapeutic relationship in order to assimilate the problematic experience (Stiles et al, 1990). Assimilation analysis has been used with a variety of psychotherapeutic approaches, including psychodynamic, interpersonal, cognitive, process-experiential and client-centred.

There seems no doubt that tracking change during the course of a pain management programme using assimilation methodology would provide very detailed insights into the process of change for participants of the programme as it occurs. It could be done in at least two ways but both would be extremely labour intensive. The first way would involve interviewing each group member at the end of each session and then examining detailed records for evidence of shifts along the assimilation continuum. An alternative method would involve asking group members to keep their own written records following each session that could then be examined in the same way as above. Both these methods are considered likely to have been impractical for use in this study due to time factors for both group participants and researchers. Group members' compliance/motivation might also have been problematic. It seems likely that the assimilation model approach might be best suited to intensive individual case studies for some of these reasons. The Task Analysis approach, where group participants were interviewed in depth on one occasion, is considered to have been a more practical way of attempting to answer the research question in the current study. This decision was supported by the fact that quantitative data was also available as a measure of change.

A second alternative methodology designed to explore helpful and hindering events during a psychological intervention is that reported, for example, by Llewelyn et al (1988) as already outlined in the background to the current study. Llewelyn et al (1988) utilised the "Helpful Aspects of Therapy Questionnaire" (HAT) (Llewelyn, 1985). Her patient sample was receiving therapy for depressive or anxiety-type symptoms. The HAT asked these clients to describe the most helpful event out of all that had occurred during the session they had just completed. They were also asked to identify any other important events occurring during the session, including unhelpful ones. HAT forms were collected from 638 sessions and then rated by three trained raters using the Therapeutic Impact Content Analysis System (TICAS; Elliott et al, 1984). Fourteen categories of "impacts" were identified and these included "personal insight",(client sees something new about themselves); "awareness", (client gets more in touch with feelings that have been previously warded off); "problem clarification", (client is clearer about what needs to change); "reassurance", (client feels supported or more confident); and "unwanted thoughts", (client is made to think about uncomfortable or painful ideas or feelings in an unhelpful way).

Using this method of analysis, Llewelyn et al (1988) were able to identify that the most commonly occurring "helpful impacts" during either exploratory, relationship-orientated therapy or prescriptive, cognitive-behavioural therapy were "problem solution", "awareness" and "reassurance". The most commonly occurring "hindering impact" was "unwanted thoughts", though this constituted only a small proportion of the total number of impacts overall. As with the current study, it was possible to relate helpful and unhelpful impacts to events occurring during therapy.

Whilst Content Analysis methodology could have been used in the current study, the types of impacts identified might have been numerous but their subsequent utility in pain management terms might have been quite limited. The benefit of developing the hypothetical "expert model" of change as occurs in Task Analysis, means that data is explored against the background of a model that is very specific to the problem area under examination. Both types of methodology bias people towards trying to identify aspects of therapy as significant and this could be a limitation for both. In both however, the method would seem to be an effective way of obtaining information as to how change occurs. As with the Assimilation Model, interviewing patients and/or having them complete questionnaires at the end of every session is somewhat impractical in relation to a pain management programme for all the reasons identified above. It was concluded that this method of obtaining

data for subsequent content analysis would probably be more manageable for individual cases as opposed to those participating in a group treatment.

There is also a third alternative to the methodology used in this study. In what has been reported, thirty patients were interviewed (twice) over the course of about one year. The data was read but not analysed using Task Analysis methodology until some time later (as this method dictates). Had the analysis been taking place on an on-going basis, a preliminary model could have been developed which could then have been tested against additional interview data. The model could then have been refined in an ongoing manner, possibly ceasing to collect further data when it became clear that this was becoming a reiteration of what had already been observed. (Satiation Model). It might also have guided the researcher about certain areas where patients could have been encouraged to elaborate further on their experiences of the process of change. Some of the existing data says little about process and leaves tantalising questions. These might only be answered by conducting further interviews with additional patients.

REFERENCES

Aldrich, S., Ecclestone, C. and Crombez, G. (2000). Worrying about chronic pain: vigilance to threat and misdirected problem solving. *Behaviour Research and Therapy*, **38**, (5) 457-470.

Allen, R., Glover, L., & Williams, A.C. de C. (2001). Proceedings of the Annual Division of Health Psychology Conference.

Asmundson, G.J.G., Kuperos, J.L. & Norton, J.R. (1997). Do patients with chronic pain selectively attend to pain-related information? Preliminary evidence of the mediating role of fear. *Pain*, **72**, 27-32.

Bandura (1977). Self-effficacy: toward a unifying theory of behavioural change. *Psychology Review*, **84**, 191-215.

Barton, S.B. & Morley, S. (1999).Specificity of reference patterns in depressive thinking: Agency and object roles in self-representation. *Journal of Abnormal Psychology*, **108**, 655-661.

Basler, H. & Rehfisch, H.P. (1990). Follow-up results of a cognitive-behavioural treatment for chronic pain in a primary care setting. *Psychology and Health*, **4**, 293-304.

Beck, A.T., Rush, A., Shaw, B. & Emery, G. (1979). Cognitive therapy of depression. New York: Guilford Press.

Beck, A.T., Ward, C.H., Mendelson, M., Mock, J. & Erbaugh, J. (1961). An Inventory for Measuring Depression. *Archives of General Psychiatry*, **56**, 53-63.

Benson, H., Pomerantz, B. & Kutz, I. (1984). The relaxation response and pain. In: Wall,P.D. & Melzack, R. (Eds.). Textbook of Pain. New York: Churchill Livingston, pps. 817-822.

Bergner, M., Bobbitt, R.A., Carter, W.B. & Gilson, B.S. (1981).The Sickness Impact Profile: development and final revision of a health status measure. *Medical Care*, **19**, 787-805

Blackburn, I.M. & Davidson, K. (1990). Cognitive therapy of depression and anxiety. Oxford: Blackwell.

Boston, K., Pearce, S. & Richardson, P.H. (1990). The Pain Cognitions Questionnaire. *Journal of Psychosomatic Research*, **34**, 103-109.

Bradley, B. & Mathews, A. (1983). Negative self-schemata in clinical depression. *British Journal of Clinical Psychology*, **22,** 173-181.

Brown, G. W. & Harris, T. (1978). Social origins of depression: A study of psychiatric disorder in women. London: Tavistock.

Castonguay, L.G., Goldfried, M.R., Wiser, S., Rane, P.J. & Hayes, A.M. (1996). Predicting the effect of cognitive therapy for depression: a study of unique and common factors. *Journal of Consulting and Clinical Psychology,* **64**, 497-504.

Coughlan, G.M., Ridout, K.L., Williams, A.C. de C. & Richardson, P.H. (1995). Attrition from a Pain Management Programme. *British Journal of Clinical Psychology,* **34**, 471-479.

Crombez,G., Vervaet,L., Lysens, R., Baeyens, F. & Eelen P. (1998a) Avoidance and confrontation of painful, back straining movements in chronic back pain patients. *Behaviour Modification,* **22**, 62-77.

Crombez,G., Ecclestone, C., Baeyens, F. & Eelen, P. (1998b). When somatic information threatens, catastrophic thinking enhances attentional interference. *Pain*,**75,**187-198.

Crombez,G.,Vlaeyen, J.W.S., Heuts, P.H.T.G. & Lysens, R. (1999). Fear of pain is more disabling than pain itself. Evidence on the role of pain-related fear in chronic back pain disability. *Pain*, **80**, 329-339.

Davey, G.C.L. (1997). Phobias. A handbook of theory, research and treatment. Chichester:Wiley.

Dickoff, H. and Lakin, M. (1963). Patients' Views of Group Psychotherapy : Retrospections and Interpretations. International Journal.of Group Psychotherapy, **13**, 61-73. N=28.GP.therapy experience of exceptionally brief duration (mean no. of meetings attended =11)

Ecclestone, C., Crombez, G., Aldrich, S. & Stannard, C. (1997). Attention and somatic awareness in chronic pain. *Pain*, **72,** 209-215.

Elliott, R. (1985). Helpful and nonhelpful events in brief counselling interviews: An empirical taxonomy. *Journal of Counselling Psychology*, **32**, 307-322.

Elliott, R., James, E., Reimschuessel, C., Cislo, D. & Sack, N. (1985). Significant events and the analysis of immediate impacts in psychotherapy. *Psychotherapy*, **22,** 620-630.

Farrar, J.T., Portenoy, R.K., Berlin, J.A., Kinman, J.L. (2000). Defining the clinically important difference in pain outcome measures. *Pain*, **88**, 287-294.

Flor,H., Fydrich, T., & Turk, D.C.(1992). Efficacy of Multi-Disciplinary Pain Treatment Centres; a Meta-analytic review. *Pain,* **49**, 221-230.

Flor, H., Behle, D.J. & Birbaumer, N. (1993). Assessment of pain-related cognitions in chronic pain patients. *Behaviour, Research & Therapy*, **31**, 63-73.

Fordyce, W. E. (1976). *Behavioural methods for chronic pain & illness.* St. Louis, Missouri : CV Mosby and Co.

Fordyce, W.E., Lansky,D., Calsyn, D.A., Shelton, J.L. Stolov, W.C. & Rock, D.L. (1984). Pain measurement and pain behaviour. *Pain,* **18,** 53-69.

Goldfried, M.R. & Padawer, W. (1982). Current status and future directions in psychotherapy. In M.R. Goldfried (Ed.), *Converging themes in psychotherapy:*

Trends in psychodynamic, humanistic and behavioural practice (pp.3-49). New York: Springer-Verlag.

Graceley, R.H. (1992). Evaluation of multi-dimensional pain scales. Pain, **48**, 297-300.

Greenberg (1984b). Task Analysis: The general approach. In L. Rice & L. Greenberg (Eds.), Ptterns of change: Intensive analysis of psychotherapy process (pp.124-148). New York: Guilford Press.

Greenberg , L.S.(1986). Change Process Research. *Journal of Consulting and Clinical Psychology,* **54**, 4-9.

Greenberg, L.S. and Safran, J.D. (1987) Emotion in Psychotherapy. NewYork:Guilford Press.

Harding, V.R., Williams, A.C. de C., Richardson, P.H., Nicholas, M.K., Jackson, J.L., Richardson, I.H. and Pither, C.E. (1994). The development of a battery of measures for assessing physical functioning in chronic pain patients. Pain, **58,** 367-375.

Hine (2002). Proceedings of the UK Pain Society Annual Conference. Bournemouth, April, 2002.

Jacobson, N.S., Roberts, L.J., Berns, S.B. & McGlinchey, J.B. (1999). Methods for defining and determining the clinical significance of treatment effects: Description, application and alternatives. *Journal of Consulting and Clinical Psychology*, **67,** 300-307.

Jacobson, N.S. & Truax, P. (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of Abnormal Psychology,* **59**, 12-19.

Jensen, M.P., Karoly, P. & Braver, S. (1986). The measurement of clinical pain intensity: a comparison of six methods. *Pain*, **27**, 117-126.

Jensen, M.P., Karoly, P. & Huger,R. (1987). The development and preliminary validation of an instrument to assess patients' attitudes toward pain. *Journal of Psychosomatic Research*, **31**, 393-400.

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

Jensen, M. P., Turner, J.A., Romano, J.M. & Lawler, B.K (1994). Relationship of pain-specific beliefs to chronic pain adjustment. *Pain*, **57,** 301-309.

Jensen, M.P., Romano, J.M. Turner, J.A., Good, A.B. & Wald, L.H. (1999). Patient beliefs predict patient functioning: further support for a cognitive-behavioural model of chronic pain. *Pain,* **81**, 95-104.

Jensen, M.P., Turner, J.A. and Romano, J.M. (2001). Changes in beliefs, catastrophising and coping are associated with improvement in multidisciplinary pain treatment. Journal of Consulting and Clinical Psychology, **69,** (4), 655-662.

Johnson, T. *Proceedings of Seventh Pain Management Programmes Conference.* Bristol, September,2001.

Keefe, F.J., Brown, G.K. Wallston, K.A. & Caldwell, D.S. (1989). Coping with rheumatoid arthritis: catastrophising as a maladaptive strategy. *Pain*, **37**, 51-56.

Keefe, F.J. & Williams, D.A. (1990). A comparison of coping strategies in chronic pain patients in different age groups. *Journal of Geron. Psychol. Sci.*, **45**, 161-165.

Keefe, F.J., Dunsmore, J. & Burnett, R. (1992). Behavioural and cognitive-behavioural approaches to chronic pain : Recent advances and future directions. *Journal of Consulting and Clinical Psychology*, **60**, 528-536.

Kerns, R.D., Rosenberg, R., Jamison, R.N., Caudhill, M.A. & Haythornthwaite, J. (1997). Readiness to adopt a self-management approach to chronic pain : The Pain Stages of Change Questionnaire (PSOCQ). *Pain*, **72**, 227-234.

King, S.A. & Snow, B.R. (1989). Factors for predicting premature termination from a multidisciplinary inpatient chronic pain program. *Pain*, **39**, 281-287.

Kori, S.H., Miller, R.P. & Todd, D.D. (1990). Kinisophobia: a new view of chronic pain behaviour. *Pain Management,* **January/February**, 35-43.

Kugler, K., Wijn, J., Geilen, M., de Jong, J. & Vlaeyen, J.W.S. (1999). The Photograph series of Daily Activities (PHODA). Institute for Rehabilitation Research and School for Physiotherapy. Heerlen, The Netherlands.

Leventhal, H.,Idler, E.L. & Leventhal, E.A. (1999). The impact of chronic illness on the self. In R.J. Contrada & R.D. Ashmore (Eds.), *Self, social identity and physical health. Rutgers series on self and social identity* (Vol. **2**, pp. 185-208). New York: Oxford University Press.

Lethem, J., Slade, P.D., Troup, J.D.G. & Bentley, G. (1983). Outline of a fear-avoidance model of exaggerated pain perceptions. *Behaviour Research and Therapy,* **21**, 401-408.

Ley, P. (1988). *Communication with Patients.* London : Croom-Helm.

Lietaer, G. (1983). Helping processes in experiential psychotherapy: Post-session comments of clients and therapists. Paper presented at meeting for Psychotherapy Research, Sheffield, UK, June.

Llewelyn, S. (1985). The experiences of patients and therapists in psychological therapy. Inpublished PhD thesis, University of Sheffield.

Llewelyn, S.P., Elliott, R., Shapiro, D.A., Hardy, G. and Firth-Cozens, J. (1988). Client perceptions of significant events in prescriptive and exploratory periods of individual therapy. British Journal of Clinical Psychology, **27**,105-114.

Marcus, H. & Wurf, E. (1987). The dynamic self-concept: A social psychological approach. *Annual Review of Psychology*, **38,** 299-337.

Martin, D.J., Garske, J.P. & Davis, M.K. (2000). Relation of the therapeutic alliance with outcome and other variables: a meta-analytic review. *Journal of Consulting and Clinical Psychology*, **68**, (3), 438-450.

Malone, M.D. & Strube, M.J. (1988). Meta-analysis of non-medical treatments for chronic pain. *Pain*, **34**, 231-244.

McCracken, L. (2002). *Proceedings of Pain Society Annual Conference.* Bournemouth, April, 2002.

Moore, J.E. & Chaney, E.F. (1985). Outpatient group treatment of chronic pain: Effects of spouse involvement. *Journal of Consulting and Clinical Psychology*,**53,** no.3, 326-334.

Morley, S., Ecclestone,C. and Williams, A. (1999). Systematic Review and Meta-Analysis of Randomised Controlled Trials of Cognitive Behaviour Therapy and Behaviour Therapy for Chronic Pain in Adults, Excluding Headache. *Pain* , **80**, 1-13.

Morley, S. & Williams, A. C. de C. (2002). Conducting and Evaluating Treatment Outcome Studies. In D.C. Turk & R. Gatchell (Eds.). Psychological Approaches to Pain Management: A Practitioner's Handbook. 2nd Edition, New York:Guilford Press.

Morris, D.B.(1991). The culture of pain. University of California Press, Berkeley.

Murphy, P., Cramer, D. & Lillie, F. (1984). The relationship between curative factors perceived by patients in their psychotherapy and treatment outcome. *British Journal of Medical Psychology,* **57**, 187-192.

Newton-John, T.R.O. (2002). The measurement of pain in adults. In J. Zakrzewska & S. Harrison (Eds.). Assessment and Management of Orofacial Pain. Pain Research and Clinical Management. Volume 14,pp. 87-104. London: Elsevier Press.

Nicholas, M.K., (1989). The Pain Self-Efficacy Questionnaire : Self efficacy in relation to chronic pain. Paper presented at the BPS Annual Conference, St. Andrews, Scotland.

Osbourne, M. (2002). Proceedings of the Pain Society Annual Conference. Bournemouth, April, 2002.

Pearce, J. & Morley, S. (1989). An experimental investigation of the construct validity of the McGill Pain Questionnaire. *Pain,* **39**, 115-121.

Pincus, T. & Morley, S. (2001) Cognitive-Processing Bias in Chronic Pain : A Review and Integration. *Psychological Bulletin,* **127**, No.5, 599-617

Pollard, C.A. (1984). Preliminary Study of the Pain Disability Index. *Perceptual and Motor Skills*, 59,974.

Price, D.D. (1999). *Psychological mechanisms of pain and analgesia.* Seattle WA. IASP Press.

Prochaska, J.O. & DiClemente, C.C. (1983). Stages and processes of self-change of smoking : towards and integrative model of change. *Journal of Consulting and Clinical Psychology,* **51,** 390-395.

Prochaska, J.O. & DiClemente, C.C. (1984). *The transtheoretical approach: Crossing traditional boundaries of change.* Dow Jones/Irwin, Homewood, Illinois.

Ralphs, J.A., Williams, A.C de C., Richardson, P.H., Pither, C.E. & Nicholas, M.K. (1994). Opiate Reduction in chronic pain patients: a comparison of patient-controlled reduction and staff-controlled cocktail methods. *Pain*, **56,** 279-288.

Rice, L. & Greenberg, L. (1984). Patterns of change: Intensive analysis of psychotherapy process. New York: Guilford Press.

Richmond, R.L. & Carmody, T.P. (1999). Dropout from treatment for chronic low-back pain. *Professional Psychology: Research and Practice*,**30**, (1),51-55.

Rosensteil, A.K., & Keefe, F.J., (1983). The use of coping strategies in chronic low back pain patients; relationship to patient characteristics and current adjustment. *Pain*, **17**, 33-44.

Rosensteil, A.K. &Keefe, F.J. (1983). The use of coping strategies in chronic low back pain patients: relationship to patient characteristics and current adjustment. *Pain,* **17**, 33-44.

Roth, A. & Fonagy, P. (1996). What works for whom? A critical review of psychotherapy research. New York, Guilford Press.

Saarijarvi, S. (1991). A controlled study of couple therapy in chronic low back pain patients. Effects on marital satisfaction, psychological distress and health attitudes. *Journal of Psychosomatic Research*, **35,** 265-272.

Saarijarvi, S., Alanen, E. Rytokoski, U. and Hyyppa, M.T. (1992) Couple therapy improves mental well-being in chronic low back pain patients. A controlled, five year follow-up study. *Journal of Psychosomatic Research*, **36**, 651-656.

Sanders, S.H. (1983). Automated versus self-monitoring of "up-time" in chronic low-back pain patients: a comparative study. *Pain*, **15**, 399-405.

Seers, C.J., Williams, A.C. de C., Richardson, P.H. &Collett, B.J. (1997). Desirable Criteria for Pain Management Programmes. The Pain Society, London.

Shutty, M.S. & DeGood, D.E. (1990). Patient knowledge and beliefs about pain and its treatment. *Rehabilitation Psychology,* **35**, 43-54.

Smith, J. A.(1996). Beyond the divide between cognition and discourse: using interpretive phenomenological analysis in health psychology. *Psychological Health*, **11**, 261-271.

Stein, M.J., Wallston, K.A., Nicassion, P.M. & Castner, N.M. (1988). Correlates of a clinical classification schema for the Arthritis Helplessness Subscale. *Arthritis Rheumatology,* **31**, 876-881.

Stiles, W.B., Elliott, R., Llewelyn, S.P., Firth-Cozens, J.A., Margison, F.R., Shapiro, D.A. & Hardy, G. (1990). Assimilation of problematic experiences by clients in psychotherapy. *Psychotherapy*, **27**, 411-420.

Stiles, W.B. (2002). Assimilation of problematic experiences. In J.C. Norcross (Ed.), *Psychotherapy relationships that work: therapist contributions and responsiveness to patients* (pp. 357-365). New York: Oxford University Press.

Strong , J., Ashton, R. & Chant, D.(1992). The measurement of attitudes towards and beliefs about pain. *Pain,* **48**, 227-236.

Sullivan, M. J. L. (1995). The Pain Catastrophising Scale. Unpublished Manuscript.

Sullivan, M.J.L., Bishop, S.R. & Pivik, J. (1995). The pain catastrophising scale: development and validation. *Psychological Assessment*, **7,** No.4, 524-532.

Tabachnik, B.G. & Fidell, L.S. (1996) *Using multivariate statistics.* 2nd Edn. Harper and Row, New York.

Tait, R.C., Chibnall, J.T. & Krause, S. (1990). The pain disability index: psychometric properties. *Pain*, **40**, 171-182.

Teasdale, J.D. (1993). Emotion and two kinds of meaning: cognitive therapy and applied cognitive science. *Behaviour Research and Therapy*, **31**, 339-354.

Teasdale, J.D. & Barnard, P.J. (1993). Affect, cognition and change: Re-modelling depressive thought. Hove, England: Erlbaum.

Turk, D.C., Meichenbaum, D. & Genest, M. (1983) *Pain and behavioural medicine,* Guilford Press, New York.

Turk, D.C. & Meichenbaum, D. (1984). A cognitive-behavioural approach to pain management. In: Wall,P.D. & Melzack, R. (Eds.). Textbook of Pain. New York: Churchill Livingston, pps. 787-797.

Turk, D.C. & Rudy, T.E. (1992). Cognitive factors and persistent pain : A glimpse into Pandora's box. *Cognitive Therapy and Research*, **16,** 99-122.

Turk, D.C. (2000). "Statistical significance and clinical significance are not synonyms!" Editorial. *Clinical Journal of Pain,* **16**, 185-187.

Turner, J.A.. & Clancy, S. (1986). Strategies for dealing with chronic low back pain: relationship to pain and disability. *Pain,* **24**, 355-364.

Turner, J.A. (1996). Educational and behavioural interventions for back pain in primary care. *Spine*, **21**, 2851-2859.

Vlaeyen, J.W.S., Kole-Snijders, A.M.J., Boeren, R.G.B.,& Van Eek, H. et al (1995). Fear of movement/(re)injury in chronic low back pain and its relation to behavioural performance. *Pain,* **62**, 363-372.

Vlaeyen, J.W.S., de Jong, J., Geilen, M., Heuts, P.H.T.G. & van Breukelen, G. (2001) Graded exposure in vivo in the treatment of pain-related fear: a replicated single-case experimental design in four patients with chronic low back pain. *Behaviour Research and Therapy,* **39**, 151-166.

Vlaeyen & Linton (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain*, **85**, 317-332.
Williams, A. C. de C., Nicholas, M.K., Richardson, P.H., Pither, C.E., Justins, D.M., Chamberlain, J.H., Harding, V.R., Ralphs, J.A., Jones, S.C., Dieudonne, I., Featherstone, J.D., Hodgson, D.R., Ridout, K.L. & Shannon, E. M. (1993). A cognitive behavioural programmed for rehabilitating the chronic pain patient: results of the first 200 cases. *British Journal of General Practice,* **43,** 513-518.
Williams, A.C. de C. & Richardson, P.H. (1993). What does the BDI measure in chronic pain? *Pain*, **55,** 259-266.

Williams, A.C. de C., Richardson, P.H., Nicholas, M.K., Pither, C.E., Harding, V.R., Ridout, K.L., Ralphs, J.A., Richardson, I.H., Justins, D.M., & Chamberlain, J.H. (1996) Inpatient vs. outpatient pain management: results of a randomised controlled trial. *Pain*, **66**, 13-22.

Williams, A.C. de C., Morley, S. & Black, S. (2002). Grant Report: Empirical evaluation of best practice in chronic pain management: influence of patient characteristics and treatment type on outcome (SPGS 558). **www.info.doh.gov.uk/doh/refr** web.nsf

Wynne, K., & Newton-John, T. (2002) Is chronic pain disability related more to fear than pain? Proceedings of 10th World Congress on Pain, San Diego, USA. International Association for the Study of Pain Press, Seattle (p.86).

Yalom, I.D. (1985). Theory and Practice of Group Psychotherapy, 3rd Edition. New York : Basic Books Inc.

Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, **67**, 361-370

APPENDICES

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PROTOCOL

AN INVESTIGATION INTO PROCESS VARIABLES ASSOCIATED WITH CHANGE AND THE MAINTENANCE OF CHANGE FOR PATIENTS ON A PAIN MANAGEMENT PROGRAMME (PMP)

Subjects

All new patients completing the COPE Pain Management Programme at the National Hospital for Neurology and Neurosurgery (UCLH), Queen Square, London WC1. Each group holds eight people and currently there are four groups per year. Up to 32 patients would therefore be involved.

Procedure

1. Quantitative measures are already collected from patients prior to their entry onto the COPE PMP, on the last day of the core treatment and at 1, 3, 6 and 12 months post-treatment. On the last day of treatment they will be asked, in addition, to complete a semi- structured written questionnaire. This will ask them about their individual experience of the changes that they have been making (to be developed). The investigator will then interview them in order to expand on themes highlighted in the questionnaire. This will be done face to face where possible but if travelling is a particular problem, telephone interviewing may be utilised. Interviews will occur within one week of completion of the programme.

2. This will be repeated at the standard six-month follow-up appointment.

The following measures will be used:

TIMING	QUESTIONNAIRE
Point of entry	Beck Depression Inventory (BDI) Pain Self-Efficacy Questionnaire (PSEQ) Pain Anxiety Inventory Catastrophising subscale of Coping Strategies Questionnaire (CCSQ) Pain Disability Index 5 minute walk (how many metres walked in 5 minutes)
Last day of interview Programme	As above plus semi-structured questionnaire, followed by
6 months interview.	As above, including semi-structured questionnaire and

Appendix (ii) - Ethics

THE NATIONAL HOSPITAL FOR NEUROLOGY
AND NEUROSURGERY

Queen Square, London WC1N 3BG
Telephone: 0171 837 3611
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07 MAR 2001

ıe NHNN and the Institute of Neurology
int Research Ethics Committee
ıairman: Dr GD Schott

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Ms K Pidout
Clinical Psychologist
Pain Management Centre
NHNN
Queen Square

26 February 2001

Dear Kate

Study Ref: **01/N025**
Title: **Factors associated with change on a pain management programme**

Thank you for sending us your application. I am pleased to say that this is suitable for approval by Chairman's Action and the Vice-Chair, and from the point of view of ethics there is no reason why the study should not go ahead.

Please ensure that you have obtained final approval from the Trust (via the R&D office) before proceeding with your research. number above

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. **Please remember to quote the above number in any correspondence.**

Yours sincerely

Dr GD Schott
Chairman

THE NATIONAL HOSPITAL FOR NEUROLOGY
AND NEUROSURGERY

Queen Square, London WC1N 3BG
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22 MAR 2001

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8th March 2001

Ms Ridout
Pain Management Department
NHNN

Dear Ms Ridout,

Study ref: **01/N025**
Title: **Factors associated with change on a pain management programme**

Thank you for registering the above study with the R&D Directorate. I am pleased to give Trust approval for the study to commence. Please ensure you have addressed any outstanding issues raised by the ethics committee.

Yours sincerely

Professor Alan Thompson
Director of Research, NHNN

INFORMATION ABOUT THE STUDY OF PROCESSES INVOLVED IN CHANGE AND THE MAINTENANCE OF CHANGE FOR PEOPLE TAKING PART IN A PAIN MANAGEMENT PROGRAMME

University College London Hospitals NHS Trust and University College London

BACKGROUND

Pain Management Programmes (PMPs) have been extensively researched over the past 30 years in terms of outcome. That is to say, they have been proven to be effective for the majority of patients who take part in a programme. However, very little research has so far been done into HOW they work. We need to know more about what helps people to make changes whilst they are on a PMP and what helps them keep going with managing their pain in the longer term. We may then be able to offer more help to those who struggle to use the techniques and who currently seem to obtain only limited benefits from the programme.

INFORMATION ABOUT THE STUDY

We are particularly interested in finding out more about:

1. Which aspects of the programme people have found to be particularly helpful and why?
2. Is there anything about the programme which people feel has not been covered in enough detail or might even seem to have been unhelpful?
3. Can people identify any "key moments" when things suddenly seemed to have fallen into place?

And later:

4. What happens once the "core" (8 days) of the programme are completed? How do people organise themselves to continue working on what they have learned? What helps? What sorts of things get in the way to make it difficult?
5. Are there further "key moments" when people recognise that they are making significant progress?

WHAT THE STUDY INVOLVES

We are asking patients to complete a questionnaire about aspects of the above points 1-3 on the last day of the Programme (when you will also be completing other measures related to your overall progress at COPE). An interview will then be arranged to discuss the questionnaire in more detail. The interview can be arranged to suit you on either the last day of the programme, one day that week, or else can be done on the telephone.

At your 3 month COPE Group follow-up, you will be asked to complete another questionnaire, this time related to above points 4-5 and a further interview will be arranged to suit you in order to discuss this in more detail.

Your help with this study will be greatly appreciated in terms of helping us understand how we may help people gain more from PMPs. It is also hoped that you may personally benefit from the process of discussing your own progress in depth. HOWEVER...

YOU DO NOT HAVE TO COMPLETE THE QUESTIONNAIRE OR TAKE PART IN THE INTERVIEW IF YOU DO NOT WANT TO. IF YOU DECIDE THAT YOU DO NOT WANT TO TAKE PART, YOU MAY WITHDRAW AT ANY TIME, WITHOUT HAVING TO GIVE A REASON. YOUR DECISION WHETHER TO TAKE PART OR NOT WILL NOT AFFECT YOUR CARE AND MANAGEMENT IN ANY WAY.

The principle investigator for this study is Kate Ridout. She may be contacted at The Pain Management Centre, The National Hospital for Neurology and Neurosurgery, (UCLH), Queen Square, London WC1; phone 020 7837 3611 x3487.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research.

CONSENT FORM

STUDY TITLE: An investigation into the process variables associated with change and the maintenance of change for patients on a Pain Management Programme

INVESTIGATOR NAME: Kate Ridout,
The Pain Management Centre,
National Hospital for Neurology and Neurosurgery
(UCLH), Queen Square, London WC1;
Phone - 020 7837 3611 x3487.

To be completed by each person participating:

1. I have read the information sheet about this study YES/NO

2. I have had an opportunity to ask questions and discuss this study YES/NO

3. I have received satisfactory answers to all my questions YES/NO

4. I have received sufficient information about this study YES/NO

5. Which health professionals have you talked to about this study?

6. I understand that I am free to withdraw from this study
   at any time
   without giving a reason
   without affecting my future medical/psychological care YES/NO

7. Do you agree to take part in this study? YES/NO

Signed: .....

Date: .....

Name in
Block Letters:.....

Signature of
Investigator: .....

Appendix (v)

STUDY OF FACTORS ASSOCIATED WITH CHANGE ON A PAIN MANAGEMENT PROGRAMME

CONSENT FORM
(TAPE RECORDING)

I give my permission for a tape recording to be made of my interview with Kate Ridout on .

I understand that this recording will be destroyed when any additional information obtained from the taped interview has been added to that already obtained from my questionnaire.

Signed:

Date:

Signature of Principal Investigator:

Date:

Appendix (vi) – Pilot questionnaire

This is completely CONFIDENTIAL to the COPE Team.

COPE PAIN MANAGEMENT PROGRAMME - REVIEW

Please don't answer using just "yes" or "no"; we are particularly interested in learning more about your experience of COPE overall and the more information we can obtain, the more helpful this will be in planning our services in the future.

Looking back to BEFORE you came on the Programme.....

Did you feel sufficiently prepared for COPE before you started the Programme?

Do you think that you were ready to adopt a self-management approach at the time you started on the COPE Progamme?

If not, can you say more about why not?

THE PROGRAMME.....

Having completed the "core" eight sessions of the Progamme, what are your main impressions of learning pain management skills in a group setting?

What has/have been the most helpful aspect(s) of the Programme (so far)?

Looking at specific components of the Programme in a bit more detail?

Exercise, Stretch and Education about Pain Mechanisms, Healing etc.....There is quite a lot of this on the Programme. Was there anything that made it easier for you to benefit from these aspects of the Programme than on previous occasions when you've had physiotherapy? Or was it more difficult? Please say as much as you can about this.

Pacing. Was this completely new to you or was it a more structured method of doing something you had already tried to practice for yourself?

Relaxation/Self-Hypnosis. Have you learned something from knowing more about these techniques (even if you already used them before coming to COPE)?

Thoughts and Feelings. Were the techniques presented for learning to challenge unhelpful patterns of thinking new to you? Have you managed to change any of the ways you think and feel since coming to COPE to any extent? Has anything else helped with this? Please say as much as you can about this.

Friends and Family Component of Programme (whether or not a friend or member of your family attended the day). Please say if you think this aspect of COPE has been at all helpful to you, and (of particular interest to us), HOW?

Follow-ups. Do you find these helpful? If so, what is it that makes them helpful? Are there ways in which they could be more helpful to you?

KEY MOMENTS. During your preparation for the Programme, during your seven weeks at COPE or anytime since, have there been any "Key Moments" when something "clicked" for you, you understood things better or felt you were suddenly making progress? Was it something a therapist said or did? Was it something another group member said or did? Something a friend/relation said or did outside the group? Or was it something else? Please say as much about this as you can.

Since the Programme.....

Has the COPE Pain Management Programme lived up to your expectations, so far? Has it met your needs? Please say anything you can about anything particularly helpful, or unhelpful....

Do you think there is anything missing from the Programme that you expected to be there or anything that has interfered with your progress,WITHIN THE GROUP?

Is there anything,OUTSIDE THE GROUP, which you believe has interfered with your progress so far?

Do you think you would have made the SAME progress learning pain management skills on a one-to-one basis, or MORE progress, or LESS?

Have you remained in contact with any group members since the end of your "core" programme (apart from follow-up days)? Has it been helpful to maintain contact?

We are very grateful for your time and effort in providing us with your responses to the above questions. We hope to utilise the information we obtain here to improve our service and individual comments will remain confidential within the COPE Team. THANK YOU ONCE AGAIN FOR YOUR HELP.

QUESTIONNAIRE: VERSION 1

COPE PAIN MANAGEMENT PROGRAMME

In order to develop the service we are currently providing, we want to try to understand more about how people experience COPE overall. We would therefore be very grateful if you would take a few moments to complete this form. Please don't answer using just "yes" or "no"; the more information we can obtain, the more helpful it will be to us. You may also find that the process of writing about the programme might be quite helpful for you too.
When the form is complete, we would like the opportunity to discuss what you have written with you in more detail. If you agree, this could be done later today or one day this week in person, or else on the telephone. There is no obligation to do this but we would greatly appreciate your participation in helping to plan our services for the future. Your answers are COMPLETELY CONFIDENTIAL.

PART 1

Looking back to BEFORE you came onto the Programme:

1. Do you think you felt sufficiently prepared for COPE before you started the Programme?

2. Do you think that you were ready to adopt a self-management approach at the time that you started on the COPE Programme?

If not, can you say more about why not?

PART 2. THE PROGRAMME

1. Having completed the "core" eight sessions of the Programme, what are your main impressions of learning pain management skills in a group setting?

2. What has / have been the most helpful aspect(s) of the Programme (so far)?

3.Can you say any more about HOW these have been helpful?

LOOKING AT SPECIFIC COMPONENTS OF THE PROGRAMME IN A BIT MORE DETAIL:

1. Exercise, stretch and education about pain mechanisms, healing, etc

There is quite a lot of this on the programme. Did you find these aspects of the programme helpful?

Was there anything that made it EASIER for you to benefit from these aspects of the programme than on previous occasions when you've had physiotherapy? Or was it more DIFFICULT? Please say as much as you can about this.

2. Pacing

Was this a completely new idea to you or was it a more structured method of doing something you had already tried to practice for yourself?

Does systematic pacing make a significant difference to you?

3. Relaxation/Self-Hypnosis

Have you learned something from knowing more about these techniques (even if you already used them before coming to COPE)?

Are you practising relaxation techniques on a regular basis at the moment? If not, can you say why not?

4.Thoughts and Feelings

Were the techniques presented for learning to challenge unhelpful patterns of thinking new to you?

Have you, to any extent, managed to change any of the ways you think and feel since coming to COPE? Please say as much as you can about this.

Has anything else helped you with the way you think and feel? Please say as much as you can about this.

5. Friends and Family Component of the Programme (whether or not a friend or member of your family attended the day).

Please say if you think this aspect of COPE has been at all helpful to YOU and, *of particular interest to us*, HOW?

6. "Key Moments"

During your preparation for COPE (initial assessment, pre-treatment assessment or anytime in between) have there been any "key moments" when something "clicked" for you in pain management terms? Whilst you have been on the programme, have there been any occasions when you realised that you understood things better or

felt that you were making some progress. Please try to remember as accurately as you can. Was it:

Something a therapist said or did?
Something a fellow group member said or did?
Something a friend or relation said or did outside the group?
Or was it something else?

Please take time to say as much about this as you can.

Has the COPE Pain Management Programme lived up to your expectations, so far? Has it met your needs, so far? Please say more about anything you found helpful **about the programme.**

Are there any aspects of the programme that you found unhelpful? **It will be very helpful to us to have as much information about this as possible.**

Was there anything you thought was missing **from the programme (i.e. that you expected to be there or think could have improved the programme). We are very interested in your suggestions but please bear in mind the resources available to us.**

Is there anything about **BEING IN THE GROUP** that you have found particularly helpful / helped you make progress on the Programme?

Is there anything about **BEING IN THE GROUP** that you feel has interfered with your progress so far?

Is there anything **OUTSIDE THE PROGRAMME** (e.g. events/ circumstances at home) which you think may have helped you make progress whilst you have been on the Programme?

Is there anything, **OUTSIDE THE PROGRAMME**, (as above) that you feel may have interfered with your progress on the Programme so far?

Now that you have completed the "core" programme, do you think you would have made the SAME progress learning pain management skills on a one-to-one basis, or MORE progress, or LESS?

WE ARE VERY GRATEFUL FOR YOUR HELP IN ANSWERING THESE QUESTIONS. THANK YOU.

QUESTIONNAIRE: VERSION 2

COPE PAIN MANAGEMENT PROGRAMME – FOLLOW UP FORM

You will probably remember completing a questionnaire on the last day of the Programme asking you about your overall experience of COPE so far. We are interested in taking this further and finding out more about how you view this experience 3 months on. We will also be asking you about your current progress.

As before, we would be very grateful if you would supply as much information as possible. We would also like the opportunity to discuss what you have written with you in more detail. If you agree, this can be done later on the day of your follow-up or one day that week in person, or else on the telephone. As before your answers are **COMPLETELY CONFIDENTIAL**.

Part 1

1. It is now 3 months since you completed the COPE Programme. How would you describe your progress in terms of managing your pain during the past 3 months (please tick one):

(1) Very good progress
(2) Generally doing well, a few ups and downs
(3) Variable, sometimes doing well, sometimes less well
(4) Quite difficult, not really making much progress
(5) Very poor progress

If none of the above seems to describe accurately how things have been going for you, you may wish to write an answer in your own words here:

Part 2

Please think back to the COPE Programme and answer the following questions:

1. 3 months after completing the "core" eight sessions of the Programme, what are your main impressions of learning pain management skills in a group setting?

2. **Looking back, what do you think were the most useful aspects of the "core" Programme?**

3. **Can you say anymore about HOW these have been helpful?**

Part 3

We are interested in how you view the COPE Programme 3 months on. We are not asking you to remember what you wrote before in the previous questionnaire but to describe your experience of various aspects of the programme as they seem to you now. Please say as much as you can in each case.

1. Stretch, exercise and education about pain mechanisms, healing etc.

Thinking back to the programme, can you identify anything that made it **easier** to benefit from these aspects of the programme than on previous occasions when you've had treatment from a physiotherapist?

Were there things that made it more **difficult** to benefit from these aspects of the programme compared with your previous experiences of physiotherapy?

Are you continuing to do stretch/exercise on a regular basis? YES/NO

If not, can you say something about why not?

2. Pacing

Looking back, can you identify a point when pacing began to make sense/ made things easier? Did this happen all at once or did it happen in stages?

Are you currently using pacing techniques to help you manage your pain?

YES/NO

If not, can you say something about why not?

3. Relaxation/Self-Hypnosis

Are you practising relaxation techniques on a regular basis at the moment?

YES/NO

If the answer is yes:

Looking back, has there been a point on the programme or since, when it became easier to do? Please elaborate.

It the answer is no, has practising relaxation techniques ever been something you have done a regular basis since attending the COPE Programme?

YES/NO

If yes, why did you stop?

If no, can you say something about why not?

4.Thoughts and Feelings.

Have you, to any extent, managed to change any of the ways you think and feel since coming on the COPE Programme?

Looking back, has there been a point on the programme or since when you were aware of this happening? Please say as much as you can about this.

Are you currently continuing to identify and challenge unhelpful thoughts?

If not, can you say why not?

Has anything else during the last 3 months helped you with the way you think and feel? Please say as much as you can about this.

5. Communicating more effectively with friends and family

Looking back, did you find this component of the Programme helpful? Please say as much as you can about this.

Have you made use of what you learned about communication during the past three months? Again, please give as much information as you can.

6. Continued setting and revising of goals

Looking back, did you find this aspect of the Programme helpful? Please say as much as you can.

Do you continue to set and revise goals? YES/NO

If you do, can you say why?

If you do not, can you say why not?

6. If you have managed to keep going with any aspect of the programme, can you say something about how you have **organised** yourself to do so? E.g. Have you established a routine, what's helped, how you've overcome difficulties?

7. At the end of the 8 "core" sessions of the COPE Programme, we asked you to identify any "key moments" which occurred during the Programme when things "clicked" / you suddenly felt that you were making progress. Three months on, can you identify what now seem to have been the "key moments" on the programme for you.

THIS IS **NOT** ASKING YOU TO REMEMBER WHAT YOU WROTE BEFORE BUT TO REFLECT ON THE COPE EXPERIENCE 3 MONTHS ON AND TRY TO IDENTIFY WHAT NOW SEEM TO HAVE BEEN "KEY MOMENTS" FOR YOU DURING THE PROGRAMME.

8. Have there been any "key moments" SINCE **completing the Programme when things "ciicked" / you suddenly felt that you were making progress/further progress. Please say as much as you can about the circumstances at this time.**

Part 3

Overall Maintenance

1. Looking back over the Programme now, do you think you were sufficiently prepared to keep going at the end of the 8 sessions (both in terms of the content of the programme and of your own confidence to cope)?

If not, can you say something about what you think might have helped you to maintain your progress or even make more progress over the past 3 months?

2. Over the past three months, it is possible that you have had to deal with either minor or major events in your life. These can sometimes make it more difficult to keep going with your pain management strategies.

If you managed to keep going with your strategies (even if you had to stop for a short while) can you say what you think has **helped** you? Please say as much as you can.

If you found it hard to keep going with your strategies, can you say what seemed to **make it difficult**? Please say as much as you can.

Part 4

In retrospect, did the "core" sessions of COPE live up to your expectations? Did it meet your needs? Please say more about anything you found **helpful** about the Programme.

Again, in retrospect, were there any aspects of the programme that you found **unhelpful?** Please give us as much information as possible.

Looking back, is there anything which you now think was **missing** from the programme (i.e. that you expected to be there or think could have improved the Programme, bearing in mind the resources available to us).

Again, looking back, was there anything about BEING IN THE GROUP that you found particularly **helpful/ helped you** make progress on the Programme?

Was there anything about BEING IN THE GROUP that you feel **interfered** with your progress during the "core" COPE programme?

In hindsight, was there anything OUTSIDE THE PROGRAMME (e.g. events/circumstances at home) that you think may have **helped** you make progress whilst you were on the "core" COPE programme?

Was there anything OUTSIDE THE PROGRAMME (as above) that you feel may have **interfered** with your progress whilst you were on the "core" COPE Programme?

It is 3 months since you completed the "core" COPE Programme. Looking back, do you now think that you would have made the SAME progress learning pain management skills on a one-to-one basis, or MORE progress, or LESS?

Once again, we are very grateful for you help with this study. We hope to be able to use our findings to help future Cope participants gain even more from the programme. Thank you very much.

Individual Scores and Rating of Improvement (n=30)

Patient No:	Measure	Pre	post	3/12	12/12	Improvement category
01.	Pain Intensity (PI)	8	6	8	7	
	Pain Distress (PD)	8	6	8	7	0
	PSEQ	29	48	54	47	1
	PCS	6	2	9	6	1
	PDI	39	21	8	1	1
	WALK (m)	170	260	240	280	1
	IMPROVED ON 2 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 6 "IMPROVED"					
02	Pain Intensity (PI)	5	5	8	99	
	Pain Distress (PD)	5	7	9	99	0
	PSEQ	28	34	10	99	0
	PCS	36	19	28	99	1
	PDI	67	33	60	99	1
	WALK (m)	50	76	999	999	1
	IMPROVED ON 1 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 2 "PARTIALLY IMPROVED"					
03.	Pain Intensity (PI	6	6	5	99	
	Pain Distress (PD)	7	6	2	99	0
	PSEQ	12	38	31	99	1
	PCS	20	21	12	99	0
	PDI	40	24	25	99	1
	WALK (m)	300	290	280	999	0
	IMPROVED ON 1 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 2 "PARTIALLY IMPROVED"					
04.	Pain Intensity (PI)	7	7	8	6	
	Pain Distress (PD)	7	4	7	4	1
	PSEQ	16	43	42	36	1
	PCS	20	21	12	19	0
	PDI	999	30	37	36	99
	WALK (m)	285	320	300	325	0
	IMPROVED ON 2 PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 4 "PARTIALLY IMPROVED"					

Patient No:	Measure	Pre	post	3/12	12/12	Improvement category
05	Pain Intensity (PI)	9	5	4	99	
	Pain Distress (PD)	9	5	5	99	1
	PSEQ	24	44	25	99	1
	PCS	33	38	21	99	0
	PDI	48	26	11	99	1
	WALK (m)	210	280	999	999	1
	IMPROVED ON 2 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 6 " IMPROVED"					
06	Pain Intensity (PI)	6	7	7	7	
	Pain Distress (PD)	6	8	5	6	0
	PSEQ	17	30	40	40	1
	PCS	30	13	14	19	1
	PDI	55	46	28	20	0
	WALK (m)	180	160	220	999	0
	IMPROVED ON 2 PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 4 "PARTIALLY IMPROVED"					
07	Pain Intensity (PI)	7	6	5	4	
	Pain Distress (PD)	8	5	3	3	1
	PSEQ	29	47	47	49	1
	PCS	30	22	13	10	0
	PDI	55	17	16	27	1
	WALK (m)	365	340	999	390	0
	IMPROVED ON 2 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 6 " IMPROVED"					
08	Pain Intensity (PI)	5	7	7	6	
	Pain Distress (PD)	3	5	4	6	0
	PSEQ	13	21	28	34	1
	PCS	28	21	14	18	0
	PDI	50	34	24	36	1
	WALK (m)	311	321	340	999	0
	IMPROVED ON 1 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 2 "PARTIALLY IMPROVED"					

09.	Pain Intensity (PI)	1	9	5	7	
	Pain Distress(PD)	1	6	5	7	0
	PSEQ	21	32	39	17	1
	PCS	27	17	18	31	1
	PDI	44	55	37	53	0
	WALK (m)	290	301	390	999	0
	IMPROVED ON 2 PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 4 "PARTIALLY IMPROVED"					
10.	Pain Intensity (PI)	8	8	9	99	
	Pain Distress (PD)	6	6	9	99	0
	PSEQ	5	5	24	99	0
	PCS	43	43	46	99	0
	PDI	60	60	51	99	0
	WALK (m)	270	270	999	999	0
	IMPROVED ON NO PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 0 "NOT IMPROVED"					
11.	Pain Intensity (PI)	7	6	99	99	
	Pain Distress (PD)	8	7	7	99	0
	PSEQ	15	34	27	99	1
	PCS	41	8	23	99	1
	PDI	54	36	48	99	1
	WALK (m)	150	140	110	999	0
	IMPROVED ON 2 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 6 " IMPROVED"					
12.	Pain Intensity (PI)	7	4	3	1	
	Pain Distress (PD)	7	4	3	0	1
	PSEQ	29	38	56	60	0
	PCS	24	14	4	0	1
	PDI	45	9	1	0	1
	WALK (m)	252	370	390	400	1
	IMPROVED ON 2 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 6 " IMPROVED"					

13	Pain Intensity (PI)	7	4	6	8	
	Pain Distress (PD)	7	2	7	8	1
	PSEQ	28	41	30	46	1
	PCS	27	23	14	16	0
	PDI	39	32	27	17	0
	WALK (m)	270	330	350	370	0
	IMPROVED ON 2 PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 4 "PARTIALLY IMPROVED"					
14.	Pain Intensity (PI)	8	6	6	7	
	Pain Distress (PD)	8	6	6	5	0
	PSEQ	4	11	13	19	1
	PCS	37	29	17	17	0
	PDI	41	41	36	40	0
	WALK (m)	280	320	290	260	0
	IMPROVED ON NO PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 0 "NOT IMPROVED"					
15.	Pain Intensity (PI)	7	5	5	7	
	Pain Distress (PD)	8	6	5	7	0
	PSEQ	25	35	33	22	0
	PCS	37	21	19	27	1
	PDI	43	22	36	35	1
	WALK (m)	60	85	80	999	1
	IMPROVED ON 1 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 2 " PARTIALLY IMPROVED"					
16.	Pain Intensity (PI)	9	9	3	4	
	Pain Distress (PD)	7	7	3	4	0
	PSEQ	30	30	30	54	0
	PCS	15	15	22	7	0
	PDI	25	25	47	40	0
	WALK (m)	315	390	345	370	0
	IMPROVED ON NO PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 0 "NOT IMPROVED"					

17.	Pain Intensity (PI)	5	4	6	5	
	Pain Distress (PD)	7	4	5	6	1
	PSEQ	28	32	32	30	0
	PCS	40	25	28	26	1
	PDI	41	44	48	33	0
	WALK (m)	240	270	260	280	0
	IMPROVED ON 2 PSYCHOLOGY AND NO PHYSICAL MEASURES OVERALL RATING = 4 "PARTIALLY IMPROVED"					
18.	Pain Intensity (PI)	9	6	7	7	
	Pain Distress (PD)	9	5	7	6	1
	PSEQ	17	36	42	41	1
	PCS	16	5	3	6	1
	PDI	48	43	39	30	0
	WALK (m)	160	200	200	180	1
	IMPROVED ON 3 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 6 " IMPROVED"					
19.	Pain Intensity (PI)	9	4	3	1	
	Pain Distress (PD)	9	3	2	1	1
	PSEQ	21	50	57	59	1
	PCS	52	29	1	1	1
	PDI	56	15	0	3	1
	WALK (m)	210	290	340	380	1
	IMPROVED ON 3 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 6 " IMPROVED"					
20.	Pain Intensity (PI)	9	9	8	3	
	Pain Distress (PD)	10	4	6	1	1
	PSEQ	15	52	54	49	1
	PCS	40	12	5	3	1
	PDI	51	23	4	3	1
	WALK (m)	145	200	280	310	1
	IMPROVED ON 3 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 6 " IMPROVED"					

21	Pain Intensity (PI)	4	3	3	2	
	Pain Distress (PD)	4	3	2	1	0
	PSEQ	41	45	51	52	1
	PCS	21	13	8	10	1
	PDI	21	33	16	10	0
	WALK (m)	280	310	352	330	1
	IMPROVED ON 2 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 6 " IMPROVED"					
22	Pain Intensity (PI)	4	3	3	4	
	Pain Distress (PD)	2	2	3	5	0
	PSEQ	46	48	59	60	1
	PCS	15	4	1	1	1
	PDI	22	18	7	0	0
	WALK (m)	175	260	320	320	1
	IMPROVED ON 2 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 6 " IMPROVED"					
23.	Pain Intensity (PI)	5	7	4	7	
	Pain Distress (PD)	5	5	4	7	0
	PSEQ	18	46	31	19	1
	PCS	29	15	23	32	1
	PDI	26	14	36	36	1
	WALK (m)	395	380	999	300	0
	IMPROVED ON 2 PSYCHOLOGY AND 1 PHYSICAL MEASURE OVERALL RATING = 6 " IMPROVED"					
24.	Pain Intensity (PI)	10	8	9	?	
	Pain Distress (PD)	9	8	9	?	0
	PSEQ	26	34	22	?	0
	PCS	52	31	44	?	1
	PDI	60	29	50	?	1
	WALK (m)	130	290	320	???	0
	IMPROVED ON 1 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 2 " PARTIALLY IMPROVED"					

25.	Pain Intensity (PI)	6	6	99	99	
	Pain Distress (PD)	8	8	99	99	0
	PSEQ	24	24	99	99	0
	PCS	29	29	99	99	0
	PDI	56	56	99	99	0
	WALK (m)	80	80	999	999	0
	IMPROVED ON NO PSYCHOLOGY AND NO PHYSICAL MEASURES **OVERALL RATING = 0 "NOT IMPROVED"**					
26.	Pain Intensity (PI)	8	8	5	?	
	Pain Distress (PD)	8	8	5	?	0
	PSEQ	25	33	29	?	0
	PCS	4	4	1	?	0
	PDI	20	21	20	?	0
	WALK (m)	355	310	999	?	0
	IMPROVED ON NO PSYCHOLOGY AND NO PHYSICAL MEASURES **OVERALL RATING = 0 "NOT IMPROVED"**					
27.	Pain Intensity (PI)	7	4	99	?	
	Pain Distress (PD)	7	3	99	?	1
	PSEQ	23	36	99	?	1
	PCS	30	17	99	?	1
	PDI	41	19	99	?	1
	WALK (m)	355	385	999	???	0
	IMPROVED ON 3 PSYCHOLOGY AND 1 PHYSICAL MEASURES **OVERALL RATING = 6 " IMPROVED"**					
28.	Pain Intensity (PI)	5	3	99	?	
	Pain Distress (PD)	7	3	99	?	1
	PSEQ	19	33	99	?	1
	PCS	30	28	99	?	1
	PDI	36	30	99	?	1
	WALK (m)	220	240	999	???	0
	IMPROVED ON 2 PSYCHOLOGY AND NO PHYSICAL MEASURES **OVERALL RATING = 4 "PARTIALLY IMPROVED"**					

29.	Pain Intensity (PI)	8	5	4	?	
	Pain Distress (PD)	8	5	3	?	1
	PSEQ	21	33	44	?	1
	PCS	24	12	6	?	1
	PDI	50	29	21	?	1
	WALK (m)	240	270	320	???	0
	IMPROVED ON 3 PSYCHOLOGY AND 1 PHYSICAL MEASURES OVERALL RATING = 6 " IMPROVED"					
30.	Pain Intensity (PI)	8	4	4	?	
	Pain Distress (PD)	7	3	2	?	1
	PSEQ	30	39	44	?	1
	PCS	33	17	8	?	1
	PDI	38	26	12	?	1
	WALK (m)	235	305	400	???	1
	IMPROVED ON 3 PSYCHOLOGY AND 2 PHYSICAL MEASURES OVERALL RATING = 6 " IMPROVED"					

KEY MOMENTS BY SUBJECT AREA

Information/Education

1. Introductory session by physiotherapist (KW) :Underactivity/overactivity cycle:

    - "Hit the spot" on first day – made me think about plans and routines and also how I got here in the first place (i.e. loss of strength)
    - Finding out that oa/ua cycle is a common phenomenon in chronic pain and that this is what exacerbates situation – "we all said it"
    - Realisation that I did oa/ua cycle on Day 1. Said to me that I was going to learn something here

2. Introductory talk by psychologist (TNJ) :"Chronic Pain":

    - Learning differences in the physical treatments for acute vs chronic pain
    - TNJ explaining that the aim of the programme was to make you functional, not to get rid of the pain. This changed my perspective considerably
    - Difference between acute and chronic pain – first time I'd heard this explained like that – very significant for me
    - Understanding the difference between acute and chronic pain

3. Session by pain management consultant (AR-Rheumatologist) :Pain Mechanisms

    - Doctor's visit and talk about the message processes – receptors, nerves, this was my key moment
    - Being told having pain doesn't mean (there has to be) damage, very significant for me (physio and doctor's sessions). Also learning you can have chronic pain for reasons other than what's caused my pain

i.e. other people's pain (physio and doctor's sessions). AR talked about causes of pain – most pain not shown on x-ray – doesn't mean (you're) not in pain. (I was) disbelieved before (this made her feel validated) "Don't want the pain". Said "VERY IMPORTANT THAT THIS CAME FROM A MEDICAL DOCTOR".

- Together with medication review (on this occasion, session done by PN, pain management consultant (Anaesthetist), doctors both non-hierarchical – very holistic. Felt for first time, treated like an equal (not a "maniac"). NEEDS TO BE DONE BY A DOCTOR (or, second thought, SOMEONE WITH CONSIDERABLE MEDICAL KNOWLEDGE). I was given information which other health professionals have treated me like a maniac for suggesting (KR thoughts – validation/respect leading to mutual respect)
- PN and AR sessions: content and doctors input/explanations. SOURCE MATTERS – TRUST IN PERSON IS VITAL.
- Pain Mechanisms talk (AR) "Showed they took the (our) problem seriously – believe that "unseen pain is real – shows they <u>believe</u> – never had any explanation before (told pain due to number of children I'd had, told got to learn to live with it). This talk (made me feel) "Yes", meant we weren't imagining it.
- AR lecture on "why still feel pain" helped (me) understand how the pain is there even though no new damage. Knew a lot about receptors (degree in biology) and he explained very well. I tended to catastrophise before – reassuring that conscientious exercise will help it (pain) lessen. Reassuring that you're not imagining it. <u>Can</u> have pain without damage.
- reading things in paper – needs clarification and we had it here. (Emphasis on) **importance of exercise <u>in combination</u> with information on pain mechanisms.**
- AR session "really stuck in (my) mind". Examples such as lady with fixed hand – I thought "I don't want that to be me so I'm going to get on with it".
- Learning about pain mechanisms (AR) and medication (PN) and healing (KW). Learning that things can go wrong in the body and its nobody's fault and it can't get fixed. First time I'd heard this. Information reduces anxiety. Reason for it (pain) – won't get worse so

O.K. to do things. (Doctors don't tell you or give enough time to this so you get very worried).

- During Pain Mechanisms session (AR), key moment where faced the likelihood that to some degree or another I would live with my back pain hereafter. That there was little use in my hoping for a miracle (though of course there are exceptions). Linked to this, I started feeling less blaming of myself too once I began to feel that in effect I was learning life management with pain rather than pain management through life (reference to pacing, time management, relaxation and cognitive restructuring as "Life Skills" made during ? Friends and Family session (7)).
- Understanding why I get no relief from pain killers anymore.
- Understanding why I get sensations as well as pain

4. Educational session with Physiotherapist (KW) : Healing

- Talk on healing : made me feel that my body still "worked" and that things could improve (woman with benign joint hypermobility syndrome).
- After healing processes (talk) I was left thinking "How can this be?" "What is causing continuing pain ?" Doctor's visit (AR) - this was my key moment. (Primed by healing processes talk).
- Session on healing with physios. Gave me the confidence to try things..."I'm not going to make my condition worse. Was so scared of **damage,** before, not now.
- Being told, not causing any more damage to myself and **believing** it. Now when I have an increase in pain, I can say "Pain has increased but I have not damaged myself". Not quite sure when this happened but somewhere in the middle of the programme.
- Physio education session (Healing). Told "muscles grow around joints to replace "wear and tear" – interesting – reinforced need to exercise to keep it all going.
- Kelly – (her) attitude helped a lot – rather than being sympathetic – implying there are ways of exercising you out of the situation (pain).

- Kelly – education session, said something about knees, explained something and I thought "I didn't know that". FELT I GOT SOMETHING OUT OF THIS – beginning to feel I can benefit from this approach. Learning about Mechanisms (AR) and medication (?) and healing (KW). Learning that things can go wrong in the body and its nobody's fault and it can't get fixed. First time I'd heard this. "Information reduces anxiety". Reason for it (pain) and won't get worse – helpful to know. (see elsewhere).

5. Catastrophising / Thoughts and Feelings

- In pre-treatment assessment – identification of core belief – being "too harsh on self" (psychologist pointed this out to her).
- TNJ (psychologist) ? week 5 – Thoughts & Feelings session. Suddenly realised state of mind can make pain worse. Hadn't seen, until then, how much own frame of mind was contributing to how I was feeling "vicious circle".
- Thoughts/Feelings : acknowledging links between the two. Not really challenged feelings before – let them get her down. CHANGE occurred during these sessions plus individual sessions (keywork) with CD (psychologist). Also – someone outside group mentioned that I seemed happier. ? when but by end of programme.

- TNJ (psychologist) ? during assessment. I was really impressed by being asked how I feel about things. LEADS TO BETTER RAPPORT. In first thoughts and feelings sessions, aware that something changing. Got to tell people how you feel.
- Thoughts/Feelings – negative thoughts lasting less long ?able to take deeper because of emotionally painful experience (person experienced traumatic bereavement during programme).
- Recognition of catastrophising (had talked to CD (psychologist) before about a frightening experience). When TNJ described it, **I thought "That's me".**

Thoughts and feelings in the context of September 11th. Been in COPE group discussing problems re: parking at children's school. Got very worked up about it "huge". Went home, heard the news and thought, my problem is NOTHING in comparison. Then thought, if I can think like this today, should be able to remind myself that I can do it again. KEY MOMENT WAS RECOGNITION THAT I CAN CHANGE THINGS FOR MYSELF. ((PASSIVITY TO AUTONOMY))
(Later, got caught for speeding, thought very positively about it: "made me slow down – might prevent me having an accident in future").

Thoughts & Feelings (KR) – help in packaging my response to people who ask why I'm not working. Made me aware of extent to which I must justify myself etc.

Thoughts & Feelings (CD) – Talk on internal dialogue.

Discussion in group re: thoughts and feelings. Lorraine talking about her mother and feeling guilty. I said "Is she cold, hungry etc"., "No", – so she's fine. Then I thought , this applies to me (i.e. I do not need to keep worrying about her (mother)).

6) Exercise/Stretch/Circuits

Physios saying "Is there another way of doing this?" has encouraged me to be more imaginative and flexible in my approach to movement (fitted with (previous experience of) Alexander technique. Made me think about how I do it (move).

Exercises – practising. About session 4, could get hands below knees in flexion, realised (I was) so much more flexible (see also "Recognising own achievements". Slow exercise the key (could only do 1-2 in the beginning). Connection between what I do and effect it has. See improvement definitely – getting muscle tone back – daughter also sees it.

Kelly (physio) saying "We have a different way of looking at pain here".(? Day 1). I thought "That's good" (?change of approach, reason to be optimistic).

Sally (physio) – Session 1 – made me realise that there are individual aspects to the programme as well as group (aspects).

Kelly (physio) – attitude helped a lot. Rather than being sympathetic, implying there are ways of exercising yourself out of situation (pain flare-up – see also elsewhere). Also seeing effects on others e.g. Michelle riding bike by end of programme. Kelly making suggestions. A few months ago I would not have tried walking from the car on rough ground – now got there.

Weeks 7 and 8 – Circuit training – doubled up pacing now – feel its hard exercise (I'm out of breath) – all falling into place. Stretch was painful – now only one or two of them are (see also "Recognising own achievements").

Behavioural signs : squatting and finding joints don't squeak!
: holding leg up
Feeling comfortable doing most of exercises (now).
Involving friends in stretch and educating them – having cumulative beneficial effect on me.(Talked about sceptical friend who started exercising and got benefits – validated patients own experience.

Physical stretch. About session 5, realised that if I stretch and exercise first (i.e. before such activity as taking tiles off walls) I will be O.K. after. Realised I should have been doing this all along.

Around Session 5 – exercises getting easier – not so tired. "Must be doing something right" – not so exhausted afterwards. i.e. growing recognition that getting fitter.

Sally (physio) gave out form – led to realisation that we're like a machine – can stretch nerves etc. Last 3 weeks of programme – recognition of some success with stretching and pacing. "A convert".

Had not noticed loss of stamina – realise its not to late to improve. "Importance of exercise in combination with information on Pain Mechanisms".

When starting exercises(around session 3) started to feel more flexible. Thinking "something's working". Exercises helped me give up crutches (around session 4). Found able to take dog for walk Could not have done this before.

Finding I could manage the exercises (patient with Benign Joint Hypermobility Syndrome. Had been quite sceptical about programme and her capacity to benefit from it).

Was considering giving up and going to live with my daughter and sit in an armchair all day. ON MONDAY 18th MARCH 2002 WAS STANDING WAITING TO CROSS THE ROAD AND REALISED I COULD TURN MY HEAD. Proof that something beneficial was happening (in response to stretch and exercise). Something working – my attitude changed completely!

7) Pacing

Coming to terms with the benefits of pacing (irritating at first – need the training).

When first try pacing, think "not getting anywhere". After 2 weeks start to see things happening. Pacing hoovering – recognised this as a Key Moment. Also cooking – know when to stop. Discovered that I can do anything – don't think "I've got to get this done by..."

During week off (between weeks 6 and 7) penny dropped with pacing. Overdid – paid the price – dealt with it without phoning G.P. (won't do that again). Sick of people saying "Take tablets". Know they can't do anything – UP TO ME NOW. All this happened at this time – quite a major shift.

Week 7 – pacing at work. Writing tolerance low (1 min.). Kelly said "Can't do anything meaningful in that time but need to keep practising". Very important because had felt "I can't function". Feel now that its quite normal...incentive to keep going.

By Week 4, seeing the difference pacing makes if you keep it up e.g. increasing times from 1 to 10mins for walking/sitting – "something's really improved". Helpful to see times written down.

Seeing positive effects of pacing. Previously struggling to work leaning over production desk for 5 minutes. Recently have been leaning over production desk for 35 minutes without experiencing any discomfort gross enough to make me leave the situation. Realisation that I'm doing some things for a lot longer without using the timer (am looking at wall clock).
Within first week realised that, despite very low sitting tolerance (3 mins) and thus exhausted by pacing over the course of the day at the office, MY BACK PAIN WAS LESS THAN IT WOULD NORMALLY HAVE BEEN AT THE END OF THE DAY. That gave me a reason to stick to pacing.

8) First Aid Plans/Set Back Plans

Flare-ups – don't get as many as I used to but my mind goes back to "lesson" (on managing flare-ups) automatically.

About session 5 – realised that if I stretch and exercise first (i.e. before activity such as taking tiles off the wall) I will be O.K. afterwards. Realised I should have been doing this all along.(Pre-emptive).

First Aid and Set Back Plans for Flare-ups. When TNJ (psychologist) first discussed them (in theory) I could not see how they could help. But realised I was wrong when had a setback for 2 weeks – used plan and found afterwards that I'd actually done a lot more than would have happened in the past (didn't know how else to cope). So then I felt much more confident about setbacks in the future. Still don't like it happening but life can be better during them (set backs) than it used to be.

Realisation that flare-ups can be dealt with efficiently and don't have to be a major worry. Don't always know the difference between a flare-up and a set back. If you nip it in the bud, you don't have to have a set back. Just seem to get flare-ups now ? to do with how I cope.

9) Individual Sessions

One to one with TNJ (psychology) – removed anxiety about being on the course in session 2 or 3. Felt it would be O.K.

First individual session with CD helped me address personal baggage that I'd added on to having chronic pain, especially the restriction to my social life and fears about talking to people about the pain. From then on, I have made plans and (mostly) kept to them.

One to one with KW (physio) re: muscles and joints. Having the information (very significant) – thought "have never heard this from doctors before".

10) Involvement of partners, friends and family

Partner read file before Friends and Family Day (about session 5). He recognised that things in the file related to things in our lives and this had an instant (helpful) effect.

11) Group Experience

Minor key moment to do with experiencing other people. Not a homogeneous group. Shocked by particular comment made by group member to observer in wheelchair. Had preconception that people would not be that insensitive. Realisation about other people. All have different experiences of pain and in way we interact with pain and how it affects us. When I heard that some people in the group had had pain for 30-40 years, I was shocked to begin with – also interested to know how it had influenced what they had become. Thought "I'm not going to let it get to me like this".

EXAMPLE OF METHOD USED FOR CODING KEY MOMENTS

K/M KW- Main factor was finding out that over/underactivity was a commmon phenomenon in chronic pain and that this is what exacerbated the situation [7.]. Surprised WE ALL SAID IT – how is it I can do loads some days… knowing this is what happens and its detrimental, can be depressing [4.] .

Realisation that a flare-up can be dealt with efficiently and doesn't have to be a major worry. Its partly the KNOWLEDGE knowing the difference between a flare-up and a setback – don't always know. If "nip it in the bud" don't always have to have a setback. I'm not just going to lie about [6]. I did not have a "flare-up plan" before, think this is very good [2].

Lecture on why still feel pain by rheumatologist (AR) helped me understand how the pain is there even though no new damage. Receptors **(knew a lot, degree in Biology)** – phantom limb stuff – he really explained very well - physiological thing – nerve pain. Tended to catastrophise before, now reassuring, know that conscientious exercise will help it lessen [1]. Reassures you that you are not imagining it. Can have pain without damage. (I'm) always reading things in the paper – needs clarification and we've had it here. (Good) when it relates to you. All diagrams of joints and information re: shrinkage of muscles – all the physiology – so helpful. I hadn't noticed lost stamina, not too late to improve it. Emphasis on importance of exercise – very comforting.

Key -

Starting Point	**End Point**
1. Helplessness and loss of control	1.Sense of what is required to achieve change (hence self-efficacy)
2. Helplessness and loss of control	2.Sense of potential empowerment
3. Personal attribution and self-blame/guilt/ shame	3. Attribution to external non-personal cause/chance
4. Sense of being isolated/unusual	4. Communal experience
5. Devalued	5. Valued
6. Fearful inhibition	6. Experimentation and learning
7. Pain as a mystery	7. Achievement of an articulated working model of pain (creation of a narrative)

SUMMARY OF OUT PATIENT PAIN MANAGEMENT PROGRAMME DELIVERED AT CENTRE X

All patients attend for eight whole days (10.00 – 16.00) over seven weeks (every Tuesday) with the exception of Week 1 when they attend on Tuesday and on Thursday during that week. Group follow-ups are planned (three hours on each occasion) at 1,3,6 and 12 months post treatment. The Programme follows a timetable and each patient receives relevant written material to complement the teaching sessions.

The Programme consists of teaching sessions plus discussion and practical sessions. A specialist chronic pain physiotherapist covers aspects of fitness, stretch and exercise. The physiotherapist also teaches the principles of "pacing", involving working out an individual's "tolerances" to certain activities (e.g. sitting, standing, walking, lying) and learning to change position on a regular basis within these "tolerances" according to a timer or watch. Regular, planned rests are incorporated and the aim is that "tolerances" will extend as the individual becomes fitter. Two psychologists cover the cognitive and behavioural teaching sessions on the Programme, though these principles are also practised by the physiotherapist in her sessions. Sessions on issues of change and on learning to identify and challenge unhelpful habits of thinking are central to the Programme. Other sessions cover issues that are frequently pertinent for people with chronic pain. These include communication issues, anger management, difficulties with sleep and sexual issues as well as weekly relaxation/self hypnosis sessions. A nurse specialist advises individuals on the reduction of analgesic medication once people feel ready to pursue this. On one particular day of the Programme, family and/or friends are invited to accompany group members. They are involved in all aspects of the day, including a specific session to explore issues from their own perspectives. A medical pain management specialist provides a single session of teaching on pain mechanisms. During each day, there is one sessions of goal setting or contracting and on three occasions during the programme, group members are offered extended individual sessions with one of the two psychologists.

STANDARDISED MEASURES

- MEASURE OF PAIN DISTRESS
- PAIN SELF-EFFICACY QUESTIONNAIRE
- PAIN CATASTROPHISING SCALE
- PAIN DISABILITY INDEX

(see following pages)

COPE Pain Assessment

Thank you for agreeing to complete these questionnaires. The information is very useful for us in helping to understand your problems better. If you have any difficulty with any of the questions, please do not hesitate to ask for help.

1. Please indicate your CURRENT pain level by circling a number on the scale below:

0	1	2	3	4	5	6	7	8	9	10
no pain at all										pain as bad as it could be

2. Please indicate your AVERAGE pain level over the past week by circling a number on the scale below:

0	1	2	3	4	5	6	7	8	9	10
no pain at all										pain as bad as it could be

3. Please indicate how distressing your pain is for you CURRENTLY by circling a number on the scale below:

0	1	2	3	4	5	6	7	8	9	10
not distressing at all										pain as distressing as it could be

4. Please indicate how distressing your pain is for you ON AVERAGE over the past week by circling a number on the scale below:

0	1	2	3	4	5	6	7	8	9	10
not distressing at all										pain as distressing as it could be

5. How many bad days have you had in the past week because of pain?: _____

6. If you take pain medications, do you ever exceed the recommended daily dose?: Yes/No

7. How many times have you seen your GP for your pain in the last 3 months? _____

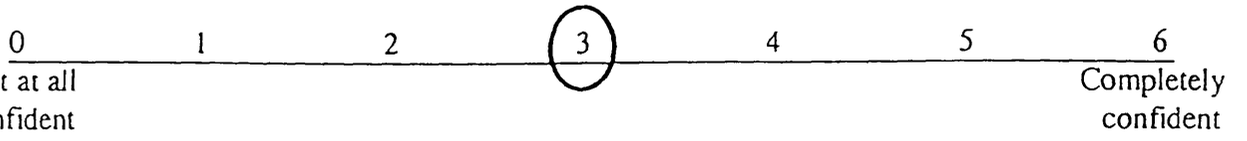
8. How many times have you seen an emergency doctor (home visit, Accident & Emergency Department, etc.) for your pain in the last 3 months? _____

PAIN: S-E QUESTIONAIRE
MKN (1988)

NAME: _____ DATE: _____

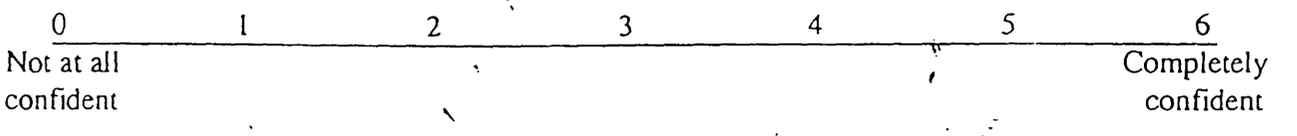
Please rate **how confident** you are that **you can do** the following things at present, **despite the pain.** To answer circle one of the numbers on the scale under each item, where 0 ="Not at all confident" and 6 ="Completely confident".

For Example:

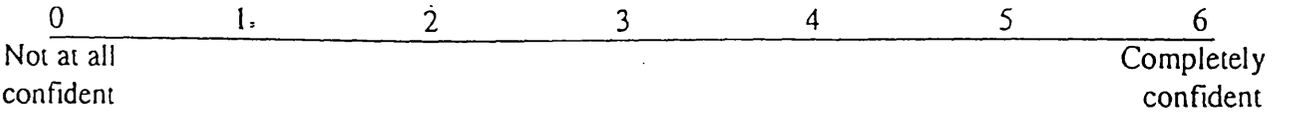


Remember, this questionaire is not asking whether or not you have been doing these things, but rather, **how confident you are that you can do them** at the present, despite the pain.

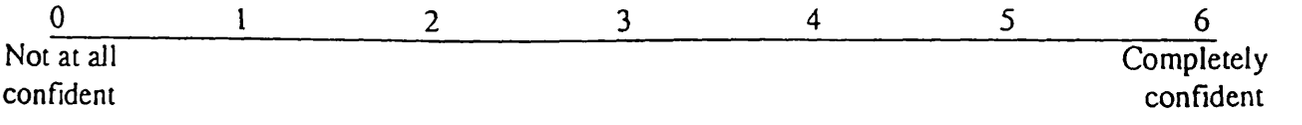
1. I can still enjoy things, despite the pain



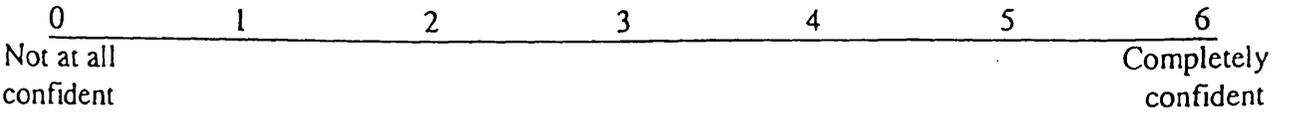
2. I can still do most of the household chores *(e.g.* tidying up, washing dishes *etc.)* despite the pain.



3. I can socialise with my friends or family members as often as I used to, despite the pain.



4. I can cope with my pain in most situations



Please turn over page

PAIN: S-E QUESTIONAIRE Cont'd

5. I can do some sort of work, despite the pain. '(Work" includes housework, paid or unpaid work)

0	1	2	3	4	5	6
Not at all confident						Completely confident

6. I can still do many of the things I enjoy doing, such as hobbies or leisure activities, despite the pain

0	1	2	3	4	5	6
Not at all confident						Completely confident

7. I can cope with my pain without medication

0	1	2	3	4	5	6
Not at all confident						Completely confident

8. I can still accomplish most of my goals in life, despite the pain

0	1	2	3	4	5	6
Not at all confident						Completely confident

9. I can still live a normal lifestyle, despite the pain

0	1	2	3	4	5	6
Not at all confident						Completely confident

10. I can gradually become more active, despite the pain.

0	1	2	3	4	5	6
Not at all confident						Completely confident

PCS

Name: _____ Age: _____ Gender: _____ Date: _____

Everyone experiences painful situations at some point in their lives. Such experiences may include headaches, tooth pain, joint or muscle pain. People are often exposed to situations that may cause pain such as illness, injury, dental procedures or surgery.

We are interested in the types of thoughts and feelings that you have when you are in pain. Listed below are thirteen statements describing different thoughts and feelings that may be associated with pain. Using the following scale, please indicate the degree to which you have these thoughts and feelings when you are experiencing pain.

0 – not at all **1** – to a slight degree **2** – to a moderate degree **3** – to a great degree **4** – all the time

When I'm in pain ...

1. ☐ I worry all the time about whether the pain will end.
2. ☐ I feel I can't go on.
3. ☐ It's terrible and I think it's never going to get any better.
4. ☐ It's awful and I feel that it overwhelms me.
5. ☐ I feel I can't stand it anymore.
6. ☐ I become afraid that the pain will get worse.
7. ☐ I keep thinking of other painful events.
8. ☐ I anxiously want the pain to go away.
9. ☐ I can't seem to keep it out of my mind.
10. ☐ I keep thinking about how much it hurts.
11. ☐ I keep thinking about how badly I want the pain to stop.
12. ☐ There's nothing I can do to reduce the intensity of the pain.
13. ☐ I wonder whether something serious may happen.

_____ ***...Total***

The rating scales below are designed to measure the degree to which several aspects of your life are presently disrupted by chronic pain. In other words, we would like to know how much your pain is preventing you from doing what you would normally do, or from doing it as well as you normally would. Respond to each category by indicating the *overall* impact of pain in your life, not just when the pain is at its worst.

For each of the 7 categories of life activity listed, please circle the number on the scale which describes the level of disability you typically experience. A score of 0 means no disability at all, and a score of 10 signifies that all of the activities in which you would normally be involved have been totally disrupted or prevented by your pain.

(1) Family/home responsibilities

This category refers to activities related to the home or family. It includes chores or duties performed around the house (e.g. yard work) and errands or favours for other family members (e.g. driving the children to school).

0 1 (2) 3 4 5 6 7 8 9 10

no disability total disability

(2) Recreation

This category includes hobbies, sports, and other similar leisure time activities.

0 1 (2) 3 4 5 6 7 8 9 10

no disability total disability

(3) Social Activity

This category refers to activities which involve participation with friends and acquaintances other than family members. It includes parties, theatre, concerts, dining out, and other social functions.

0 (1) 2 3 4 5 6 7 8 9 10

no disability total disability

(4) Occupation

This category refers to activities that are a part of or directly related to one's job. This includes non-paying jobs as well, such as that of a house-wife or volunteer worker.

0 1 (2) 3 4 5 6 7 8 9 10

no disability total disability

(5) Sexual Behaviour

This category refers to the frequency and quality of one's sex life.

0 (1) 2 3 4 5 6 7 8 9 10

no disability total disability

(6) Self-care

This category includes activities which involve personal maintenance and independent daily living (e.g. taking a shower, driving, getting dressed, etc.).

0 (1) 2 3 4 5 6 7 8 9 10

no disability total disability

(7) Life-support activity

This category refers to basic life-supporting behaviours such as eating, sleeping and breathing.

(0) 1 2 3 4 5 6 7 8 9 10

no disability total disability