

VOLUME 1

A QUALITATIVE STUDY OF THE
PROCESS OF CHANGE IN PATIENTS PARTICIPATING
IN A RESIDENTIAL PAIN MANAGEMENT PROGRAMME

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ABSTRACT

The study aimed to identify non-specific aspects of a residential pain management programme that influenced the changes patients made whilst attending. Specific aspects of the programme consisted of input from psychologists, physiotherapists, occupational therapists, doctors and nurses. In identifying non specific aspects of the programme, literature concerning therapeutic alliance and group therapeutic factors were reviewed.

The prospective study recruited 13 patients with chronic pain who were attending the residential pain management programme. Patients eligible for the programme completed a comprehensive assessment and had had pain for longer than 12 months. Patients were interviewed during week 2 and week 4 of the programme. The interviews were recorded and subsequently transcribed. Open ended interview questions were administered in 3 areas: (i) what was/was not changing for the patient during the residential programme, and their perceptions of what had influenced these changes; (ii) how patients perceived the staff; and (iii) the experience of being in a group of people with chronic pain. Interpretative Phenomenological Analysis (Smith 1997) was used to identify themes from the recorded interviews.

Patients reported physical, behavioural and psychological changes whilst attending the programme. Emergent themes influencing change were; (i) the acceptance of patient's pain by staff and fellow patients (ii) group identity as patients with chronic pain, and as patients participating in the programme (iii) mutually supportive group environments, including altruism (iv) witnessing change in others and (v) staff perceived as giving time.

Tentative conclusions suggested that patients felt sufficiently safe to attempt changes whilst attending the programme. Factors that contributed to this safe environment were staff attitudes, empathy and the therapeutic factors of universality and cohesion associated with being in a group of patients with chronic pain.

THIS THESIS IS DEDICATED TO MY PARENTS

ACKNOWLEDGEMENTS

Very many thanks go to the patients who participated in this research. They gave me at least some insight into how difficult a life with chronic pain can be.

Thank you also to my research supervisors, Lesley Glover and Amanda C de C Williams for their professional and personal support.

Finally, many thanks to all my friends for their support.

Particular love and thanks go to Liz McGrath who, for not the first occasion in her life, had been here before me and was significantly more cool about it.

CHAPTER 1: INTRODUCTION

The thesis presents a qualitative study of the process of change during a residential chronic pain management programme (PMP). The foci were the non specific factors that patients perceived helped them to make changes whilst attending the group programme, rather than which specific components of the programme were useful. In setting the context for the research, the ‘typical’ patient with chronic pain is described in the context of societal views of chronic pain. There will be a short introduction to the models of pain which provide the basis for PMPs. The efficacy of such programmes will be briefly described. Two non specific aspects of therapy that have been shown to influence the process of change will be introduced; the therapeutic alliance, and curative aspects of group membership. The introduction concludes with the aims of the thesis.

CHRONIC PAIN

Research literature focuses on the multi agency treatment of chronic pain and seldom includes a description of the ‘typical’ individual who has experienced pain for a long time. Sternbach (1974; cited in Gatchel, Baum et al. 1989) described the experience of a chronic pain patient;

“Pain patients frequently say that they could stand their pain much better if they could only get a good night’s sleep. They feel as though their resistance is weakened by their lack of sleep. They never feel rested. They feel worn down, worn out, exhausted. They find themselves getting more and more irritable with their families, they have fewer and fewer friends, and fewer and fewer interests. Gradually as time goes on, the boundaries of their world seem to shrink. They become more and more preoccupied with their pain, less and less interested in the world around them. Their world begins to center around home, doctor’s office, and pharmacy.”

Chronic pain (CP) has been defined as any constant pain lasting longer than six months. The average patient attending a pain clinic reports a history exceeding 7 years (Turk and

Rudy 1992). CP is not an observable illness and as such can be difficult for patients and health care professionals to deal with. Patients with acute or chronic pain may exhibit what have been termed “pain behaviours” (Gatchel, Baum et al. 1989). These include taking time to lie down during the day, sighing, grimacing and rubbing. Similarly, patients may use a walking stick or neck collar. Turk and Rudy (1992) wrote; “living with chronic pain requires considerable emotional resilience and tends to deplete one’s emotional reserve” (p103).

Chronic pain has been labelled as hysterical, or considered psychological in origin (Shapiro and Teasell 1997). This may be due clinical signs being inconsistent with conventional understandings of the nervous system and the pain not responding to standard medical interventions. Additionally, patients with chronic pain may have concurrent psychological problems. The combination of these factors may result in the misdiagnosis of CP as hysterical (Shapiro and Teasell 1997).

Shapiro (1997) described how the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM) categorised chronic pain over the years. The 3rd edition (1980) included the diagnostic category of “Psychogenic pain disorder” which was revised to “Somatoform pain disorder” in 1987. In the 4th edition (1994) chronic pain was categorised as a “pain disorder associated with psychological factors”. The validity of criteria for psychogenic pain has never been adequately established and changes with each edition of the DSM. The diagnosis of myofascial pain remains controversial. The title of Shapiro’s paper, “misdiagnosis of chronic pain as hysterical”, points to the continued negative fashion in which patients with chronic pain can be viewed by the medical profession and often are by society.

CP has been viewed as psychogenic and hence attributed to a variety of psychological factors such as the inability to express emotions. Theories of the psychogenesis of pain originate from experience with the ‘conversion’ disorders (Shapiro and Teasell 1997). ‘Conversion’ has a specific aetiology whereby psychological conflicts are somehow

converted into physical symptoms. Patients experience 'primary gain' by keeping an internal conflict and its associated anxiety out of consciousness (Shapiro and Teasell 1997). Classic 'conversion' symptoms mimic neurological disorders, for example paralysis and co-ordination disturbances. Some conditions that were thought to reflect 'conversion' disorder were later found to have a medical aetiology once medical knowledge had advanced and diagnostic tools were more sophisticated. The absence of proof concerning physical aetiology does not constitute proof that physical aetiology does not exist, nor that psychological aetiology does.

Shapiro (1997) posits the question: "Why does the tendency to view chronic pain as a psychological disorder persist despite the absence of empirical support?" It may be that the tendency to misdiagnose pain as hysterical is because many physicians still think in terms of mind-body dualism and conceptually see pain as either organic or psychological. Additionally, some may misinterpret the psychological correlates of chronic pain as causal. Alternately, it may be simply due to basic disbelief and an attribution of malingering because no organic cause can be identified. Although there have been improvements in attitudes amongst health care professionals towards patients with pain, there remain significant vestiges of the traditional psychogenic conceptualisation associated with mind-body dualism (Shapiro and Teasell 1997).

Many patients with chronic pain present with depressed mood (Williams 1998; Shapiro and Teasell 1997; Turk and Rudy 1992; Pearce and Erskine 1989; Gatchel, Baum et al. 1989). Psychological problems can be due to iatrogenic complications such as the overuse of medication, or due to work disability, financial difficulties, inadequate social support and sleep disturbance (Turk and Rudy 1992). Physicians can fail to appreciate the consequences of attributing chronic pain to psychological factors (Shapiro and Teasell 1997). For most lay people, and many health care professionals, stigmata of weakness and inadequacy are associated with chronic pain. The diagnosis of chronic pain may carry the specific belief that a patient can overcome the condition by a simple act of will. Failure to do this is seen by others as lack of motivation or personal inadequacy. Patients

typically react to this attitude defensively with anger and self-deprecation. Patients report not being believed (Osborn and Smith 1998). Patients who feel that others do not 'believe' their pain can become preoccupied with proving the legitimacy of their symptoms and may believe that if their symptoms were acknowledged as 'real' there would be successful attempts to provide relief (Shapiro and Teasell 1997). These patients may focus on finding a diagnosis and appropriate treatment rather than optimising their function despite the pain. Additionally, in seeing the psychological label as an incorrect diagnosis these patients may view encouragement to increase function despite the pain as tantamount to asking them to risk further injury and increased disability. Shapiro's comments (1997) were based on clinical experience rather than research yet ultimately, a psychological diagnosis in these patients extricates physicians from further responsibilities, offering little for their management.

Models of chronic pain

Sensory models of pain no longer give an adequate explanation of the experience of the pain patient, failing to account for pain phenomena such as chronic and phantom pain (Gamsa 1994). The evolution from linear causal models to multidimensional explanations for the experience of chronic pain has been recent (Eccleston, Williams et al. 1997; Gamsa 1994).

Research in the 1960's to 70's aimed to identify personality traits that would explain otherwise unexplained pain (Turk and Rudy 1992; Gamsa 1994). The term 'pain prone personality' was used by Engel (1959). The psychoanalytic view was that intractable pain with no organic explanation was a defence against unconscious psychic conflict (Engel 1959). Hence emotional pain (a metaphoric condition) was displaced into the body and pain was seen as the expression of unconscious conflict. Pain was attributed to problems such as repressed hostility, guilt, masked depression or a defence against threatened loss (Gamsa 1994). Much of the theory was based on a limited number of case histories, usually of the theorists themselves, with little distance or objectivity between researcher and theory.

Engel (1959) developed a theory to explain pain in the absence of peripheral stimulation, “psychogenic” pain. Engel (1959) suggested that from birth the individual builds a library of pain experiences. Hence pain acquires a meaning depending on the context in which it was initially experienced. The meaning itself may later become a trigger. Engel (1959) continued to propose that from these early associations individuals came to use pain unconsciously to resolve developmental conflicts. Engel (1959) suggested that “psychogenic” pain promoted “psychic equilibrium” by fulfilling the emotional needs of the patient. There is little evidence to support the theory of “psychogenic” pain although Gamsa (1994) suggested it may explain chronic pain in a sub-group of patients.

Psychoanalysts have aimed to demonstrate that emotional problems generated and perpetuated chronic pain. Inconclusive research has examined factors such as birth order, problems in early family relationships, and personality disorders. Evidence has failed to provide support for the tenet that emotional conflict gives rise to chronic pain. In the last decade research suggesting direct causal relationships between emotional disturbance and pain have reduced in the published literature. When psychological causation is postulated, multiple determinants of pain are also usually discussed (Gamsa 1994).

Behaviour theory defined pain by the observable presence of “pain behaviour” (Fordyce, Fowler et al. 1968; Fordyce 1986). “Pain behaviours” were actions such as crying or facial grimacing. The meaning to the patient of such behaviours was not explored. Acute pain may become operant and persistent pain if the environment offered pain contingent reinforcement. The behavioural explanation proposed that operant pain persisted because it elicited ‘secondary gains’. Such secondary gains could be the avoidance of chores, unpleasant sexual activity or aversive interactions with family members. Similarly, operant pain could serve to control family members and to obtain otherwise unattainable attention and care.

The basis of operant pain management programmes was to abolish “pain behaviours” and in doing so remove the pain problem. Pain contingent reinforcers such as medication, bed rest and avoiding aversive situations were eliminated while reinforcement contingent on “well behaviours” was introduced. Behavioural management of pain was based on a linear causal model of pain which disregarded the variables in a patient’s life in which the pain was embedded. Thus the chance of maintaining changes was reduced as once back in their social context the ‘secondary gains’ would still be present.

The gate-control theory of chronic pain (Melzack and Wall 1965) established the role of cognitive-evaluative processes in the modulation of pain. Cognitive theory examined intervening variables that had an impact on the individual’s experience of chronic pain. Examples of intervening variables were attention, attributions, beliefs, coping strategies and self-efficacy. Self-efficacy appeared to be particularly important. Self-efficacy expectations were a personal conviction that one could successfully execute a course of action to produce a certain outcome (Turk and Rudy 1992). Pain patients’ beliefs about their capabilities appeared to be predictive of their behaviour (Turk and Rudy 1992). Once individuals had sufficient motivation their self-efficacy beliefs would determine the choice of activities initiated, the amount of effort, and how long the individual would persist in the activity in the face of obstacles and aversive experiences. Hence coping behaviours were mediated by the individual’s belief that the situational demands did not exceed their coping resources. Self-efficacy beliefs (Bandura 1977) were influenced by four sources of information;

- performance and enactment experience
- vicarious experience
- verbal persuasion and social persuasion
- emotional/physiological arousal

Mastery experiences gained through performance accomplishments were hypothesised to have the greatest impact on establishing and strengthening expectancies because they provided reliable information about actual ability.

Research from the cognitive perspective has investigated the influence of thought processes on the experience of pain. Cognitive pain management strategies seek to alter the appraisal and meaning of pain, divert attention and increase the patient's self-efficacy. Self-efficacy research has suggested that the subjective appraisal of situations and beliefs about one's ability to cope, influence the experience of stress (Nicholas, Wilson et al. 1991). Cognitive processes including automatic cognitive distortions have been found to have a central role in patients' coping abilities. Of particular importance was "catastrophising". Melzack and Wall (1965) integrated psychological and physiological factors and brought the psychological study of pain to mainstream research. It is now generally recognised that psychological factors play an important role in chronic pain (Gamsa 1994).

Shapiro (1997) proposed a biopsychosocial model of pain with physical and psychological factors inextricably linked. The number of symptoms had little to do with the aetiology of pain *per se* but was best conceptualised as the individual's response to pain. Hence the investigation of each symptom by health care professionals missed the significance of the pain experience for the patient.

The psychophysiological approach examined the influence of mental events (thoughts/memories/emotions) on physical changes which produced pain. There were three assumptions; (i) relationships existed between psychological states (stress) and physical changes (autonomic arousal); (ii) relationships existed between specified physical changes and pain (iii) physical changes which were said to precipitate pain actually preceded it. There have been expensive studies of muscle tension, vascular changes and autonomic arousal mostly relating to headaches, myofascial pain and lower back pain. The findings of this research have been inconsistent (Gamsa 1994).

Biofeedback and relaxation techniques have been used to reduce muscle tension and autonomic arousal. These techniques have been shown to be effective in the reduction of pain in muscle contraction headaches and back pain, but not necessarily more so than

other psychological interventions. It may be that these diverse treatments, such as relaxation, biofeedback, hypnosis and pill placebo, work by giving the patient an enhanced perception of control over the pain, and by offering hope of change, rather than by specific physiological mechanisms.

PMPs research has identified that multi-discipline pain management programmes are efficacious in helping people cope better with their chronic pain. Particularly, inpatient programmes have been reported to result in both greater initial gains as well as better maintenance a year after a programme (Williams, Richardson et al. 1996).

The psychological treatment component of pain management programmes has generally used Cognitive Behaviour Therapy (CBT) methods (Williams, Richardson et al. 1996; Pearce and Erskine 1989). The programmes include exercise and stretch, contingency management, goal setting, graded activity scheduling and education e.g.: anatomy and physiology. Cognitive techniques are taught e.g.: identifying thoughts and feelings, learning the links between thoughts and feelings, challenging thoughts using evidence, and anger management.

In a systematic review and meta-analysis of randomised clinical trials of cognitive behaviour therapy (CBT) and behaviour therapy for adults with chronic pain, the authors concluded that CBT was associated with significant improvements in terms of pain experience, cognitive coping and appraisal, and the reduction of behavioural expressions of pain (Morley, Eccleston et al. 1999). Increased activity levels and changes in social role functioning were also reported. In the studies reviewed, the pain management treatment was typically delivered in groups over a 7 week period. The outcome was primarily patient self-rating (Morley, Eccleston et al. 1999).

THE PROCESS OF CHANGE

The process of change could be considered to be the process through which patients are hypothesised to improve and tends to be viewed as occurring within the patient but not

exclusively or even mainly during therapy sessions. Carl Rogers (1961) discussed process in psychotherapy as the stages of change in a patient's psychological functioning. These could comprise the manner of experiencing, the construed meaning or the manner of relating. The therapist's behaviour during sessions was not seen as part of the process but rather as creating an environment which was more or less "facilitative" of the patient's process. The focus of the current study was to explore the process of change during a residential pain management programme.

Psychological therapies focusing on different factors underlying the causation and maintenance of depression, have used dissimilar interventions (cognitive/behavioural/interpersonal), yet reported similar effects in terms of outcome measures. In attempting to explain this, theorists postulated that non specific factors common to all forms of therapy played a more significant role in clinical improvement than specific factors unique to the type of treatment (Orlinsky 1994). The division of specific and non specific factors in therapy has a long tradition. In cognitive behaviour therapy (CBT) a specific factor would be the identification of how a thought related to an emotion, a non specific factor would be the therapist's warmth in helping the client make such a connection. Aspects of the relationship between the therapist and client that have been suggested to contribute to changes made by patients have included; warmth, empathy, acceptance, and the expectation that treatment will help (Safran and Segal 1996).

Forty-five percent of variance in outcome findings in psychotherapy has been estimated to be due to non specific therapy factors, 15% attributed to specific technical factors (Lambert, Shapiro et al. 1986). Jerome D. Frank (1991) emphasised the importance of common therapy factors and proposed that factors common to psychotherapies included the presence of a trusting relationship, a convincing rationale, and faith that the treatment would help (Frank and Frank 1991). Faith was a factor that helped reverse patients demoralised feelings, this may be of particular salience in the field of chronic pain where the disease history is often lengthy.

Non specific factors described in psychotherapy are present in relationships and social institutions outside of therapy. Hence it has been argued that there is nothing unique about therapy and that it was pointless to do research to develop new therapeutic mechanisms of change (Safran and Segal 1996). Butler and Strupp (1986, cited in; Safran and Segal 1996) addressed this by challenging the distinction between specific and non-specific aspects of therapy. They suggested this distinction was based on the inappropriate assumption that psychotherapy was analogous to medical treatment. Unlike treatment through medication, where there was a proposed biological action, psychotherapeutic techniques were intrinsically linked to the interpersonal context in which they occurred. Hence, Butler and Strupp (1986) argued that the complexity of psychotherapy processes could not be reduced to a set of disembodied techniques because techniques gain meaning and hence effectiveness from particular interactions of the individuals involved. The impact of therapist's behaviour upon the patient should be understood in terms of the patient's perception of the behaviour. This perception would be determined by the patient's unique learning history. The meaning patients attribute would determine their response, as well as whether the event would lead to new learning or confirmation of the patients' perceptions and interpersonal patterns.

Safran and Segal (1996) similarly suggested the specific versus non-specific debate was a "mistaken separation". They considered it partially responsible for the difficulties of demonstrating the superiority of various forms of psychotherapy and highlighted the treatment versus placebo effect. The construct of placebo in pharmacology, where biochemical changes can be contrasted with psychosocial mechanisms of change, was appropriate. However, it was inappropriate in psychotherapy where the mechanisms of change were primarily psychosocial.

In any treatment group there are a range of patient outcomes. Some do extremely well, others moderately well. Some make no changes, meanwhile others actively deteriorate. There have been attempts to identify variables that will predict treatment outcome.

Initially these attempts focused on the patients' characteristics, the results were disappointing. This led to speculation that the crucial predictive factors may not be apparent until the patient and therapist met (Safran and Segal 1996).

In the preface of their review of the interpersonal process in cognitive therapy, Safran and Segal (1996) emphasised a trend in cognitive behaviour therapy (CBT); the evolution of a constructivist approach to CBT. They suggested there was an increasing focus on the interpersonal context in which modifications of schematic structures occur, emphasising that change took place through the dialectical engagement between the patient and therapist. Safran and Segal (1996) emphasised the importance of an "in-depth phenomenological exploration" of the patient's experience, keen not to privilege the perspective of the therapist over the patient's.

It is no longer uncommon in CBT to explore the therapeutic relationship. This is typically done from the perspective of the therapist, assuming that patients enact their characteristic interpersonal patterns independent of the therapist's contributions. Safran and Segal (1996) concluded that there had been a paradigm shift in psychoanalysis to two-person psychology that emphasised the importance of understanding everything that occurred in therapy sessions as involving patient and therapist contributions.

Process outcome studies aim to identify the parts of therapy that, singly or in combination, bring about what therapy does (Orlinsky, Grawe et al. 1994). Orlinsky, Grawe and Parks (1994) presented a meticulous overview of process outcome studies from the 1960's to the early 1990's.

The observational perspective could be the patient's, therapist's or observer's. Data from these differing perspectives were not often correlated and produced divergent findings in relation to other process/outcome variables (Orlinsky, Grawe et al. 1994). The term process has been used in terms both of the process of treatment and the process of change.

There is debate as to how meaningful it is to use the term psychotherapy when there are many specific types of therapy available (Orlinsky, Grawe et al. 1994). Orlinsky (1994) proposed that it was possible to use the general term psychotherapy with reasonable confidence when discussing a broad range of professional psychosocial interventions. The authors proposed a generic model of psychotherapy which focused on the commonalities and the systematic variations that differentiated therapies. The generic model of psychotherapy distinguished six aspects of process that could be found in all forms of therapy; formal, technical, interpersonal, intrapersonal, clinical, and temporal. These aspects of the therapeutic process were concurrent features of psychotherapy, functionally inter-related (Orlinsky, Grawe et al. 1994). The strongest evidence linking process to outcome has been in research investigating the therapeutic bond. There has been considerable theoretical interest (Horvath and Luborsky 1993) continuing the work started by Carl Rogers (1957). No aspect of the therapeutic process has been as thoroughly investigated as the therapeutic bond or alliance (Orlinsky, Grawe et al. 1994).

Therapeutic alliance

The psychoanalytic literature provides the original notion of the therapeutic alliance (Safran and Segal 1996). By 1912 Freud had emphasised the importance of friendliness and affection between the patient and therapist. Varying psychotherapy traditions have explored its value as a generic psychotherapy construct. The therapeutic alliance was important in psychoanalysis, but not until the 1970's did it attract the interest of psychotherapy researchers (Safran and Segal 1996).

Psychotherapy research has proposed that the benefits from therapy may be due to variables common to the technically differing therapies, namely the therapeutic alliance. There have been four major theoretical formulations concerning the therapeutic alliance (Horvath and Greenberg 1989); Rogers' client centred theory (1951); Strong's social influence theory (1968); Greenberg's psychodynamic perspective (1967), and Bordin's integrationist formulation of the working alliance (1975). Client centred theory proposed three active components of the therapeutic relationship; empathy; unconditional positive

regard, and congruence. Social influence theory suggested that the degree to which clients believed their therapists to be trustworthy, expert and attractive was proportional to the likelihood of a successful therapy outcome. The psychodynamic perspective, as proposed by Freud, drew a distinction between 'neurotic' and 'friendly' feelings of the client towards the therapist.

The most identified author associated with the term therapeutic alliance was Edward S. Bordin. Bordin (1979) partitioned the therapeutic alliance into *tasks*, *bonds* and *goals* and suggested that these were essential if change were to occur. *Tasks* were the in-counselling behaviours and cognitions that formed the substance of the counselling process, they could be overt or covert. In well functioning relationships the tasks were perceived as relevant and efficacious and participants accepted the responsibility to perform them. *Goals* were general objectives, the outcomes mutually endorsed and valued by the client and the therapist. *Bonds* were the complex network of personal attachments between the client and the therapist which included mutual trust, acceptance and confidence. Bordin suggested that different therapies made different demands on the relationship.

Bordin (1979) proposed that the strength of the therapeutic alliance depended both on the amount of agreement between the therapist and patient concerning goals and tasks, as well as the strength of the therapeutic bond between the therapist and patient. Bordin's theory of the working alliance was a re-conception of the psychoanalytic notion of the working alliance to encompass all change-inducing relationships. The working alliance was a participative collaboration and was what made it possible for the patient to accept and follow treatment faithfully (Bordin 1979). During therapeutic collaboration patients self-defeating bad habits should occur and could therefore be overcome. In this way clients were provided with new ways of thinking, feeling and acting which could be generalised to other areas of their life (Horvath and Greenberg 1989).

Bordin's understanding of the therapeutic alliance added a dimension of mutuality in terms of collaboration, concordance and a sense of joint purpose to the therapeutic process (Bordin 1994). Other approaches had solely considered that client's perceptions of the therapist's qualities, or the attitude and behaviour of the therapist. Bordin stated that the working alliance was the vehicle that enabled and facilitated specific counselling techniques. Hence it was not a counselling intervention in itself or a sufficient condition in itself.

Up to 80% of research assessing the predictive value of the therapeutic alliance in psychotherapy has produced positive results (Orlinsky, Grawe et al. 1994). Research results differed depending on the perspective from which the therapeutic alliance was measured. When assessed from the patient's perspective, therapeutic empathy was related to psychotherapy outcome. This was much less so when the therapeutic alliance was assessed by the therapist or an observer. Patient warmth and investment in the therapeutic process, and mutual affirmation between the patient and therapist, were consistently predictive of outcome even when rated by observers. Hence patient's perception of the meaning of the therapist's behaviour was critical in terms of whether psychotherapy would be effective.

Process outcome research has focused both on specific aspects of the therapeutic bond as well as its overall quality. Orlinsky and colleagues (1994) in their extensive overview concluded that the global quality of the therapeutic bond was significantly positively associated with therapeutic outcome. They reported that effect size was greater than or equal to .25 for at least 25% of the recent positive findings. In group programmes there were significant positive associations between group cohesion and outcome suggesting that group cohesion formed a similar role to the therapeutic alliance.

Orlinsky and colleagues (1994) reported studies that had assessed specific aspects of the therapeutic bond such as personal role investment, communicative contact and mutual affect. Within research investigating *personal role investment*, Orlinsky and colleagues

(1994) reported that the personal involvement of the participant in the patient role was significantly positively associated with therapeutic outcome. *Communicative contact* was good when the patient and therapist reported being on the same “wavelength” and did not talk past each other. In terms of *mutual affect*, therapist affirmation (acceptance, non possessive warmth and positive regard) was associated with positive outcome as assessed from the patient’s perspective (Orlinsky, Grawe et al. 1994). Hence, the therapeutic bond was central to outcome in both individual and group psychotherapies, particularly when assessed from the patient’s perspective (Orlinsky, Grawe et al. 1994).

Empathy has been investigated as a necessary feature of the therapeutic alliance. It has been defined as the sympathetic identification with another person which promotes the understanding of that person’s point of view and motivation (Burns and Auerbach 1996). Data have demonstrated that therapists did not accurately estimate how their patients perceived them (Burns and Auerbach 1996). Patient’s perceptions of empathy and therapeutic alliance were more related to outcome than therapist’s assessments (Orlinsky, Grawe et al. 1994). Regardless of which view was “realistic”, when discrepancies existed it was the patient’s perceptions which predicted changes in their self esteem and depression (Burns and Auerbach 1996).

Carl Rogers (1957) wrote that a warm empathic relationship was necessary and sufficient for personal change. Beck (1979) proposed that a good relationship was necessary but not sufficient for change. Others have reported that empathy can lead to the client being ‘addicted’ to the therapist in that a warm supportive therapist may make the client ‘feel better’ but could prevent the client from doing the hard work necessary for ‘getting better’ (Burns and Auerbach 1996). There appeared to be a fine line between being sufficiently empathic to encourage clients to disclose personal feelings yet not let the patient feel too attached to the therapist so that they did not disclose the more unpleasant aspects of themselves in case the therapist would like them less (Burns and Auerbach 1996).

Separating the cause and effect relationships between empathy and clinical improvement has not proved to be straight forward. Therapist's estimates of empathy may be biased and frequently have not related to recovery (Burns and Auerbach 1996). Patient's perceptions of empathy may be 'contaminated' by the severity of their depression. Similarly, when patients improved they and the therapist may develop more positive feelings about each other and hence improve the quality of the alliance so that outcome and alliance may be correlated, but not solely due to a cause-effect relationship.

Therapeutic alliance and the current study

There has been no assessment of therapeutic alliance within pain management programmes (PMP). Programme staff were not therapists in the psychological tradition, however they collaborated with patients towards goals that involved the patients making changes. Within structured PMPs the tasks and goals of therapy were well defined. Whether they were shared by staff and patients has not been investigated. The importance of interpersonal relationships between 'therapists' and patients during a PMP have not been investigated. The role of the therapeutic bond and empathy within the process of change at a residential PMP will be assessed by the current study.

Group membership

Frank and Frank (1991) wrote; "Any group process that provides members with a coherent system of values and relieves alienation and despair is a form of psychotherapy" (p244, 1991). Small groups are powerful environments that exert a pervasive influence on aspects of their members assumptive worlds (Frank and Frank 1991). In society at large, supportive groups form to buffer social outcasts from discrimination and neglect. Examples include Alcoholics Anonymous and the Alzheimer's Disease Society. Such groups provide a place to experience mutual support and validation giving the illusion, if not the reality, of safety. They may prove to be a valuable method of counteracting certain damaging features of contemporary life, such as alienation. Small groups can be forums in which members feel that they have some power to influence one another (Frank and Frank 1991).

It has been suggested that all humans struggle against three basic fears (Masserman 1977; cited in; Frank and Frank 1991); loss of health; alienation from others, and that life is meaningless. Groups foster unity with fellow human beings and hence a meaningful universe restoring the faith that existence has meaning. This may appeal strongly to those who feel alienated from the past and from fellow humans. Carl Rogers (1971) suggested that encounter or religious groups helped members achieve a greater sense of self-acceptance and acceptance of others with increased spontaneity and happiness.

Group members experience groups from four perspectives (MacKenzie 1998);

1. The group as a whole, comprising a global reaction to the group system, which has been proposed to reflect early attachment patterns.
2. Subgroups within the group where the participant experiences “their” subgroup as different to other members’ subgroups.
3. Individual interactions with other group members.
4. Individual interactions with group leaders or therapists.

Individual members can have opposing perspectives (MacKenzie 1998). They can describe the group as a whole or their personal reaction to the group. MacKenzie and Tschuschke (1993) found a cluster of group members in long-term psychodynamic group therapy who described the group as positive and hard working. At the same time they described themselves as not being understood, and as feeling isolated and insecure in the group.

MacKenzie (1994) proposed a basic developmental sequence of groups from engagement to differentiation to interpersonal work to termination. The *engagement stage* involved two processes. The first was the identification of common issues and interests, the process of universality, which made the group safer because group members had some means of relating comfortably to one another. The second was the recognition that the

group was a special place which had its own features, making it different from the outside situation, and hence 'firming' the external boundary.

The *interactional work stage* was the initiation of 'group work' for the group members and would consist of the specific issues that each group member had brought. The personal nature of work at this level may result in increased closeness among members. This can lead to an increased intimacy but there was also the threat of rejection by people who had become close. Self-esteem and trust were important issues as well as independence and over involvement. The *termination stage* can lead to resentment and anger with the individual feeling they have not received as much as they wanted. There can be a sense of loss with the ending of brief yet important relationships. MacKenzie (1998) proposed that the intensity of the termination process would be directly related to the amount of time members had spent together and the degree of interpersonal exchange.

The primary task for the group therapist was to develop and maintain a cohesive and working group atmosphere and alliance. The degree of homogeneity within a group promoted rapid group cohesion, allowing movement to differentiation issues at a relatively early point. Homogeneity could interfere with confrontational activity as group members reinforced mutual "blind spots". Alternatively, homogeneity could enhance members' ability to see the defences of others. Groups had the capacity to elicit strong affective responses within members that could be due to major underlying issues often connected with critical or shameful self-concepts. Within a group patients could express what others may feel, but were unable to express. Within groups there could be extended criticism as well as an attitude of non acceptance or outright rejection. MacKenzie (1998) suggested that the concept of therapeutic alliance could be applied to the group context with adjustment for additional levels of organisation and perspective.

Group and individual psychotherapy share three key features; the relationship between a socially sanctioned healer and the sufferer in a therapeutic setting; the effort to relieve confusion and isolation; and the mobilisation of hope. Admission to a group for therapy

was precisely because the individual had failed to solve certain problems of living (Frank and Frank 1991). As part of the group process, members gained status depending on their own sincerity and ability to become involved and discuss their own and others problems, rather than on outside achievements. Group members were accepted and respected because of who they were within the group rather than what they had accomplished outside (Frank and Frank 1991).

In classifying group therapies Frank and Frank (1991) referred to directive, evocative and mixed groups. The interactions in directive groups followed a format specified by the leader or manual. In evocative groups there were free interactions with the therapist, aiming to facilitate spontaneous interactions that enabled members to become more comfortable both with their own feelings, and in relating intimately with others. Mixed groups used directive methods to achieve evocative ends.

Directive groups aimed to counteract demoralisation (Frank and Frank 1991). The cogency of the rationale kindled members hopes of overcoming their difficulties. Through direct praise and acknowledgement of success, members feelings of self-worth and mastery were enhanced. The effectiveness of directive therapies depended on finding a balance between their rationale and the participant's individual experience. The lack of fit between the individual's formulation of the problem and a group's rationale would be one reason for the failure of a self help approach (Frank and Frank 1991). An example of a directive group would be Alcoholics Anonymous (AA). Ways in which AA helped people was by suggesting they made restoration to those they harmed and hence increased their self respect. AA also encouraged the helping of others, altruism, which increased feelings of self worth for the individual (Frank and Frank 1991).

Evocative group therapy aimed to stir emotions and promoted members self knowledge through free discussion and honest self-revelation (Frank and Frank 1991). Because most patients starting group therapy still participated in social groups and were doing so without losing their symptoms, evocative groups must have had healing features that

social groups did not. Frank and Frank (1991) suggested these were; acceptance; encouragement of the open expression of feelings, and continued communication in the face of antagonism. The first aim of evocative groups was that patients were encouraged to engage in “uninhibited conversation”.

Group therapeutic factors

Evidence from group research has suggested the efficacy of group treatments (Bednar and Kaul 1994). The mechanisms of change within groups have been suggested to be; hope; corrective emotional experience; modelling; and the promotion of self-awareness (Roth and Fonagy 1996). More global attributes unique to group treatments were that (i) group members participated in an evolving social microcosm that was the object of continual review, and (ii) that individuals were given the opportunity to function in an open social system that valued authenticity, candour and the open expression of feelings (Bednar and Kaul 1994).

Process research has identified specific treatment elements operative in effective forms of group treatment (Bednar and Kaul 1994). Such group therapeutic factors, also called curative factors, were the mechanisms within groups that were independent of the theoretical orientation of the therapist and were mutually reinforcing (MacKenzie 1998). There has been much research concerning group treatment effectiveness but little success in isolating the more specific treatment elements that account for the variable success in group treatment results (Bednar and Kaul 1994).

Bednar and Kaul (1994) emphasised the consistency with which some factors about group treatments had been universally acknowledged. Yalom (1975) identified twelve curative factors in small group treatments, see table overleaf. Yalom’s (1975) formulations about the curative processes in small groups were indigenous to group therapy. Catharsis, insight, interpersonal learning and cohesion were particularly useful in understanding the curative processes in group treatments (Bednar and Kaul 1994).

Curative group factors (Yalom 1975)

Universality	Installation of hope
Cohesion	Self-understanding, insight
Altruism	Interpersonal learning - input
Catharsis	Interpersonal learning - output
Guidance	Existential factors
Identification	Recapitulation of the primary family

There was evidence that the most influential curative factors may vary from group to group depending on the type of group and the clients being treated (Yalom 1985). Similarly, the value of specific curative factors was not the same at all stages of group development (Yalom 1985), hence universality was an important factor in early group development, whereas interpersonal learning was important in later group experiences. A brief description of curative factors in group treatments is detailed below.

Universality has been defined as the perceived similarities among group members which led to an appreciation of group membership (Yalom 1975; Yalom 1985). Demoralised patients felt isolated and believed their problems were unique. Universality was considered an antidote to isolation and demoralisation experienced by individuals. All group members tended to endorse the value of hearing that other members had similar problems and weaknesses. Mutual self-revelation could bring enormous relief to the individual (Frank and Frank 1991).

Acceptance into the group was considered important for individuals who may have experienced increased alienation from 'normal' life. Acceptance had to be earned in the group setting, and hence provided a strong boost to self esteem. Non acceptance could be damaging. Acceptance by peers may be more valuable to group members than acceptance by the therapist (Frank and Frank 1991). Possibly due to feelings of universality, patients perceived that other patients may know what they were "really" like. Additionally, patients could find it easier to open up and confess their transgressions

before a group of peers who they had witnessed others 'owning up', than to a therapist (Frank and Frank, 1991).

Altruism has been defined as the opportunity to help others within the therapeutic group. It was considered to re-inforce self esteem, creating a feeling of self worth. Helping others encouraged others to help one, hence it was a dynamic process. Patients may have felt they were a burden to others due to their difficulties, whether depressed mood or chronic pain. In individual therapy help flows from the therapist to the client. In a group setting members were provided with incentives and opportunities for altruism. Each member of a therapy group could give as well as receive, aiding one another by comparing their experiences or sharing useful information, advice or insights.

MacKenzie (MacKenzie 1998) described universality, acceptance and altruism as "supportive" group factors. These factors helped individuals to regain a sense of mastery from a context of demoralisation and low self-esteem.

Vicarious learning and models In group therapy, unlike individual therapy, group members provided role models and sources of feedback. Patient's perceptions of professionals as different from ordinary people limited the therapist's role as a model. As sources of feedback, group members may be more acceptable than the therapist, providing models closer to the patient's personal experience (Frank and Frank 1991). Each patient learned from observing how others handled issues arising within the group and hearing how others coped with problems similar to their own (Frank and Frank 1991). Seeing others succeed led to a surge of hope and desire to emulate success, rather than jealousy (Frank and Frank, 1991).

Group cohesion MacKenzie (1998) suggested group cohesion was a close analogue of the working alliance or therapeutic bond. He defined group cohesion as how important and attractive the group was to the collection of its individual members. It has been defined as a "complex developmental process involving the expression and resolution of

varying levels of anger and intimacy within groups” (p650; Bednar and Kaul 1994). Group cohesion developed out of the group members’ shared history of supportive and tension-arousing experiences. Directive groups with structured activities fostered early cohesion. Group cohesiveness reflected group morale with high cohesiveness associated with high morale, and fragmentation associated with a demoralised group. One step on, the morale of the group was correlated with the morale of its members. The more cohesive the group, the more its standards will influence members, both during and between sessions. Research has highlighted that deliberate efforts to speed up the development of cohesion has led to the accelerated symptomatic improvement and change in group members (Frank and Frank 1991).

MacKenzie (1998) proposed that high levels of cohesion suggested group members were committed to the goals of the group and could identify their common tasks. A bond was the sense of compatibility with group activities. High cohesiveness was indicated by trust, spontaneity, eagerness to learn as well as higher levels of challenging, confronting, and risk-taking behaviour. A low level of cohesion in group psychotherapy could be indicated by the drop out rate, attendance, tardiness, low participation and inhibited affect (MacKenzie 1998).

Research has identified positive correlations between cohesion and outcome (Bednar and Kaul 1994; MacKenzie 1998). There was a reciprocal relationship between group cohesion and the presence of therapeutic factors such that in a cohesive group the therapeutic factors would be “healthy” and vice versa. Hence promoting group therapeutic factors could enhance group cohesion (MacKenzie 1998).

When cohesion occurred in a group, individual clients were reported to have participated more freely and more fully; attended more consistently and were more susceptible to therapeutic interventions (Bednar and Kaul 1994). Cohesion has been ascribed a role more important than other sources of gain in group treatments. In their research review, Bednar and Kaul (1994) concluded that cohesion was still seen as a cause-effect, and as

necessary and sufficient for change. They discussed 9 studies conducted between 1983 and 1989. Three of these studies used patients, the rest mostly students. In 6 of the studies, cohesion was seen as a predictor variable. Silbergeld and colleagues (1975) found that group cohesion seemed to be a function of six sub-scales; spontaneity; support; affiliation; involvement; insight and clarity.

Difference and conflict In groups patients cope with the real or anticipated reactions of others. Groups can have little patience for 'private worlds', members preferring to discuss topics in which all have an interest. Group therapies may be strenuous for patients easily hurt by criticism or who have difficulty holding their own in a competitive atmosphere.

Unresolved or uncontrolled hostility can leave group members feeling traumatised and may drive members from the group (Frank and Frank 1991). Sources of conflict within groups can be;

- i) Group members come from different positions in society.
- ii) Rivalries can be generated by aspects of the group situation, such as attention from staff.
- iii) Distorted perceptions of the self and others arising from different life experiences.

Frank and Frank (1991) discussed the 'mirror reaction'. This was the tendency that people had to detect and disapprove of in others, traits they disliked in themselves, without necessarily recognising the source of the dislike. "Group members are likely to fear and dislike others they perceive as similar to themselves" (p 258; Frank and Frank 1991).

The therapy group has been described as society in miniature (Frank and Frank, 1991). Member's reactions teach a person what to expect outside the group. The group was a testing ground for new behaviour. When friends and family opposed patient's efforts to apply what they have learned in therapy, the patient's ability to maintain improvement

may depend on how well group participation had taught them to deal with conflict and withstand antagonism.

CURATIVE FACTORS AND RESEARCH

Identifying which curative factors were more salient to which group in aiding the process of change has not been investigated. Studies that have involved specific populations have found different group therapeutic factors more or less useful (Bednar and Kaul 1994). In a group of incest survivors, self-understanding and family re-enactment were valued as group curative factors (Bonney, Randall et al. 1986). For women with bulimia, self understanding, acceptance, the installation of hope, vicarious learning and universality were important factors (Hobbs, Birtchnell et al. 1989). However, both of these studies involved mostly women and it could be that different factors would have been helpful for men.

Most research supports the general relevance of Yalom's characterisation of the basic curative factors (Bednar and Kaul 1994). The most potent curative factors for any group vary as a function of the group being studied, the stage in group development and the type of clients (Bednar and Kaul 1994). Hence, the curative factors between groups will not be identical and a variety of schema are needed to identify, describe, classify and understand curative processes. Yalom made an important step in doing this by emphasising the importance of careful observation and the description of central group phenomena.

Group therapy research and the current study

There appeared to be no literature discussing the role of group dynamics in the process of change in non-psychotherapy groups. At the current pain management programme (PMP), patients were treated in groups to facilitate the delivery of treatment to as large a number of patients as possible. At the outset, group membership was incidental to the treatment process. As a teaching programme, there was no interpretation concerning group dynamics, and staff were not seen as traditional therapists. Similarly, member to

member relationships were encouraged, but were not a focus of the treatment process. Orlinsky (1994) identified that changes did not necessarily occur within therapeutic sessions. This may be particularly so at a pain management unit where it was not anticipated that change would occur during each session. In such PMPs, group members were not presumed to be integral to the therapeutic process by helping other members change. At the pain management programme if the groups got on all well and were supportive that was by default rather than design. It may be that for patients attending a residential pain management programme, the therapeutic setting was the group, both during the hours of the programme and during 'out of hours' socialising.

The focus of the current research was not "is the group treatment effective?" The aim of the current research was to identify what helped or hindered the process of change for individuals whilst attending a group programme. Group theory was used for observing whether group curative factors were relevant in a treatment programme that was group delivered but not group focused.

THE USE OF A QUALITATIVE METHOD

Post modernists emphasise that knowledge is constructed within human relationships, social discourses and cultural contexts (Henwood and McQueen 1997). This view posits that there can be no absolute objectivity in research. Hence, research is less about following the rules of method, than seeking to bridge the gap of interpretation that exists between the "realities" one wishes to know and what is claimed by way of knowledge about them (Henwood and McQueen 1997). Research is invariably shaped by the researchers' starting perspective, placing parameters on the "answers" that can be attained. Standpoints imposed upon participants do not necessarily allow them to raise their concerns about the situations they find themselves to be in. At times the relevance of the research questions can be questionable and the participants appear constrained by the questions they are asked. The researchers' view is often supported by limited prior research. Unexpected ideas and theories may be more likely to emerge during qualitative rather than quantitative research because of its less structured nature. Qualitative research

can explore sensitive topics within the individual's social context. A qualitative method was adopted for the current thesis due to the explorative nature of the research and in order to describe patient's experiences of change, or no change, whilst attending a pain management programme.

The acceptance of qualitative research methods within clinical psychology remains problematic. Clinical psychologists work in a culture influenced by medical models and traditional views of science. These influences determine how research is evaluated. There has been vitriolic criticism concerning a move away from this position, with concerns about reductions in professional status. There appears to be polarisation between those "for" and those "against" qualitative research (Cooper and Stevenson 1999; Morgan 1998; Sherrard 1998). This is unfortunate in a world where there are few true dichotomies. The concept of a continuum from one extreme to the other seems far more "realistic". Qualitative and quantitative methods have much to offer as research techniques and can be used to complement one another. It may be that much of the criticism levied at one or other approach is done so from the basis of limited knowledge.

The usefulness of the qualitative approach includes its alertness to differences of perspective; a flexible responsiveness to research design, as well as the recognition of differences both within and between individuals. Well conducted and presented qualitative research seeks to interpret data with readers invited to examine these interpretations as a method of evaluating the integrity of the research (Withers 1997). Withers (1997) described the large amount of data collected yet reportedly did not feel overwhelmed because he had remained close to the data. Quantitative research can lead the researcher to feel distanced from their findings as the data is reduced to numbers (Withers 1997).

The qualitative method chosen for the current thesis was Interpretative Phenomenological Analysis (Smith, Osborn et al. 1998). Interpretative Phenomenological Analysis (IPA) is predominantly used in the analysis of semi-structured interviews although may be used

with diaries or personal accounts (Smith, Osborn et al. 1998; Smith, Osborn et al. 1998). IPA was first introduced as a qualitative method in the mid to late 1990's (Smith 1996; Smith, Flowers et al. 1997; Osborn and Smith 1998; Smith, Osborn et al. 1998). The aim of IPA was the detailed exploration of participants' views of particular topics. It is the individual's personal account of an event rather than the objective statement which makes the framework "phenomenological". Access to the participants views is, however, mediated by the researcher's conceptions. The researcher engages in interpretative activity to produce themes from data. To date IPA has been used primarily within health psychology research, concerned with connections between verbal reports, cognitions and physical states (Smith, Osborn et al. 1998). IPA has been used to identify individual experiences with chronic back pain (Osborn & Smith 1997) and to facilitate the identification of shared experiences across a group of nurses working with children with anorexia nervosa (Smith, Osborn et al. 1998).

IPA was chosen rather than other qualitative methods, such as grounded theory, because;

- i) IPA is a new method used within clinical health psychology, the discipline within which patients with chronic illnesses are treated.
- ii) IPA was developed specifically for health psychology rather than sociology.
- iii) IPA aims to look for explorative links between data and theory rather than generating new theory.
- iv) IPA appeared to be very straight forward to use and, as a new method, there were well documented instructions for its operationalisation.

AIMS OF CURRENT RESEARCH

The objective of the current research was a qualitative assessment of the process of change reported by patients whilst attending a programme for the management of chronic pain. It was the process of change rather than aspects specific to chronic pain that was the focus. The aims of the study were to:

- Identify patients reports of what changed for them physically and psychologically whilst attending the residential pain management programme.
- Identify which aspects of the residential programme, excluding the specific treatment techniques, patients identified as helping them to make changes.
- Identify the role of staff in helping patients make changes.
- Identify which aspects of meeting other patients with chronic pain helped or did not help patients to make changes during the residential programme.

CHAPTER 2: METHOD

Thirteen patients attending a 4 week residential pain management programme were interviewed on two occasions. Semi-structured interviews focused on changes the patients reported making whilst attending the programme and the role of staff and group membership in aiding these changes. Interviews were conducted during week 2 and week 4 of the programme and were analysed using Interpretative Phenomenological Analysis (Smith, Osborn et al. 1998). At the end of each interview patients completed two brief questionnaires assessing staff empathy and group climate.

RESEARCH SETTING

THE PAIN MANAGEMENT PROGRAMME

The large psychology based in-patient pain management programme had been running for 10 years at a London teaching hospital. The programme aimed to enable the chronic pain sufferer to improve his or her life quality of life, despite the pain. Referrals to the unit were made from across Britain. All patients attending the programme were screened by a clinical psychologist and a doctor. It was clarified at screening that the programme did not aim to reduce the level of pain experienced by the patient, but rather to enhance their coping strategies. To be accepted for the programme patients needed to have reported two of the following acceptance criteria; impaired physical activity; impaired work; evidence of over/underactivity; excess medication use; significant pain related distress; use of unnecessary aids; or maladaptive behaviour, such as guarding.

The programme comprised professional input from doctors, nurses, occupational therapists, physiotherapists and clinical psychologists. The key components of the programme and the associated staff are detailed in Table 2.1.

Table 2.1: Components of the pain management programme

Staff member	Components of programme
Clinical psychologist	Relationships between thoughts, feelings & behaviour; use of thoughts & feelings forms Identification of unhelpful thoughts e.g.: catastrophising Problem solving Changing maladaptive or unhelpful behaviours Maintenance of new behaviours Use of re-inforcers Communicating with others
Consultant anaesthetist	Education: Chronic and acute pain Physiology of healing Gate control theory Medical/surgical treatments
Nurse	Medication reduction Relaxation Education: Medication Sleep and sleep problems
Occupational therapist	Pacing - regular breaks in activities and use of timer Setting tolerance levels for building blocks Goal setting; short- and long-term work and leisure
Physiotherapist	Exercise Stretch Posture Education: Joints, muscles, tendons Disuse and healthy function

Programme sessions were between 30 minutes and an hour and a half long. They were interactive, using patients' experiences. In addition, patients made set-back and flare-up plans in sessions with several staff members.

The 4 week pain management programmes ran from Monday morning to Wednesday or Thursday evening. Patients stayed in hostel rooms above the unit and went home at weekends, returning Sunday evenings. The hostel comprised single bedrooms and communal sitting rooms (smoking/non smoking). Programmes consisting of 10 patients started every two weeks so that at any one time, two intakes were attending the programme. Each intake overlapped in its first two weeks with the last two weeks of the earlier intake, and in its second two weeks with the first two weeks of the new intake.

The pain management unit was self-contained with two large and two small teaching rooms and a gym. Staff were based in the unit and were generally available to patients during the hours of the programme. The unit also comprised a kitchen, dining and sitting area, as well as a conservatory with access to a small courtyard. Sessions started at 08.30 hours and finished at 16.00 hours. There were coffee, lunch and tea breaks. Lunch was provided for the patients in their dining room, they had to cater for breakfast and their evening meal. Patients were encouraged to see their keyworker during lunch or at the end of the day.

PARTICIPANTS

All patients who attended the residential programme were eligible to participate in the current research. Patients attending the programme were mostly women (60-70%) with a mean age between 45 and 50 years. Pain chronicity varied considerably and could range from 1 year to over 30 years.

PROCEDURE

Ethical approval was given by the local Research Ethics Committee (see Appendix I). Due to the overlapping nature of the scheduling of the programmes, specific intakes were selected for recruitment rather than all intakes. This eased the scheduling of interviews. In order to facilitate a range of views about the programme, the participants were recruited from intakes between November 1999 and March 2000. Four intakes were

approached to participate in the study. The research was designed to ensure that patients were not inconvenienced by participating. Hence, interviews were conducted at lunch-time, or early evening, in the patient's hostel room.

The intakes were approached just before the first session on the Monday morning of the second week at the programme. The study was explained to the group and information sheets were distributed (see Appendix II). Volunteers were encouraged to approach the researcher at this point or later in the day.

Each participant was interviewed twice; first during week 2, and for the second time during week 4 of the programme. The interviews lasted between half and one hour and were recorded. The tapes and transcripts were coded so that names did not appear with the data. Consent forms were signed at the beginning of the first interview (see Appendix III). Two questionnaires assessing staff empathy and group climate were administered at the end of each interview (see Appendices IV and V).

MEASURES

STRUCTURED INTERVIEW

The structured interview questions are detailed in Table 2.2. Pilot work developing semi-structured interviews and determining the interview schedule was completed by the researcher who worked as a psychologist in training on the unit prior to conducting the research. Patients were interviewed, using the same interview schedule, twice whilst attending the programme. It was anticipated that the process of change would be observable by interviewing at different time points as patients progressed through the programme.

Table 2.2: Interview schedule

INTERVIEW QUESTIONS

CHANGE

What has changed since you have been at INPUT?

Why do you think you have made these changes?

What is the most powerful aspect of INPUT that has helped you make these changes?

Has anything not changed that you expected to change?

Why do you think these things have not changed?

STAFF

How do you find the staff at INPUT?

What is helpful/unhelpful about them?

In what way are they important?

In what way have staff influenced the changes you have made?

Have you had any keywork sessions? How do you find these?

What do you tend to talk about during keywork?

GROUP MEMBERSHIP

Before coming to INPUT had you met anyone who had chronic pain?

Are there any other people on the programme who you consider to have similar problems to yourself?

Is it helpful to talk to others with chronic pain?

What aspects are helpful/unhelpful?

Do you feel you all get on as a group?

Is there anyone who isn't part of the group?

Do you feel part of the group?

Do you feel others in the group understand you?

WEEK 2: How was it meeting the group ahead of you at INPUT?

WEEK 4: How was it meeting the new group of patients last week?

ADDITIONAL MEASURES

To complement the qualitative interviews, quantitative data were reported as part of the current study. These data comprised (i) measures of change routinely assessed at the pain management programme, and (ii) standardised questionnaires assessing staff empathy and group climate used specifically for the current study.

(i) Measures of change

Measures of physical and emotional change were routinely assessed at the pain management programme. Patients attended the pain management unit the week prior to starting a programme when baseline physical and psychological measures were taken. These measures were taken again in the final week of the programme.

Physical change

The two measures of physical change reported in the current study were how far a patient could walk in 5 minutes, and how many stairs s/he could climb in one minute. These were assessed by a physiotherapist at the unit. Patients were instructed to try their best, but not to 'overdo' as a realistic assessment of their abilities would be most useful (Harding 2000).

Psychological change

Two of the measures that were administered routinely to patients as part of their participation in the programme were chosen to be reported in the current study; the Pain Self Efficacy Questionnaire assessing coping efficacy and the Beck Depression Inventory assessing depressed mood.

The Pain Self-Efficacy Questionnaire (PS-EQ) was developed at the pain management unit (Nicholas 1989). It comprised 10 questions which asked how confident the respondent was in doing certain activities despite their pain. The activities were; household chores; working; leisure activities; socialising; coping; general enjoyment; accomplishing goals; normal lifestyle; becoming more active; and coping without

medication. The 7 point Likert scale ranged from 0 (“Not at all confident”) to 6 (“Completely confident”). The questionnaire was situation specific rather than general, asking how patients felt “at present”. Total scores ranged from 0 to 60 with a higher score denoting confidence in performing a range of activities despite pain. It would be expected that scores on the PS-EQ would increase once a pain management programme had been completed.

The Beck Depression Inventory (BDI) is a widely used assessment of depressed mood (Beck, Ward et al. 1961). The BDI was designed to measure behavioural manifestations of depression in quantitative research. Twenty-one symptom categories were defined: mood; pessimism; sense of failure; lack of satisfaction; guilty feeling; sense of punishment; self-hate; self accusations; self punitive wishes; crying spells; irritability; social withdrawal; indecisiveness; body image; work inhibition; sleep disturbance; fatigability; loss of appetite; weight loss; somatic preoccupation and libido loss. The questions originated from descriptions in the psychiatric literature and systematic observations of the attitudes and symptoms of depressed patients during psychotherapy. Initial validation was with a random sample of clinic and hospitalised psychiatric patients (Beck, Ward et al. 1961). Varying degrees of depression were identified by the inventory and there are now widely recognised categories of depressed mood. Each question has a graded series of 4 statements (scored 0-3), reflecting the severity of the symptom from neutral to severe. The total score was the sum of the 21 items. The higher the score the more depressed an individual was deemed to be. Standard cut-off scores for severity of mood have been reported; 0-9 'no/minimal' depression; 10-18 'mild to moderate'; 19-29 'moderate to severe' depression; and over 29 'severe' depression (Beck, Steer et al. 1988). The BDI has been used extensively in patients with chronic pain (Williams and Richardson 1993). It would be expected that scores on the BDI would decrease once a pain management programme had been completed.

(ii) Standardised questionnaires assessing staff empathy and group climate

To complement the information gained from structured interview, patients completed standardised questionnaires assessing staff empathy and group climate at the end of each interview.

Empathy Scale (ES)

The ES was developed to assess empathy as a particular aspect of the therapeutic alliance (Burns and Auerbach 1996). The ES is a 10 item questionnaire asking patients to rate their interactions with therapists. It was modified for the current study by replacing “therapist” with “staff” (Appendix IV). Patients rated how warm, genuine and empathic they felt the staff were on a 4 point Likert scale from “not at all” to “a lot”. The first 5 items are written so that strong agreement indicated a good therapeutic relationship. The last 5 items are written so that strong agreement indicated a poor therapeutic relationship. The total score is achieved by adding the 5 positively worded items and the 5 negatively worded items. Scores range from +15 (highest rating) to -15 (lowest rating).

Group Climate Questionnaire-Short Form (GCQ-S)

The GCQ-S was developed for use with therapeutic groups (MacKenzie 1998). The GCQ-S assesses the perceptions of group members about their group on 3 independent dimensions; engaged; conflict; and avoiding (Appendix V). It is a 12 item questionnaire with answers rated from 0 (not at all) to 6 (extremely). There are 5 items on the ‘engaged’ dimension, 4 on the ‘conflict’ dimension and 3 on the ‘avoiding’ dimension.

ANALYSIS OF QUALITATIVE DATA

Data from the structured interviews were analysed using Interpretative Phenomenological Analysis (IPA) as discussed in Chapter 1. Verbatim transcripts of the audiotaped interviews were made. See Appendix VI for a copy of a patient interview. Initially data from the first and second interviews were reviewed separately to determine whether different changes, or influences on changes were apparent. There did not appear to be

significant differences between the interview content in week 2 and week 4. Issues mentioned during week 2 were generally expanded on at week 4, rather than new issues being introduced at the second interview. As there were few observable differences, data from the 2 interviews were combined and overall changes and influences reported.

INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

Interpretative phenomenological analysis (IPA) was first introduced as a qualitative method in the mid to late 1990's (Smith 1996; Smith, Flowers et al. 1997; Osborn and Smith 1998; Smith, Osborn et al. 1998). The aim of IPA was the detailed exploration of participants' views of particular topics. It was the individual's personal account of an event rather than an objective statement which made the framework "phenomenological". Access to the participants' view was mediated by the researcher's conceptions. The researcher engaged in interpretative activity to produce themes from data provided by participants.

THE PROCESS OF IPA

IPA has six key stages (Smith, Osborn et al. 1998);

1. The transcripts were read a number of times and notes were made in the left margin about relevant text. The example below shows how this was done, using an excerpt of the first interview with patient 01, describing what had helped him make the changes he reported during the second week of the programme:

	Int. What is it that has made you “see the light” do you think, what’s helped?
talk to them as one to one	01 It’s the staff for one, plus they, you can
doesn’t matter who it is	talk to them as one to one it doesn’t matter
	who it is you can go to them and ask them
always answer	a question, tell them how you feel, they’ll
don’t look down nose	always answer it. They don’t look down
	their nose at you which is what you used to

what you used to get	get even outside. Not so much from my
	doctor but a lot of it from the hospitals.
weren't interested	They turn round and say blah blah blah and
feel comfortable	they just weren't interested, they shove you
	from pillar to post. Here I feel comfortable,
doesn't matter how stupid	I can ask any question I like, doesn't matter
	how stupid it might seem, they always give
practical answer that works	me an answer and it's always a practical
	answer that works.

2. Emergent themes were noted in the right margin. Again using the transcript of patient 01, the emergent themes were noted.

Int. What is it that has made you “see the light” do you think, what’s helped?

01 It’s the staff for one, plus they, you can talk to them as one to one it doesn’t matter who it is you can go to them and ask them a question, tell them how you feel, they’ll always answer it. They don’t look down their nose at you which is what you used to get even outside. Not so much from my doctor but a lot of it from the hospitals. They turn round and say blah blah blah and they just weren’t interested, they shove you from pillar to post. Here I feel comfortable, I can ask any question I like, doesn’t matter how stupid it might seem, they always give me an answer and it’s always a practical answer that works.

Approachability

Non judging

Expertise

Difference

Dismissed

Acceptance

Able to help

3. This process was repeated for all the interviews. The researcher attempted to read each transcript afresh, however, due to the sequential design of the analysis, themes that emerged in the earlier transcripts had been noted and may have ‘primed’ the researcher.

4. Once the themes had been noted the transcripts were read again and the emergent themes organised into tentative clusters. Clusters were groups of themes that appeared to share aspects of commonality. For example, themes concerning how the patients’ experience at the programme had been *different* to prior experience with health care professionals. Once these tentative clusters were formed, the transcripts were read again to identify any further statements that could be included in the clusters.

5. Clusters and themes were then examined and inter-relationships considered. This may result in the re-grouping of themes, or clusters.

6. The last stage was to create a narrative account from the analytic themes and clusters. Within the domains of change, staff and group the shared themes and clusters were organised to try and produce a meaningful account of the patients experiences using their words.

To check on the analyses, four transcripts were read and coded by the research supervisors. These transcripts were compared and any different readings discussed until a consensus was reached concerning data. The emergent themes and clusters were discussed with the research supervisors.

CHAPTER 3: RESULTS

Patient characteristics

Thirteen, out of 28 patients who were invited to participate, agreed to be interviewed for the study. There was no 'drop out' between interviews 1 and 2. The interviews were conducted by the researcher in the patient's hostel room above the pain management unit. The interviews were scheduled in the early evening, subsequent to a period of rest after the programme. The interviews lasted between 30 minutes and more than one hour. The length of the interview was primarily dependent on the eagerness of the participant to talk about the programme, and their experiences of chronic pain.

Table 3.1 shows the demographic and pain characteristics of the participating patients. The participants comprised 7 women and 6 men, with ages ranging from 39 to 71 years. There were 4 single, widowed or divorced women, all the men were married or in relationships. Twelve of the patients who participated in the current study were of white European ethnicity. There was one Afro-Caribbean black woman and one Irish man. For two patients English was not their first language although they were proficient having lived in Britain for over 20 years. These were two women, Spanish and Austrian. None of the patients were employed outside the home. They had stopped work a median of 7 years before attending the programme. Four of the patients reported significant financial difficulties due to the disabling nature of their chronic pain.

The participants in the current study had a history of chronic pain lasting from 6 to over 30 years. Six had had pain for 10 years or less, and 7 had had their pain for over 11 years. The sites of chronic pain varied with 11 patients reporting more than one site. Ten of the 13 patients reported at least some back involvement. Nine of the patients could identify a specific event or injury that started their pain. Two reported a gradual onset and 2 reported a sudden onset for no reason.

Table 3.1: Demographic and pain characteristics of patients participating in the current study

ID	Sex†	Age	Relat. status	When last worked	Finances	Pain duration	Pain site	Pain onset
01	M	55	Married	6 years	Pension & benefits	6 years	Lower back	Sudden; lifting at work.
02	F	39	Married	6 years	Benefits only* - Husband carer	24 years	Back, knee & pelvis	Accident; playing rounders.
03	M	60	Married	9 years	Pension & benefits	10 years	Back, knee, hip & elbow	Injury & infection post Total Hip Replacement.
04	F	54	Married	8 years	Pension & benefits	14 years	Low back & shoulders	Sudden; "Out of blue."
05	M	62	Married	3 years	Benefits & Wife working	19 years	Neck, spine & shoulders	Gradual
06	M	47	Married	7 years	DK	7 years	Neck & back of head	Sudden; laying carpet at work.
07	F	42	Married	4 years	Benefits & Husband working	6 years	Back, coccyx & rectum	Accident; fell down stairs.
08	M	44	Girlfriend	6 years	Benefits only*	25 years	Shoulder & spine	Accident (25 yrs.) & assault (5 yrs.).
09	F	55	Single	7 years	Benefits only*	8 years	Back of knee & hip	Injury; polishing/bending at work.
10	F	71	Widowed	Housewife	Pension & benefits	>30 years	Neck & back	Gradual
11	M	50	Married	7 years	Benefits only	10 years	Neck. head & arm	Sudden; no reason.
12	F	54	Single	8 years	Benefits only*	30 years	Lower back	Accident; fell down stairs.
13	F	62	Divorced	12 years	Pension & benefits	26 years	Knee, back & arm	Accident; fell.

Key: † F = female, M = male: * significant financial difficulties

Table 3.2: Measures of physical function in patients pre course and during week 4 of the pain management programme

ID	5 minutes walking		1 minute stairs	
	Pre course	Final week	Pre course	Final week
01	46m	175m	9	24
02	122m	164m	27	42
03	260m	279m	62	67
04	120m	109m	29	21
05	120m	241m	43	24
06	293m	280m	59	74
07	168m	263m	29	57
08	220m	117m	56	38
09	235m	235m	35	36
10	185m	262m	48	57
11	234m	217m	59	57
12	140m	237m	27	49
13	80m	186m	26	47

Table 3.2 shows the results of two physical measures completed by patients pre course and during the final week of the course. During their time at the pain management programme, 8 of the 13 patients increased the distance in metres that they could walk in 5 minutes. The increases ranged from 19 to 129 metres. Patient 09 walked the same distance in 5 minutes pre course as she did during the final week. Four patients reported decreases in distance walked in 5 minutes. The decreases ranged from 11 to 103 metres.

During their time at the pain management programme, 9 of the 13 patients increased the number of stairs they could climb in 1 minute. The increases ranged from 1 to 28 stairs. Four patients reported decreases, ranging from 2 to 19, in the number of stairs they could climb in 1 minute. Three patients (nos. 04, 08 and 11) reported decreases both in the distances walked and the number of stairs they climbed.

Questionnaire data

Table 3.3 shows the results of two psychological measures completed by patients pre course and during the final week of the course. During the programme, 8 of the 13 patients reported decreases in their depressed mood. The largest decrease was from a score of 29 to 4 for patient 02. Patients 02 and 37 who had answered that they would self harm pre course, no longer reported so at the end of the programme. Patients 06 and 11 reported no change in their depressed mood. Patients 04, 05 and 08 reported increases in their depressed mood during the course, patients 04 and 08 answering that they would consider self harm.

Table 3.3: Depression and pain self-efficacy scores for patients pre course and during week 4 of the pain management programme

ID	Beck Depression Inventory		Pain self-efficacy questionnaire	
	Pre course	Final week	Pre course	Final week
01	24	0	13	54
02	29 (Harm)	4	11	28
03	9	5	48	58
04	25	35 (Harm)	26	12
05	6	17	23	18
06	3	3	20	36
07	17	12	16	50
08	17	29 (Harm)	21	24
09	14	0	34	47
10	16	4	18	29
11	10	10	25	26
12	37 (Harm)	18	13	30
13	13	2	25	35

During the programme 11 of the 13 patients reported increases in their pain self efficacy scores, increases ranging from 1 to 41. Patients 04 and 05 reported decreases in their pain self efficacy scores whilst attending the programme.

Table 3.4: Empathy scores reported by patients during weeks 2 and 4 of the pain management programme

ID	Empathy questionnaire	
	Week 2	Week 4
01	15	15
02	15	15
03	15	15
04	3	12
05	14	14
06	12	15
07	15	15
08	14	14
09	14	13
10	9	11
11	12	15
12	15	15
13	15	14

Table 3.5: Patient's scores on the engagement, conflict and avoidance dimensions of the Group Climate Questionnaire (Short Form) during weeks 2 and 4 of the pain management programme

ID	Engagement		Conflict		Avoidance	
	Week 2	Week 4	Week 2	Week 4	Week 2	Week 4
01	18	26	0	0	3	6
02	18	26	0	0	5	6
03	25	22	13	0	18	6
04	24	29	6	1	3	7
05	22	20	2	1	10	9
06	29	24	24	0	9	0
07	15	25	1	1	5	8
08	19	22	1	0	1	4
09	24	25	1	0	11	5
10	13	21	14	4	7	15
11	17	20	7	5	8	10
12	26	18	1	1	11	11
13	26	25	8	10	15	7

Tables 3.4 and 3.5 show the data for the Empathy Scale and Group Climate Questionnaire. Mean scores on the Empathy Scale varied very little between weeks 2 and 4. This may indicate that the measure was insensitive.

Qualitative analysis

The domains covered in the structured interviews were the changes patients had made whilst attending the programme and patients' perceptions of what had helped them make these changes in terms of the staff, and the patients' experience of being in a group of patients with chronic pain. The clusters of themes appeared to be similar to the domains of the interviews with patients reporting that the staff, and being a group participant had been important factors in helping them make changes whilst attending the programme. Additional emergent domains were that the programme was a safe environment, and that the programme was highly valued in terms of being seen by patients as a 'centre of excellence'. Throughout this chapter the codes at the end of each quote detail its source, e.g.: **07b.03 22**. The number and letter in bold, e.g.,: **07b**, refers to patient 07, the quote being their second in a particular section. The following numbers refer to the page (03) and line (22).

CHANGES REPORTED BY PATIENTS

In reporting the influence of factors on the process of change for patients it was considered pertinent to analyse what patients reported had changed for them whilst attending the pain management programme. Table 3.6 shows the clusters and themes patients reported concerning the changes they made whilst attending the pain management programme. Some patients reported changes and gave examples whereas others observed change in others more readily than themselves. Acknowledging change in others suggested that patients were willing to accept that change occurred for some whilst attending the pain management programme, if not for themselves.

Table 3.6: Summary of clusters and themes from the analysis of patients' perceptions of what had changed for them since attending the pain management programme

Physical	Pain	Behavioural	Psychological	Others see change
<ul style="list-style-type: none"> • Flexibility • Looseness • Stamina • Fitness • Tension 	<ul style="list-style-type: none"> • No change • Increase • Reduction 	<ul style="list-style-type: none"> • Use of timer • Pacing • Planning • Medication • Use of aids • Working through pain • Routine 	<ul style="list-style-type: none"> • Attitude • Relating thoughts to feelings • Less loss of temper • Communication • Mood • Insight • Concentration 	<ul style="list-style-type: none"> • Family • Friends

Themes that emerged concerning the changes patients had experienced created five clusters; physical; pain; behavioural psychological; and reports of what others had observed had changed in the patients. These clusters mapped onto the components of the pain management programme, with the exception of the final one. It may have been that the patients unconsciously reported changes in this manner. This final cluster was considered distinct as it consisted of patients description of how others perceived them, rather than how they perceived themselves.

All thirteen patients reported physical change, the most marginal being an increase in flexibility or looseness. Patients shared expectations that change would occur in the second two weeks rather than early in the programme (01,05,11). Some suggested that change occurred towards the end of the second week: *"At the end of the second week you're just beginning to grasp things a bit"* (11n. 16. 13). Others suggested: *"It has taken, let's say the third week, everything we learnt over the first two weeks has really sunk in on the third week"* (01v. 10. 27). A patient who reported few changes suggested during week 2 that he was not expecting to make changes until after the second week: *"I was...thinking to myself that you've got to give it a couple of weeks and then its the last 2 weeks where you really find the, you know, the good and that it's doing"* (05k. 01. 10).

Patients 01 and 11 reported feeling better than when they had first arrived at the programme: *"Moodwise and even healthwise, I feel that little bit, that little bit better than when I come in"* (11. 20. 15). At the beginning of week two patient 01 was feeling extremely optimistic concerning change: *"I now know I'm going to have a different quality of life to start with. When I first came here I was living in a black hole. Everything was going wrong and I couldn't get out of this black hole but now I've got a little pin prick of light at the end of the tunnel and I can say yes I'm making for that light and by the time I'm finished it's going to come out into a nice blue sky. It's going to be absolutely brilliant"* (01a. 01. 06).

Physical change

FLEXIBILITY/LOOSENESS: Most reported feeling more flexible: *"I feel looser, probably the exercises every day which you **have** [05 emphasis] to do, you know" (05j. 15. 08), or reported having more movement: "When I came in here I could hardly move my arms, especially this one, because it was always so tensed up with the pain in the neck and that you know, like this, but now you know I can throw it all over the place" (11q. 31. 24). Patient 06 reported: *"I didn't realise as I say that I'd become so immobile and how I'd actually started to seize up. But with the programme of stretch, the building blocks and everything I have begun to notice a great difference" (06a. 10. 29).* Patient 09 described physical and mental looseness: *"There's quite a bit of change really. I'm more looser all over my body. I'm more mobile, my mind seems more clearer" (09b. 12. 20).**

STAMINA/FITNESS: Others highlighted increases in fitness and stamina: *"I think me stamina's gone up" (07x. 03. 05).* Patient 01 was pleased with an increase in muscle tone: *"I've just had a 5cm. loss on my leg, it is now only 4cm., so in a month I've built up a centimetre" (01u. 11. 31).* Patient 03 was almost running up stairs: *"My legs are strong. I'm going up stairs two at a time." (03b. 24. 02).*

EASING TENSION: *"I have an awful lot of problems with the neck, headaches and that, and a lot of tension along the shoulders....and I've found these last few days a gradual easing off of the tension and that so that has been quite good for me" (11. 01. 03).* Patient 12's report of change included her whole body: *"I can see my body is more relaxed. Even I walk now, I swing my arms" (12a. 03. 22).*

Pain

It was not anticipated that patients would report changes in their pain as this was not a function of the pain management programme.

NO CHANGE: For many patients there was no change in their level of pain: *"Pain wise none whatsoever" (05i. 15. 06).* Others suggested that the pain remained but was more bearable: *"I mean the pain's still there but it's not getting, where it used to get that*

unbearable" (07s. 05. 26). There was a hope that the pain may reduce in the future: *"It would be lovely to think the pain levels went down, but they don't, perhaps that does come later, perhaps with relaxation or the fitter you get perhaps they go down, I don't know, but as I say my pain level is exactly the same, but I'm not increasing it"* (07v. 20. 21).

INCREASE: For others who had experienced an increase in their pain, the sense of control they had developed was important and they were able to suggest why they had more pain: *"You're going in a vicious circle all the time. Pain, tension, tension, frustration, anger, pain. Pain gets worse and that's how it carries on. That's how it was at home for the last 6 years. I'm beginning to control it now. I must say that I'm in more pain at the present moment in time than when I first came in but that's only because of the exercises. And using muscles I've never used before"* (01s. 06. 33).

REDUCTION: Patient 11 reported: *"The headache that I couldn't cope with is not there"* (11. 19. 29). He went on to suggest that the pain had reduced: *"Headaches kill me they do you know but since I've been doing the various stretches and other stuff the tension along the shoulders here has decreased tremendously you know, I mean the headaches are there but they're not at the level that they were at when I started"* (11.19.21). Patient 11 reported that: *"If there is any more improvement then great, you know, if not the way that I am at the moment, if the rest of my life is like that I'll be more than happy, to be truthful with you. This is the first time in years, you know, that I've had so much release from the pain. Yeah it's there it's still there but not as bad you know"* (11p. 31. 31).

For others, being more relaxed led to a reduction in tension-related pain: *"Me teeth didn't ache, I'm forever grinding me teeth like with the pain and I suddenly realised that I'm not doing that anymore"* (07t. 05. 27).

Behavioural changes

USE OF TIMER/PACING: Patients reported changing their behaviour by adopting pacing and reducing their tendency to overdo activities: *"The pain was controlling me, I'd take two steps and stop. Sorry I can't do it or I won't do it. Now it's one two three, blow the pain, stop and have a rest, one two three and you just carry on like that, as long as you rest and relax in between, which is something I wasn't doing before. I wasn't relaxing, I was, my attitude was that don't leave tomorrow what can be done today, my attitude now is I'll do today what I can and if the rest doesn't get done till next Sunday I couldn't care less"* (01n. 13. 33). Similarly patient 07 acknowledged her tendency to overdo and her achievement at overcoming that behaviour: *"I can overdo things but with that on the weekend I was using the timer all the time... and I rested when I was supposed to and just by being on that even keel. You know, the whole pain pattern of up and down that is me all over. On a good day I want to climb Everest and on a bad day I'm on the floor, that's it. So as I say I think Saturday I did meet it, I really did meet it half way"* (07g. 06. 10).

Patient 10 acknowledged that she had work to do: *"They keep on telling me I'm pushing myself too much. You can't change the habits of a lifetime in a month. So, I have to work at that. Pacing myself a bit more."* (10a. 28. 16). Once patients had changed their behaviour to incorporate pacing they found how this had an impact on their ability to sustain activity: *"We went shopping on Saturday morning which normally meant tablets, shopping, home again, more tablets, lay down for the afternoon"* (07f. 05. 13). This time she reported: *"I've been shopping and everything and paced it all and used the timer and it worked. I actually went out Christmas shopping for 6 hours which I, it was too much at the time I thought, but I did keep stopping and resting and everything and I got home and I had a little rest and I was fine"* (07h. 16. 09). Patient 03 had paced up lying on his back: *"I can lie on my back for twenty minutes now where as I never could do that"* (03d. 30. 10).

PLANNING: Before attending the pain management programme patients may have stopped planning due to their chronic pain. They may have set unrealistic goals and been

disappointed when these were not attained. At the programme patients were encouraged to set realistic goals: *"I've got a goal. I mean I know it won't happen in the next 6 months outside. I know within, I reckon within a month I'll be walking around the whole house without a walking stick because if I can do the hallway now, I know we've only got a short hallway but I can do it now with confidence"* (01i. 04. 23).

Patient 12 described herself: *"I used to be like a ship and you don't have nowhere to go. But now, I know where I'm going. I know what I want to achieve and I know I'm going to be doing it"* (12b. 08. 16).

MEDICATION REDUCTION: For some patients cutting down medication was an important goal of attending the programme: *"Today I'm down to one dose of tablets a day (Int. ..and that was from?) That was from 3, but they was both tablets that I was really worried about"* (07o. 01. 03). *"I dropped one dose last week and I've dropped another dose today. Touch wood, I'm OK so far..."* (07p. 02. 02). By week 4 patient 07 had ceased all medication saying: *"I'm totally off my medication.....I feel so much better being off those tablets, I feel like I've come alive"* (07r. 16. 07).

Others had reduced or stopped medication before reaching the programme, often unsupervised (patients 05 and 11). For patient 01 reducing his medication led to better sleep: *"I'm not taking X anymore which is a godsend. I've cut down on my Y, by sort of having three at night and now I only have two....I get a decent nights sleep instead of waking up 4 or 5 or 6 times, I'm only waking up 2 or 3 times in the night now"* (01q. 12. 21).

REDUCED USE OF AIDS: With increasing confidence came the reduction of the use of aids such as sticks or collars. Patient 01 described being able to walk around the unit without a stick: *"I have got my confidence back for walking without a walking stick, full stop indoors, not outside but.. I can walk all the way round the unit"* (01j. 10. 06) This was a substantial change for him. More helpful behaviours appeared to become automatic: *"I*

do it automatically now, when I'm standing up without the stick, instead of just standing like a rigid pole or something, I'm doing stretches on my knees and my legs at the same time as standing" (01l. 11. 26). Similarly patient 03 reported: *"I am now walking for ten minutes without a stick, I'm walking up and down five flights of stairs without a stick, I can get across the centre bridge without a stick but I have to carry it with me because sometimes the leg lets me down" (03a. 01. 19).*

Patient 02 described a change in the use of her calliper: *"I've been wearing these now for three years, and when I go upstairs it's normally one at a time, with this bad leg completely straight. But they have managed to get me walking up and down stairs now with the calliper unlocked and I've actually been using that leg" (02b. 01. 27).*

WORKING THROUGH PAIN: Patient 11 reported that since attending the programme he had worked through his pain when doing exercises rather than giving up at the first hint of pain: *"Like the exercises, in the middle of them if I get a bad touch I'll just stop for a few moments and then continue again but more gently obviously this time around whereas beforehand I would have just stopped" (11d. 01. 15).* *"I've found that I'm able to, maybe work through the pain a little bit better than, beforehand I would sort of give up and not bother but now there's a little improvement there" (11e. 01. 09).* Similarly patient 01 described how he continued to work through pain using a setback plan: *"We worked out a set back plan, I went home over the weekend and it took from, it happened on Wednesday, it took right up until Sunday afternoon before the pain started to subside, but I didn't turn into my bed as I used to. I carried on doing exercises" (01m. 12. 01).*

Patient 11 gave an example of changing his behaviour once in pain which incorporated many of the aspects of the programme: *"We went swimming and as I was getting out of the minibus, and that, I realised that the roof was lower at the door section than the rest of it and I was close to banging my head so I sort of [gestured pulling head back] and I pulled a muscle in the back of my neck...during the night it played up hell it did you know every time I fell asleep and obviously when I was turning in my sleep it woke me up and*

that and I felt that, whereas in the past I would have probably wound up swearing and all the rest of it and feeling sorry for myself I was able to do some stretches and things like that, and again in the morning when I eventually got out of bed to do the stretches whereas before hand I wouldn't probably even bothered getting out of bed. I would have said to my wife 'I'm too sore to get out of bed today'" (11f. 17. 06).

An educational element of the pain management programme was information that in chronic pain, as opposed to acute pain, there were no links between pain and physical damage. Patients were warned that they could experience increased pain whilst attending the programme but this was attributed to increased activity both in terms of the stretch and exercise schedule as well as general mobility around the unit. As patient 01 was no longer fearful of increased pain, his behaviour changed and he worked through the pain: *"I'm not frightened to start to start to stretch my back, to turn my back which before I was stiff as a board" (01g. 10. 21).*

CHANGE IN ROUTINE: All patients faced an enforced change in their routine whilst attending the programme. Some reported these types of changes as beneficial, such as forgoing an afternoon nap: *"I must admit when I seen the schedule here I was quite apprehensive and thought 'my God 8.30 to 4.30- 5 o'clock' whatever, no break, you know I can't have my kip in the afternoon. But funnily enough that hasn't bothered me too much...cutting out the sleep in the afternoon that has been quite something for me" (11m. 04. 17).*

Psychological changes

ATTITUDE: A number of patients described changes in attitude since attending the pain management programme: *"I think my whole attitude has changed... over the last week" (07a. 09. 01).* Patient 11 reported having a more positive attitude *"when I had a flare up or whatever, I went, that would be it I would just give up and start feeling sorry for myself and it would be all sort of negative sort of thing and that but now little by little there is the positive side beginning to come through a little bit" (11a. 03. 06).*

Patient 06 described how his attitude towards the programme rather than the pain had changed: *"Having tried so many places in vain...it was just the sense of being locked in, you've got no way out but coming here has been a great asset, and what the team's put forward, the programme, it comes a bit hard in the first two weeks because obviously they're trying to pump into you as much as they can get into you and afterwards it all starts to fall into place"* (06b. 09. 09).

RELATING THOUGHTS TO FEELINGS: Changes in 'attitude' and the 'positive side coming through' were probably due to patients adopting cognitive behavioural techniques (CBT) taught on the programme. Patient 01 described a reduction of fear by using evidence that chronic pain and damage were not linked: *"I'm not frightened of doing anything anymore, I know that I if do twist by back, I'm not causing any more damage. All right, I might cause a flare up but I can cope with it now, before I couldn't cope"* (01e. 13. 01). Here patient 01 is describing how he changed the way he thought about his chronic pain, reducing fear and feeling he could cope. He also reported feeling more in control of his pain: *"I'm in control now, not the pain, I'm the one that's in control"* (01f. 13. 28).

Patient 01 reported feeling more confident since starting the programme: *"It's getting the confidence, this is the most powerful thing. Confidence was a thing I was lacking. And I've got my self-confidence back, it's coming back, bit by bit every day.... I'm not frightened any more from walking from the unit to here on my own. Whereas before I would have been. But I know we invariably come back in two's or three's but I have come back from over the unit to here on my own. Which I'd never have done before, never, not in a million years.... I'm gaining every day, I'm learning every day. I'm building up confidence every day"* (01h. 05. 29). Patient 01 may have improved his confidence by using CBT techniques to challenge his fearful thoughts, using the evidence of his exposure to walking.

Patient 07 found that thinking about chronic pain as a type of bereavement helped her accept her situation: *"I think the best one was probably the worst one which was the one where they actually come across that it is like a bereavement and they was going through the seven stages of bereavement or whatever it is. Now, I mean I did go through bereavement counselling when I lost my mum and that so I knew what that was all about and then when you stop and look at what having chronic pain is like you can tally it all up and that made an awful lot of sense that one. How angry you get, and all the rest of it. So after that one I did actually feel better I think. So it did, it put everything into perspective that did"* (07b. 17. 11). Acceptance of her situation was a change and move forward for this patient: *"all the time you think 'oh well next time I go to the hospital perhaps they'll do so and so' and you think 'I'll be all right after that'. And it don't, it just goes on and on. So I think now that I've accepted it, I know what me limitations are and just, you know, just get on with it now. Not keep waiting for this miracle cure that's never, ever going to happen"* (07c. 17. 24).

Patient 11 suggested his way of thinking had changed: *"One of the things that has changed quite a bit is my way of thinking when I get the pain"* (11b. 16. 19) and gave an example of how he had used the thoughts and feelings sessions in a situation to do with his chronic pain: *"When I catch a cold it seems to set everything off on me and that and 'cos I've got arthritis in the neck and at first, again you know I started thinking I suppose positive thoughts, there were negative ones there as well but to challenge them and that and to put into action some of the things that I was thinking and picked up along the way. So you know for me that is something quite, it's quite good. Quite an achievement I think"* (11c. 17. 22).

LESS LOSS OF TEMPER: Patient 01 reported that he had been more focused since attending the programme and less likely to loose his temper: *"I can focus on something and I can control my feelings, now that's what I'm looking for...I don't immediately flare up at somebody. I put my brain into gear before my mouth goes into gear"* (01c. 02. 44). He found he had become more relaxed and was able to listen to his wife and think before he

spoke: *"I can now find that I can relate to the wife easier, I can talk to her without losing my rag about it"* (01d. 07. 25). This also demonstrated to this patient that it was he who had been 'difficult' rather than his wife: *"I'm not arguing the wife anymore full stop. I used to think it was her but I know damn well now that it wasn't, it was me, picking up on tiny, everything, I just used to blow my top for no reason at all"* (01k. 10. 23). This theme was categorised here because it was considered to be the behavioural expression of a psychological state. Relating thoughts about control, with feelings, helped the patient to make changes.

Similarly patient 02 reported not losing her temper at home: *"I've got three young children...normally I tend to lose my cool, especially if I'm in a lot of pain, and I tend to shout. My husband said on Sunday before I come back, he said have they taught you to relax or anything at this [programme], I said yeah, he said you notice it, you are nowhere near as uptight"* (02c. 01. 06).

IMPROVED COMMUNICATION: Patient 07 reported changing her behaviour having realised that others will not know what she wants unless she communicates with them: *"I've learned not to be, to expect them all to be mind readers. Erm there was a stage were I used to, I got sick of hearing myself say look I don't feel so good can you do so and so. I wanted them to volunteer to do it which don't happen. So I've learnt now if I need help I've gotta ask for it, not just sit and think oh why aren't you getting up and giving me a hand doing this"* (07d. 19. 20).

MOOD: By week four, patient 01 thought he had returned to his 'normal' self and laughed more: *"I can laugh a lot more, I laugh at anything now, I'm back to my normal self, taking the Mickey out the wife when I used to shout at her"* (01w. 20. 03). Patient 05 was one of two patients who reported few changes whilst at the programme. However, he did feel that he was less down and short tempered saying: *"In the head I got things into perspective as well. You know because I was a bit, when I come up here I was so down [05 emphasis], you know I was just, I just couldn't get on top of anything you know the*

slightest little things getting me down, worrying me and I was getting over the top about, but now, all that's sorted out" (05g. 17. 17).

Three patients described how they had returned to how they used to be: *"everyone says I'm more bubblier....You know because they said when I first came here I never smiled very much, very withdrawn, which you do get like when you're suffering, well I do anyway" (02a. 09. 39): "I've kicked out of that, I can feel the real me coming back, and as I said I'm thinking that I'm nearly back there you see but I'm not but I'm well on my way to being there." (09a. 08. 45): "I never laughed so much in ten years and I laugh here now. It's a wonderful experience for me" (12c. 06. 16).*

INSIGHT: Patients 04 and 08 both reported significant shifts in the way they thought about themselves: *"They're teaching me here how to think differently about myself, and funnily enough I'd never thought about myself properly before." (08b. 05. 07): "And I'm finding out one or two things about myself, which is quite unusual. You think you're self sufficient in all you do but it works out to be punishment" (08a. 01. 20).*

CONCENTRATION: Patient 01 reported that his concentration had improved since attending the programme and he could now read books: *"I can feel the change...I don't know how to describe it, the brain is beginning to, I'm beginning to read books again for arguments sake, now I've read a book since I've been here, I'm on the second one now. For the last six years I just couldn't concentrate on even reading" (01r. 14. 04).*

Others seeing change

Almost all the patients reported changes that family members had seen in them. For these patients this was valuable evidence that the changes were apparent, that they had been working hard and that the pain management skills were valid: *"As I say everybody's noticed it and I mean it just makes you feel, you know, I must be on the right thing here if they're all noticing it as well" (07l. 05. 06).*

The changes patients reported that relatives commented on included similar themes to the changes patients reported themselves: physical changes: changes in behaviour and mood. Physical changes included walking straighter: *"She said to me you're walking slower, I said yeah, she said you're calmer and do you know, your holding yourself straighter. Now that was encouragement"* (01p. 07. 31). Patient 01 reported that his wife and son had told him of the changes they had seen in him: *"My son and my wife, they both said to me, 'have you noticed anything over the weekend Dad?' I said 'no what?' I said 'I've been me normal self'. He said 'You haven't jumped down our throats, you haven't lost your temper once'. He said 'and another bad habit you had was strumming your fingers on the table'. I said 'I'd never ever done that in my life'. He said 'honest Dad', he said, 'you drove us mad by it'. So over a period of just one-week I've calmed myself down only through what I've been taught here"* (01o. 03. 02).

Patient 03 was more able to help his wife so she noticed the changes in him: *"I put the Christmas decorations up this year, I mean I helped last year but she said you don't look well. This year she could see me reaching up, picking things up, getting up into the loft and getting things down. I had to climb up a ladder to get things down. I did it one at a time, and then I get a load downstairs and back into the stables and you know, she said 'oh, you've done a lot more this year than last year". So she's noticed a difference"* (03c. 30. 28). Patient 06 faced disbelief from his wife: *"They've noticed a complete change in my well-being and my attitude, definitely. My wife can't believe I'm doing exercises"* (06c. 12. 09).

Patient 05 reported few changes himself but did describe his family's comments: *"Before that I was all screwed up with the pain you know, but even my wife and my eldest boy notice the difference in me.... I'm not snappy, in that way. Before, up until I come in here, I was getting terrible. Nobody could talk to me, you know. It's taught me how as basically, in a way, count to 10, think"* (05h. 23. 08).

Patient 07 appeared to have a supportive husband who noticed how she had changed: *"Each weekend he says you're walking faster, the pain's gone out of your face, you look better. So, all the family has noticed"* (07m. 19. 05). Reduction in facial stress was also reported: *"My son said the "stretch" had gone out of my face. Now what does that mean? But thinking about it where I'm always in pain I've always got a constant frown on me face and I didn't"* (07k. 04. 26). All the patients who reported that relatives or friends had seen changes also mentioned how much of an encouragement that had been to them: *"They just all said they could see a difference in me which was so much encouragement"* (07j. 04. 22).

Staff and group membership data

The 13 patients participating in the current study were asked what had helped them make changes whilst attending the pain management programme. Five patients suggested the programme staff and their group (patients 01, 04, 07, 11, 13): 2 mentioned only the staff (patients 05 and 06), and 5 mentioned only their group (patients 02, 08, 09, 10, 12). One patient did not mention the staff or their group saying that it was the "general attitude"(patient 03) he had been given.

Staff

There were two main clusters of themes that patients perceived as helping them to make changes whilst at the programme; difference to prior experience with Health Care Professionals (HCPs) and personal qualities. There were three further themes that appeared to stand alone; expertise in chronic pain; non pushing; and support and encouragement, see table 3.7.

Table 3.7: Summary of clusters and themes from the analysis of patients' perceptions what it was about the staff that had helped them make changes whilst attending the programme

Difference from previous experience with Health Care Professionals	Personal qualities	Additional themes
<ul style="list-style-type: none"> • Being believed • Able to help • Understanding • Time • Availability 	<ul style="list-style-type: none"> • Demeanour • Approachability • Listening • Patience 	<ul style="list-style-type: none"> • Expertise in chronic pain • Non pushing • Support and encouragement

Difference to prior experience with HCPs

Most patients reported that the staff at the pain management unit were different to the health care professionals they had met before.

PATIENTS BEING BELIEVED: For many patients with chronic pain being believed and respected were no longer their experience: *"When I went back in January [to the hospital], well I didn't, I crawled back, I was in such a state and they more or less told me it was in my mind and I went mad. I said you know, it's not my mind I'm quite sane this is terrible pain and it's worse than before"* (07i. 07. 25). Patient 11 described how the staff at the programme believed and accepted his pain: *"From the very start you know they turned round and said that we're not going to cure your pain, that's going to be there, and, they just seemed to understand that you have pain"* (11m. 21. 26).

For patient 09 the combination of being believed and listened to was different: *"Well I think the difference of being here, and I found this when I came on the first assessment was that they sat here and they listened, they didn't question me ... they listened and they agreed, whole heartedly they went down the list with me and they said "that's right, you are right, that is possible" ...well this persons got that, now she's sitting here telling me that, I don't really know whether it's true or not but I believe her and I felt really good about it, I thought blimey after nearly eight years someone believes me"* (09a. 05. 09).

Patient 12 perceived: *"They don't help you with the pain like they do here. They know. They listen. They know you're in pain. They know you don't put it on"* (12b. 10. 09). Not being judged was important for patient 02: *"They're here to help, they're not here to judge you, they're just here to help you cope with the pain, you know, and to live a better life basically"* (02a. 06. 26).

STAFF ABLE TO HELP: Patients had often felt dismissed by previous health care professionals (HCPs). Patient 07 felt that being referred to the pain management unit was

a dismissal: *"There is nowhere to go outside of here, there's no one. Even down to the pain specialist I go to, he's not particularly sympathetic. You know he's given me epidurals, he's given me like the beta blockers and I actually felt when he sent me here he basically washed his hands of me"* (07l. 10. 17). Similarly patient 05 thought he had been given up on.

Patient 09 had had little help in the past: *"You feel that they're not taking no notice of you, they haven't done for years, you're just a number and you've got to go back to an appointment, and they couldn't give a monkeys what you said to them. It's hello, goodbye, you ain't no different from the last time and off he went. And you know I'm saying well what about this, what about that. Bye bye, off he goes. There's no point in going to the GP because she can't do nothing. I gave up going to see her a long while ago"* (09b. 03. 43). *"When you're told by physios and that, "there's nothing else we can do for you, go home and do what you like", again you think, that's it"* (09c. 04. 32). Similarly patient 08 described his time urgent doctor: *"the doctor that I'm with I don't like, you know he's very brusque, very harsh, gives you 4 minutes and out. He's not interested really"* (08a. 07. 09).

Patients perceived that the previous HCPs they had seen had not known how to treat patients with chronic pain: *"Basically with hospitals it's well you've had your operation that's it. You've got to get over it now, and as I say the doctor he hasn't got a clue"* (07k. 09. 25). Earlier patient 07 had said: *"My consultant, he's very sympathetic, but it always seems, well we'll try this, but if not have another operation and I've had three, and if they haven't got it right by now they're not going to get it right next time"* (07d. 02. 26).

Similarly previous health care professionals had not known how to help their patients in any way: *"My GP is a total waste of time. He told me basically, this is as good as it gets, I've got to learn to live with it and that's it"* (07c. 02. 24): *"The same with doctors. I suppose it's not their fault really but you know after them trying to help you the best that they can they sort of give up a little bit on you. I've been very lucky with my GP but I've*

found the doctors in the hospital not as understanding. That's right, you've had this operation, you've had that, you've had this medication whatever, none of it's helped and sort of we don't know where to go from here come back again if you need us sort of thing, but we feel there's no need to come back sort of thing" (11b. 05. 30).

In contrast to prior experience, patient 01 reported that at the programme: *"They don't look down their nose at you which is what you used to get even outside, not so much from my doctor, but a lot of it from the hospitals they turn round and say blah blah blah and they just weren't interested, they shove you from pillar to post" (01b. 01. 17).*

Associated with not being dismissed, patients reported that at the programme they had a sense that something could be done to help them deal with their chronic pain. In addition to accepting and understanding that the patients had chronic pain, patient 11 described how the staff at the programme were able to offer patients help: *"They just seemed to understand that you have pain, and, but they can show us means of reducing hopefully the pain level or working through it and not turning round and saying it's all in your head and all this sort of thing but helping" (11n. 22. 29).* Similarly patient 12 felt she had learned a lot whilst at the programme: *"They don't explain to you - you have an operation, you get better, you go. When you come to here, in four weeks I learn more than in thirty years I've been sick" (12d. 04. 08).*

Patient 03 reported: *"The first thing that bucked me up, everywhere I've been, I've been to psychiatrists, I've been to hospitals, I've tried pain clinics and everything else under the sun and nothings worked, they said well there's nothing we can do for you. I came here for assessment and the first thing, well when I went home I was over the moon, I said someone's listening to me, they know what's the matter, they're going to do something" (03a. 08. 25).*

UNDERSTANDING: In being asked what was helpful about the staff patient 07 said: *"Being understood...The hospital more or less said to me I was imagining it. Me doctor*

said well this is as good as it gets, like get on with it and that's it and you think, I could, I remember sitting there once saying look I'm 42 I'm not 72, I've got, please God, another 30, 40 years in front of me and if this is as good as it gets what's the point? So, as I say just for people to understand what pain is, understand when you're on a low or whatever, it's, that is the main thing" (07g. 09. 05). For patient 07, understanding was linked with the ability of staff at the programme to help her cope with her pain rather than give tablets: *"The staff understand what you're going through. You know you go to hospital and basically you're a number, if they give you tablets and it makes you go asleep and you don't matter 'cos if you're asleep you're not suffering pain and so they've done their job. That's basically it. But here it's giving you a life not just an existence"* (07m. 18. 08).

Being understood and not pushed were also important in helping patient 07 make changes: *"They're all so understanding,... everything you do they encourage you. You know, it's not "you're not doing that", "you're not doing enough" like, I always feel with doctors it, at home, you're not a nuisance, that's not the right word but they've tried everything and you know there's, what else can we do like?... Whereas here, this is just a fresh challenge all the time and as I say I think they're excellent"* (07n. 21. 16).

For patient 11 the understanding of staff based on their experience with chronic pain patients was more valued than the understanding of his family: *"The family they get quite fed up listening to you going "oh, argh" and all the rest of it. And you know when you do turn round and have a bad patch maybe it's because they don't understand, you know, and I feel there is this understanding there. They've, whatever training they've got, which makes them, mixing with people who've had pain and that they've learnt a lot on the way and they're passing this on to us"* (11k. 07. 27).

Not all patients felt the staff understood their pain experiences: *"It's I got the pain. It's not you got the pain. So you don't know. You can only go by what you are getting on the*

tape. But unless you have been in the position yourself, you don't know what pain can do to you. It really drives you round the bend if you let it" (10b. 07. 04).

TIME: In addition to having more time together due to being in the same physical space with staff, patients felt that staff 'gave' them time as a group: *"I've been to a few physiotherapists in the past...but they're on a, time is always precious sort of thing ... or we're running over so your session will have to be cut short today, things like that. But here there's a much more relaxation that if we run over a little bit it doesn't matter sort of thing. I mean like today we ran over on one of the sessions so it meant we were 5 or 10 minutes late getting out for our tea and that, so we were rushing to get the tea and hurry up but no we were told take your 15 minutes and then come back" (11i. 05. 20).*

Patients and staff spent a lot of time together due to the structure of the pain management programme. This was different to previous experience with health care professionals. In her experience with a physiotherapist patient 07 described: *"I could only get to see her once a month so you're sort of given some exercises and stuck with them for a month" (07f. 03. 24).* Similarly patient 11 reported that: *"When I used to go for physiotherapy you know there was always a time limit on things and once that time was up out you go and you're only allowed so many sessions" (11s. 35. 03).* He went on to say: *"But here there hasn't been any of that, you know, time has no, you know, it doesn't matter" (11s. 35. 06).*

Patient 11 suggested that receiving time from HCPs was not something he or his fellow patients had experienced before the programme: *"They don't just say "oh sorry I've got to be somewhere else I can't wait." You know they do give you the time... this is something I think most of us probably have experienced in the past, that we haven't been given this time. Not by the medical profession" (11j. 07. 21).* Patient 12 reported similar experiences: *"Because in the hospital ..They don't have time to talk to you. Only five minutes. Another number come in and it's... Here is different. They have time for you and talk to you, explain to you where your body and your bones and parts of your bones*

you never know before. But they got time." (12c. 02. 17): As did patient 02: *"Elsewhere you always get the impression that they are, they rush you, and you've got to be on a very tight timetable"* (02e. 18. 25).

Patient 06 felt he was given time and that help was available: *"If you went and saw a consultant you'd be lucky if you'd get 5 minutes, 10 minutes, he wouldn't really know much about anything, he'd just push you aside because you've got no answers but whereas they don't offer you a cure here they offer you a way to work round it and manage your system"* (06b. 11. 35). Similarly patient 08 described how different his experiences at the programme were: *"They've got time for you whenever you want to and they'll sit and talk to you, that's not a problem. I find that's a great bonus, I've never had that before. Never had that before. I even got told by my previous doctor not to come to the surgery because they'd done all they can do, 'if you want tablets, I'll give you whatever you want' and what's that, who needs that?"* (08b. 08. 05)

As an individual patient 11 also felt he had been given time, unlike his previous experience: *"Like this afternoon we were writing out our circuits for the weekend, that sort of thing, and....one of the physiotherapists, she came over just to check, to see how it was going and that and I mentioned a bit about the pain I was in last night and, 'cos I get very bad headaches with the neck and that, so instead of moving on to the next person she stayed there and started going, explaining some of the exercises again that might be good for me at this stage and that so you know it's, they're very good"* (11g. 07. 10).

AVAILABILITY: In addition to giving time, staff were seen as available both from day to day: *"They're there if you needed them, they were always you know let you know their availability"* (11q. 34. 08) or if the patient had a crisis: *"I really haven't had a crisis yet where I feel that the keyworker would be of great help to me. But again, I know that if I do have a crisis he's there and this is important, that he is there for me and that"* (11d. 08. 13). Patient 06 also commented on staff availability: *"Everybody's got positive ideas, the unit itself, access to everybody, the instructors etc."* (06c. 11. 34).

In contrast to prior experience, at the pain management programme patients' perceptions were that they were not given up on, and were encouraged to contact staff once they had finished for continued support: *"Here you're encouraged to come back afterwards as well, either to phone up and that if you hit a problem and that so you know, this is something you know that there is, I suppose a lifeline there, if you do hit as bad patch"* (11c. 06. 09).

Personal qualities

DEMEANOUR: For some patients their perception of the personal qualities of the staff was important. Patient 01 commented upon his keyworker's personality: *"It's C as a person to start with, her personality is absolutely fantastic"* (01l. 15. 31) and that: *"She's always got a smile on her face"* (01d. 01. 39). It may be that such friendliness and familiarity, helped some patients to feel more supported. One of the nurses who would talk the patients through the relaxation sessions was reported to have a particularly soothing voice: *"Her voice is so soothing, she's really wonderful"* (01c. 01. 37).

One patient commented on the staff's gentleness: *"They're friendly and they always can have a giggle with you. A giggle and a laugh makes a hell of a lot of difference. Okay some of them are a bit more serious. You can't expect everybody to take on moods just like you and I have. But generally speaking everyone's nice. They never tell you off or anything. They might say "oh come on R. Or you can do it. Just try gently or something like that"* (10c. 08. 22).

Patient 11 believed that the staff cared about their job and the patients they worked with: *"They never once give the impression that they were fed up with you or couldn't care less or anything like that, they always made you feel that you were special you know, they were there for you and that was it....it's made a lot of difference... OK I know it's their job, their work and that, but to me anyway they didn't give the impression that it was just a job, it's something that little bit more than a job and that, OK it's paying their bills but*

we're here to help you sort of thing.. Int. And you haven't come across that before...11
No, no. You know it was always time's up sort of thing" (11r. 34. 13).

APPROACHABILITY: Most patients described how approachable staff were and how they could ask questions: "*You can go and ask them about anything*" (05c. 09. 28): "*I wouldn't be worried about asking them anything*" (07j. 09. 19). Patient 01 was pleased he could ask any sort of question, however silly, and get a practical answer: "*It's the staff for one... you can talk to them as one to one it doesn't matter who it is you can go to them ask them a question tell them how you feel they'll always answer it.....Here I feel comfortable I can ask any question I like, doesn't matter how stupid it might seem they always give me an answer and it's always a practical answer that works*" (01a. 01. 15). Getting a practical answer may have encouraged him to ask further questions. Being able to approach staff was mentioned by patient 06: "*In here you have got a chance, whether you agree or disagree with it, to put your objections forward, and if you don't like something go and ask someone*" (06a. 02. 50).

LISTENING: Patients reported that being listened to was helpful. In most cases they where probably seldom listened to by anyone, whether at home or when seeing health care professionals: "*I know C is listening to me and if I go back with the same problem maybe in a weeks time she'll say yes M, you came here last week did you do so and so, yes I've done that then she might give me an alternative to do*" (01f. 02. 12). For patient 01 it appeared that gravitas was added by having what you said recorded: "*She does write down what you say, everything gets written down, you know she's keeping a note of you*" (01g. 02. 06).

Patient 03 found being listened to helpful: "*There was nothing she could do really, I don't think, except that I know that she's listening to me which is giving me something*" (03b. 11. 01).

PATIENCE: Staff patience was commented upon: *"If they're explaining something and you don't understand, they're quite willing to repeat it as often as you want"* (11a. 05. 11). It may have been that the patience to explain things was interpreted by the patients as respect, not dismissing their difficulties or their right to have help and understanding. Patient 01 reported a patient explanation of the thoughts and feelings forms: *"I got a few answers 'mixed up' but she said that didn't matter. She understood what I was trying to say and then she went through it again and I said ah yeah that should have been in there. She didn't tell me but I realised that I'd gone wrong"* (01h. 06. 10).

Expertise

Patients with chronic pain generally have had considerable contact with health care professionals. Patients perceived that programme staff had a lot of expertise in chronic pain: *"You go to any of the physios, any of the doctors, it doesn't matter who it is, they know what they're talking about, they don't run around and say 'I'll just go and have a look in the book'"* (01p. 16. 33). Patient 06 combined expertise with approachability: *"Interviewer: What's different? 06 Well everybody seems to know what they're doing, it's informal, you can chat to them"* (06d. 06. 25).

This may have been quite different to prior situations where staff did not know how to help and were dismissive or just gave up. Using their expertise staff were able to help patients solve individual practical problems: *"I know I could phone her up at anytime, I could phone V up 'cos I've got a bit of a bladder problem, V's done a bit of problem solving there, told me exactly what to do and, I'm putting that into practice when I go home... the physios they come up with answers, what V doesn't know, well it's not worth knowing. She knows what she's talking about and she's genuine"* (01o. 16. 22).

Patient 07 was keen to reduce her medication and had prior experience of trying this to no avail. It seemed at the programme she felt secure in the staff's expertise to start reducing her medication: *"I don't know what effects drugs have on you, you know if you just suddenly stop 'em. What are the withdrawals or whatever, whereas here they know what*

they're talking about so I was quite happy to try it" (07b. 02. 18). She continued saying: "They said they was quite happy here that I come off them so I dropped one dose last week and I've dropped another dose today. Touch wood, I'm OK so far" (07a. 01. 26).

Patient 05 did not appear to be as confident as other patients in the staff's expertise and was reluctant to relinquish control. He reported that at the beginning of the programme it had been suggested that he could eventually walk without a stick, he did not think this possible: *"They turned round and said to me that by the end of 4 weeks they'll have me walking out of here without any walking sticks. Now I just can not believe that. I can not believe that at all" (05a. 04. 25).* Similarly he was not keen to change his medication at what he saw as the behest of the staff: *"I've been having a few problems with drugs because it seems that their main intent up here is so they can, at the end of your period up here, that they can turn round, well, in my eyes one particular person, whether she's got any weight with the others or not I don't know, so she can put it in her report "oh I've cut his drugs completely in half"" (05d. 16. 07).* Patient 10 also felt pressurised to make changes to her medication: *"Medicine. They keep on trying to push me down. And I've come down a bit but they want me to go further. I just, I told R. I can't" (10a. 06. 22).*

Patient 05 did find the expertise of the doctor/anaesthetist helpful: *"It was nice talking to somebody who ...who knew quite a bit about my case. You know, whereas, I don't think the physios do. You know, I don't think they've sat down and read the whole of my notes from '69, I mean, I don't think any of them have" (05b. 06. 19).* Additionally he perceived that having staff supervising him helped: *"I suppose they played a part in it, you know, actually knowing that you've got someone there supervising you" (05f. 24. 20).*

Not pushing

The majority of patients commented on not being 'pushed' whilst attending the programme: *"You're allowed to go at your pace, you're not pushed, you're not shoved and it doesn't matter if you can't do it, you're not pushed, you're encouraged" (01r. 22. 05).*

Not being pushed was mainly in terms of physical exercise: *"The changes are me but the*

staff don't push me. When I first come here I thought it was gonna be you're gonna do this and you're gonna do that, you're gonna touch your toes inside a month. They let you do it at your own pace" (01i. 11. 06). Similarly patient 07 commented how much activity she perceived the staff expected: *"I mean you're not expected to jump in and do like a 100 push ups or something are you, it's, if you do one you've achieved something so you just do whatever you can"* (07e. 04. 05).

Patient 02 reported experiencing being pushed elsewhere: *"We didn't feel like we were being pushed, whereas other places they, you know like other physios and that they tell us, come on you've got to keep on and they can see the pain in your face but you've still got to do it"* (02d. 18. 45): Having described her experiences at the programme: *"Very supportive and, like if you're really hurting rather than tell you to just keep plodding on they will tell you that it might be a good idea to cut back, you know, and then when you're feeling better if after a couple of days you start improving then just start gradually...very supportive and I don't think they've made me do anything I haven't wanted to do"* (02b. 17. 21).

Patient 11 combined the fact that staff did not push the patients, with the technical aspect of pacing, and his tendency to 'overdo': *"They are not pushing you to do more than, what some people might do and they're always telling you to take it easy and to pace yourself and this is something that I find very good and that because I've always been someone...you set yourself standards and that and if you don't reach those standards you know there's all sorts of anger and frustration and things like that but here even though I'm inclined at times as well to maybe to overdo because I'm feeling that little bit better but there's the staff have always been encouraging you not to overdo but to take it very gently and that so this is very good for me"* (11h. 02. 05).

Not being pushed was linked with staff expectations. It seemed that the patient's perceptions of the staff's expectations facilitated patients not feeling pushed to do too much, or to try and do too much: *"They've never give the impression that they're*

expecting too much of you, it's been, the opposite you know to encourage you to do what you feel comfortable with...I might turn round and say OK I can do 21 of them and they say now are you sure you won't overdo it, maybe it might be better if you do 18 and then build up" (11p. 33. 29).

Support and encouragement

Patients described support from staff. Much of the support was of a practical nature directly relating to problem solving around the tasks of the programme. Caring staff were seen as important by patient 12: *"How has [the staff] caring helped you make changes would you say? 12 Thinking somewhere people care for you. Care really. Not just pretending. It has helped me a lot Interviewer: And how does it help you? Does it make you feel ..? 12 Secure. Like somebody will listen to me if I want them to. They have time for you. Even if you're not in the course. If you go home and you want something they can arrange for you" (12e. 09. 19).*

Patient 01 described how the staff were supportive, including a psychologist who requested the patients do forms they did not enjoy: *"You can go to any one of the staff, it doesn't matter who it is, even J, his thoughts and challenges and his flippin' forms he asks us to fill in. He drives us potty but even he will sit down and help you, listen to you and talk to you" (01k. 12. 12).* Similarly this patient described how having support from staff in aiding him to do a particular exercise resulted in him trying rather than giving up: *"I still can't do it, tuck ups from the floor, lying on my back, bringing my knees up to my chest, they've got a way round that for me. Lay on the floor, put my feet on the chair and then bring them up that way. That way I'm beginning....if that hadn't of been for them I would've given up on that" (01j. 11. 11).*

Patients found encouragement from staff helpful: *"It's their whole attitude towards you, the encouragement, I mean this is what I find great, is this encouragement" (11f.07.08):* as did patient 03: *"The way they treat you and way they listen to you, the way they talk to you encourages you to do things properly" (03d. 32. 19).*

Not all the patients felt supported all of the time. Patients felt that staff withdrew in the second half of the programme: *"I think once you get to your 3rd week and you've got the new batch come in, they tend to put, or seem to put, all their efforts into that new batch what come in and leave you to your own devices basically"* (05e. 21. 15).

Group

Patients reported that meeting other patients with chronic pain and being part of a group had helped them make changes whilst attending the pain management programme. Table 3.8 summarises clusters and themes identified by patients as helpful.

All the patients reported that they had been in good groups: *"We all have a laugh and that and help one another out. It is a damn good group"* (05f. 12. 12). It seemed that the groups functioned on a group and individual level: *"We do talk, more I think individually. I've noticed...even though we may be there socially, there are more moments when little groups are talking among themselves...and you can always hear there's pain mentioned whatever, building blocks, exercise"* (11u. 14. 07). Patient 12 described how she felt about her group at the beginning of the fourth week after she had had to go to casualty for an eye problem: *"My eye was really hurt and I was worried about losing my eye. But I was worried about letting these people down as well. I worry more about these people than I worry to my eye. That's why I want to come back. But now I am happy. When everybody saw me they embraced me, they kissed me, they say "oh we missed you and worry". And that lift your morale up so much"* (12d. 14. 15).

The group clusters presented here were conceived whilst considering the group therapeutic factor literature. Within the domain of group there were three key clusters of themes: identity: support and change. The identity cluster comprised two lessor clusters: chronic pain and group which appeared to correlate with universality and cohesion respectively.

Table 3.8: Summary of clusters and themes from the analysis of patients' perceptions what it was about being in a group that had helped them make changes whilst attending the programme

Identity		Support
Chronic pain		
• Experience	Group <ul style="list-style-type: none"> • Anxieties pre programme • Experiences of programme • Expectations of change • Patient witnessing change in others • Others witnessing change in patient • Difference 	• Caring
• Isolation		Caring for fellow patients
• Understanding		Being cared for by fellow patients
• Tolerating others with CP*		• Mutual support and encouragement
• Comparing self to others with CP		Within group
		Between groups

* CP Chronic pain

IDENTITY

Chronic pain identity

EXPERIENCE: The cluster of themes called pain identity was based on the shared experiences of patients with chronic pain. The nature of chronic pain, its duration, meant that patients attending the programme had considerable personal experience: *"We're all sort of sympathetic to one another...one thing we've all got is years of pain behind us"* (07a. 12. 25). They shared a chronic pain identity and with it their experiences of treatment and its impact on their lifestyle, such as the ability to work. Patient 01 described how in sessions individuals would describe their experience or feelings and this would remind him of his: *"We are all in the same boat. Everybody, and sometime like during a, we're having a talk I'll go completely brain dead but someone else will come up with something and then I'll say "ah, yeah" now then I'll chime in and that's how it works"* (01d. 03. 21). Similarly, patient 05 described how patients had had the same experiences, or reactions to medication as him: *"It seems that everyone does the same thing. When you say something they say to you "yeah, that's exactly what I do" you know. It is, its the things, and when you mention tablets "oh yeah I was on them" and "how did you feel?" you know and any side effects and I'd say yeah had so and so they said yeah we had them 'n' all"* (05e. 11. 22).

ISOLATION: Individuals with chronic pain frequently report feeling isolated. None of the patients reported knowing others with chronic pain until they attended the programme: *"You meet people with the odd aches and pains but I've never met anyone in the same situation as myself"* (11k. 08. 21). The discovery of so many others with chronic pain was mentioned by every patient: *"We all had the same problem, we all thought we were the only ones"* (01e. 07. 16): *"You realise you're not on your own. You're not the only one. We've all got something in common"* (07b. 12. 21). Meeting and talking with other patients with chronic pain was seen as helpful: *"I suppose another thing that's been helpful as well is talking to other people who've got it... I live in T and you've got people here from what must be the other end of the country see and when you're down there on your own you think you're the only one"* (05a. 03. 22). Patient 09 said: *"You know it lifts you. You know it makes you feel that you're not alone. You know there are people out there"* (09c. 13. 40).

Patient 08 described how his pain led him to identify with fellow patients and reduce his sense of isolation: *"When there's 4 or 5 of you then there's automatic identification, flying across the room as to certain pains, how you suffer, how you cope with it, yeah. It's amazing. That people can have different ranges of suffering but immediately identify with someone who is not suffering quite as much. That's good, that's good 'cos you're not the only one any more"* (08f. 12. 01).

UNDERSTANDING: Patient 07 described the constant experience of chronic pain, and remarked about fellow patients that: *"They just understand what it's like and how debilitating it is all the time and you think it's just there you never, you never ever go to bed and think oh I'm comfortable and wake up feeling oh right lovely"* (07e. 14. 15). It seemed that part of the understanding for this patient was that fellow pain patients, possibly from a position of being limited themselves, would understand each achievement made: *"They know how a stupid little thing to anybody else is such a major step for you"* (07d. 14. 13).

Patient 08 found it most helpful to talk to fellow patients: *"Talking to the psychologist and everything is helpful but I honestly firmly believe that it's better to talk to the other people you are on the course with. Because the psychologist, no matter how good they are, are not the ones who are suffering. And we don't flood each other with our pains we bounce off each other and that's where you build that relationship of closeness and understanding and everybody's so friendly to each other"* (08c. 09. 27).

Chronic pain patients felt more understood by their fellow patients than their families. It seemed as if the understanding was to do with having the same or very similar experiences with chronic pain: *"I think they understand more what you're going through...it's not that the family don't want to help I just think they don't quite understand and it's as simple as that, you know, everyone here has some sort of pain, one form or another, so they understand that's what you're going through because they've been through it themselves"* (11x. 23. 20).

Being in the 'same boat' as fellow patients was helpful for patient 05. He felt it was impossible to explain his experiences to outside people, particularly as chronic pain was not visible: *"You got people there who are in the same boat as you, which, people outside don't know what it's like. You can't tell 'em. It isn't something you can see"* (05i. 23. 31). Similarly patient 09 talked about the invisibility of chronic pain: *"It is very difficult to make people who haven't got that sort of pain understand. You can't see it. As we said, if you could put a bandage or walk around with this and that you know they'd say "oh dear", but back ache's always been a myth hasn't it?"* (09b. 13. 33).

For patient 05 being with people with chronic pain seemed to be helpful because fellow patients knew what it was like to be in pain and because he was believed: *"I mean they know more about what pain is than what your loved one does. You know, I mean my wife knows I'm in pain but she doesn't know what its like. Interviewer And you find it helpful to be with people who really know what it's like? 05 Oh yeah. Because you're not getting someone saying to you 'oh it's all in your head'"* (05k. 26. 03).

As well as not understanding as completely as fellow patients, patient 11 suggested that family members may feel inadequate because they do not know what to do to help: *"Members of your family, they haven't experienced what you're going through...I get the really bad headaches and that I just go away up into me ...so they leave me alone and that which is a good thing because I do get quite narky with them ...but at the same time there's been times when I've thought a cuddle would be nice.... Whereas here, even though you're allowed that space but at the same time you know there's someone there that will come to see you, or you can go and see them"* (11za. 23. 27).

As well as understanding in terms of having common experiences, it seemed that group members understood that individuals needed time by themselves: *"One of the things that I like, even though we're in a group, and even though we meet socially, if after a while you want to be on your own no one bothers you, no one tries to stop you,*

they allow you this time, this space" (11r. 13. 11). Similarly, patient 08 felt that he could do as he wanted without interference because fellow patients understood how he felt: *"If you're not well, you just want to flop down or do something you just do it. Everybody knows what's happening to you, or they can see it, but they also know, with the vast amount of experience in years of the group, they know to sit back and just let you get on with it"* (08e. 10. 14). The "years of experience" may have been referring to the first session on the programme during which staff total the number of years patients have experienced chronic pain. The result is usually over 70 years and frequently over 100 years.

It seemed that the patients were patient, and gave encouragement to one another, support they no longer received from their families, possibly due to the duration of chronic pain: *"It's all right when you get these things first everyone's there... but as the years go on and that "ah it's only D, he's just going through one of his black periods" or whatever and that leave him alone and that's the end of it. But here you know there was always someone here for you and that to give you that little bit of encouragement and that. And I think that made a lot of difference"* (11w. 23. 07).

TOLERATING OTHERS WITH CHRONIC PAIN: Sharing the pain identity appeared to mean that individuals were able to understand the individual with pain more appropriately than family members: *"Being with people who are in pain as well has been a tremendous help. You know, with the best will in the world you're with your family, they know that you've got pain but when you start to "argh its hurting" you know the sort of the attitude "tch, there he goes again" sort of thing and there's none of that here. It's total, everyone, people sympathise with you, you know, they give you a little bit of support, so this is something I find quite good"* (11j. 02. 18).

Patient 01 felt he could behave in an extreme way within the group, such as loosing his temper, because the group would understand and not take offence: *"If I got frustrated and lost my rag, at least they understand, at least I know that I can blow my top and say 'shut up', or 'be quiet', or 'what did you do that for?', they understand, so we take no notice, we listen to them and we talk about it and I think that helps no end, I really do"* (01i. 08. 19). It seemed as if due to this understanding

there would be few repercussions attached to possibly unacceptable behaviour. Patient 08 described how he was able to behave at the programme: *"I just crawled under a table and curled up into a ball and that was it, I'd had enough. And I was so embarrassed, so ashamed, somebody had to bring me back up here, I couldn't even look at that person in the face. But nobody cares. Nobody cares. Wow! Fantastic!"* (08d. 10. 07).

Patient 01 felt other patients could let out their frustrations because the group would understand: *"They're maybe a little bit apprehensive still but they will come out with it in the class as well. They will bring out their frustrations, so that helps us, it helps them. We can understand what they're going through"* (01h. 08. 14). Similarly patient 11 reported that fellow pain patients were able to tolerate other patients being angry or upset because they understood what it was like to have chronic pain. Patient 11 described the confidence he felt patients had that other patients would be able to understand their behaviour, because of their shared pain identity: *"I think possibly because they feel confident that because we are all in the same boat that we'll be fit to understand a little bit what they're going through and that you know"* (11m. 10. 02).

COMPARING SELF WITH OTHER CHRONIC PAIN PATIENTS: Patients reported that due to their chronic pain they had a lot in common and lots to talk about: *"You start to talk to one another and you can relate to them because they are suffering from the same problem, or the same pain, all be it in the back, the shoulder, the neck, they are all suffering that chronic pain and you can talk about it"* (01f. 07. 21). *"We've all varying degrees of disability but we've all got the same chronic pain. So everyone understands one another"* (07h. 18. 06). Patient 11 reported that knowing that others had the same symptoms as himself was helpful: *"I mean listening to quite a few of them in one way or another yeah, we all relate to, near enough the same symptoms. Yeah so and again you know this is very helpful for each one of us and that"* (11i. 09. 01).

As well as things in common, patient 05 commented on experiencing or observing the different ways people thought about chronic pain: *"We chat about the pain and that a lot yeah. That's basically all we do chat about you know is the problems and that we*

got. *It's interesting the way different people think about it*" (05b. 04. 10). Patient 08 was not sure he should have been on the programme initially: *"I was dubious with coming in 'cos I didn't know whether I should or not, and then when I got here I seen lots of people suffering far worse than I looked to be. I felt I was here under false pretences for the first 2 days"* (08b. 03. 13).

Not all patients felt they were similar to their fellow patients. Patient 05 reported that he was different to his fellow patients, and thought all the patients were different: *"No one quite like me..... No, I don't think there's anybody who's very much alike. They all seems to be different sorts of pain and different areas and that"* (05d. 11. 11). This patient made few changes whilst at the programme but appeared to enjoy being part of the group: *"You got people there who are in the same boat as you...It isn't something you can see. But I find it's with the others that's what helped me"* (05i. 23. 31). Patient 03 suggested: *"I realise that I'm not as bad as most of them which has pleased me"* (03b. 11. 29). He continued to describe how he saw himself as different to others: *"I mean everybody's got back problems but I don't think that there's anybody who has had a total hip operation and it's gone totally wrong. Well there isn't, I know that"* (03c. 13. 23).

Group identity

The helpfulness of sharing the experience of participating in the pain management programme with other patients was reported by all the patients. This cluster of themes has been called group identity as opposed to pain identity which was based on the shared experiences of chronic pain. Patient 11 was pleased to be surrounded by a diverse group of patients: *"I thoroughly enjoy such a great variety of people there and that. All walks of life sort of thing and er it really makes the group quite lively and that you know"* (11a. 12. 09).

Patient 01 described his group commenting that nobody ignored anyone and that he felt happy being in that group saying: *"We all talk to one another, there's nobody ignores anybody. If I'd have been in the other group I would have been, this group and that is a laugh from start to finish"* (01g. 07. 46). At the end of the programme similarly patient 01 described his group: *"The whole group is so, a very happy group,*

they are, they really are a happy group" (01l. 18. 31). The group atmosphere was worth braving cigarette smoke for: *"Even people who don't smoke go into the smoking room with them because it's so light hearted, blow the smoke, I mean who cares"* (01o. 19. 21).

Patients described how with time the group got on: *"It's nice that the group all actually get on. I think this week we've sort of all settled down we know each other's ways and we're all pretty supportive"* (07f. 14. 20). As well as how they shared the experience of going through the programme: *"We're all sort of pulling together and you're all trying the same things together"* (07j. 23. 05). Patient 06 described how sharing experiences led to understanding and hope: *"People bring out ideas that you might not actually brought out in your own mind...you get a better understanding of how the people have got problems and how they cope, and if they're managing to get off their med. and one thing or another then maybe there's a way forward"* (06a. 07. 35).

ANXIETIES PRE PROGRAMME: The groups first met on the Sunday afternoon before the programme started. Patients were greeted by a member of the programme staff, but once registered, were left to their own devices until Monday morning. Most patients expressed some anxieties about being away from home whether it was missing family members or changes in their routine: *"I mean the first night obviously when I came here it was a strange place and all that it was quite, and not having my wife beside me and that you know, it was quite daunting"* (11am. 04. 28). Patients reported anxieties about meeting other patients with chronic pain on first arriving at the unit: *"You come on these things not expecting, wondering who's going to be here, what are they going to be like and you come with all sorts of maybe little worries and anxieties and that"* (11bm. 09. 25). Meeting a senior group on the first day was worrying for patient 01: *"I thought crikey if they are as much as they are now, what am I going to be like at the end of the month"* (01dm. 08. 40). The group he met had mixed feelings about their time on the programme.

Patients arrived worried about being judged: *"I was worried first night because you didn't know who the other people were... you didn't know if they were going to be one*

of these, "oh my pain's worse than yours" or they're going to judge you in any way, and it turned out none of them are like that" (02b. 19. 30). Patient 09 described how overpowering she found meeting others: "Very over powering, because they're all sort of talking over one another and trying to tell you stories and some more dramatic, some people express themselves more, some don't say anything you know and living on my own basically I find it a bit sort of over powering, you know all these people, but on the whole we turned out to be a fairly good bunch and we all get on well together" (09a. 08. 25).

EXPERIENCES OF PROGRAMME: In participating in the group programme it seemed that for some individuals and groups a strong sense of group identity developed, fostering a sense of responsibility. Patient 01 described how he and his group managed silences during the teaching sessions, by 'breaking the ice' and using humour: "Sometimes the whole meeting goes quiet because none of us can think of anything and then someone, probably me invariably, comes up with some stupid joke and it starts the whole thing rolling again... everybody laughed and it eased the tension 'cos there was a bit of tension building up, but it just rolled out of my mouth for some unknown reason" (01a. 03. 25). In doing this he was taking some responsibility for the group as a whole.

Similarly, patient 05 referred to his group helping a more junior group when they had a difficult member, emphasising that when attending the programme people were in the "same boat" and it seemed as if he felt there was a responsibility to help others. both individually and between groups: "I mean we've all in the same boat together when you're in these places. While you're there you've got to help one another out" (05m. 27. 09).

As well as sharing the experience of going through the programme, group members also shared individual tasks. Completing the Thoughts and Feelings forms was a task many patients did not enjoy: "The writing bit of it, we didn't find too clever us older ones" (05h. 23. 17). Group members shared the difficulty of completing these forms: "I was never any good at that sort of thing at school and I've heard, especially the older people, I've heard them down there in our group. They're mostly 40 odd and

above you know and we're the sort of people, we don't like all this writing and that, you know" (05g. 20. 11). Patient 01 described how his group shared the annoyance of doing the forms: "**Interviewer:** How about doing it in a group, does that make it a bit better? **01** Yes it does because you've all got the same feeling "oh we've got to go and do that again" but never mind, when we go out for a meal like now I say "so have you finished the forms S?" "Yeah mine's done". I say "I've done mine, ain't got to do it now have I"" (01c. 04. 10).

Patient 07 described how when a member of staff was off sick the group pulled together and did their exercise task: "*Suddenly like, there's no one there to keep an eye on you. But we all did it! You know, we were sort of taking it in turns to be at the front of the class and we carried on. All right we might have counted, did our counting to whatever number it was, a bit faster then the actual physios and that but as I say we did it*" (07i. 23. 22). Patient 10 described the same group: "*Left to our own devices what we are doing. And we tried to keep them up. I mean this morning there was nobody there so we started ourselves*" (10a. 30. 18).

EXPECTATIONS OF CHANGE: Part of the group identity was sharing expectations concerning change whilst attending the programme. Patient 05 found it helpful to hear from the senior group that the future of the programme held promise: "*Hearing people saying, especially those who on their last week or on their 3rd week saying it's really bucked up in the last couple of weeks you know. Most of them have said that the first two weeks you don't notice a lot of difference...but they said that in the last 2 weeks you really notice the difference*" (05c. 10. 19).

PATIENTS WITNESSING CHANGES IN OTHERS: Seeing change in other group members, or members of other groups, appeared to be helpful. It may be that this consolidated their own changes, or give them hope for continued change. Patient 01 described how it had been to see other patients making progress: "*I mean next door he's come on leaps and bounds, he really has, I mean the way he goes around, I think it's fantastic*" (01n. 18. 38). Patient 05 reported few changes in himself but felt that seeing change in others had done him good: "*I mean I can see the change in a lot of the people down there on the course... I've noticed the difference in 'em, the way they walk they seem*

looser, you know and that, it has toned them up and that's what's done me good" (05n. 27. 13).

OTHERS WITNESSING CHANGE IN PATIENT: There appeared to be particular value attached to patients commenting on change in fellow patients, more so than staff: *"Plus the group, because they are really more important shall we say than the physios, because we all talk about things, we all see achievements everyone is making"* (01j. 10. 33). Patient 01 reported an encouraging atmosphere with patients pointing out to him what he had achieved: *"A couple of them have come up to me and said "M do you know what you've just done?", I said "yeah, I've just stood up for five minutes without a walking stick" and they give you a pat on the back, it's that type of atmosphere all the way round the group"* (01m.18.32).

Patient 02 felt that fellow patients saw change first: *"We all say you know, how we've seen the other people doing, how they progress because I mean they're the first ones to see it, and we're the last, I mean obviously yourself is the last person to notice that it's happening. I mean it's normally outsiders who notice things first, so I mean they do tell you what they've noticed"* (02d. 20. 21). Patient 06 described: *"Encouragement comes from other parties in the group from them saying "you're doing so much better than you were" and that tends to lift people"* (06c. 13. 26).

DIFFERENCE: Patients described fellow patients who they perceived as 'different' and who had not 'fitted' into their group(s). The toleration and management of difference within the groups was a key area of discussion within the research interviews. The presence of difference within the groups may have had an impact on group identity and the process of change for individuals. Some patients were seen as different by more than one other patient. However, during the interviews it became clear that in a group it was not always the same patient who was seen as different. Patient 10 was seen as different by patient 09 but in the same group, patient 08 saw patient 03 as different. Patients did not report during the interviews that they perceived themselves as different from others in their group(s). In the extracts below patients agreed about a 'different' patient in another group. Hence the assessment of difference was both individual and group based.

Patients perceived that 'different' patients were not genuine: *"If someone's got a genuine disability, no problem, but when they start putting it on like a certain person was, it was, well it was you know knocking everybody for six"* (02g. 22. 34). Similarly: *"The first day when we saw what happened, we told the new lot "please don't help her". We've got pain. We don't know her pain. But we all have pain"* (10g. 41. 22). Patient 12 did not believe that the 'different' patient in her group had a sore throat: *"She was talking normal and she was shouting to the other girl because she said "you took my pillow". Well, if I have something wrong with my voice I don't scream to the other people. So I said to myself "phoney or what?""* (12c. 14. 10). Similarly patient 10 did not believe the abilities of a patient in a different group were genuine: *"If she can carry all that, she can bloody well open the door and get her food out of the thing. And when we saw that we just said nobody's going to help her. Either she accepts like everybody else, because we all have pain"* (10j. 39. 09).

The key characteristic of 'difference' appeared to be choosing to be separate: *"She's always ... me, me, me all the time. There is no me, me. We are us, us, us. We all stick together. We all here for the same thing and we stick together. But she will separate herself. We tried to communicate with her. But she didn't respond. So we leave her"* (12b. 13. 19). *"I think there's probably one lady who probably feels a bit left out, perhaps because she's older and she doesn't sort of communicate with us very much. She's a bit of a loner you know, she'll go off on her own, or she'll have her lunch and nip off you know. I've tried to involve her and that but she's a bit of a pain"* (09e. 11. 30).

Group members perceived that the 'different' patient was more critical of the programme and its staff: *"It's something you've got to live with and you just don't need someone like that mainly taking the mickey I think, out of the staff and bringing down the other patients which I think is totally wrong"* (02f. 21. 29). Additionally, 'different' patients were perceived to see themselves above others in the group: *"This one drives everybody [gestures mad], just floods it. He just opens his mouth and comes out with shit, OK? He's absolutely full of it. Mr "I-know-it-all", he even had the cheek to sit in the class and say "I'm more intelligent than every other person in*

this group". How dare you, how dare you insult people like that. And that's the way he goes on" (08g. 11. 07).

It seemed that difference could be very recognisable: "We told the other ones not to help her because she doesn't belong in a hospital like this. **Interviewer** And did you discuss that before you told the other people. **10** No. It just happened. Because immediately when we saw it we just looked at each other and that was it...Look we might be sorry for her. I don't know what's wrong with her. But the way she behaves, we all feel she belongs in a loony bin" (10f. 40. 12).

Patient 07 described how her group discussed the motivations of a patient who did not fit into their group: "We've all got our own theories on why she was here but no, she should have stayed back. It shouldn't be detrimental to the other 9 people, to have someone like that" (07o. 26. 13).

Group members perceived that the 'different' patient could have an influence on the group: "**Interviewer:** What effect do you think that particular person had on, your group? **02** Annoyance, putting it mildly, because we felt that this one particular person was trying to bring everybody down... we've worked hard and we know we've worked hard...And we know that it's helped us, and we don't want anybody that needs, I mean anybody like that brings you down, you're going to find it hard to get up again and we didn't want anyone falling at that and we felt they weren't, you know, this particular person was not being fair to the new group because we saw it as a set back to them, perhaps they're not progressing as well as they could have done" (02e. 21. 07). Similarly, 'different' patients could have an impact on individual patients: "That was one particular person in that group who was upsetting. I mean J I take home and bring back again and she was so upset that it upset me. It was the way X was treating her" (03e. 35. 17).

Patient 10 described how the different patient received attention: "She always had to have someone there helping her. She got on our nerves. Even when food came around. One of the employees kept on helping her. We got so mad because we thought, here she gets all the attention. One person. Which we should actually get

that time" (10i. 38. 12). She continued to describe how her group reacted to the different patient: "*We started putting trays on the table so she couldn't go and sit there. I know we were a lousy lot. But you see the moment she saw weakness in someone, she tried it on. So we had to educate her*" (10h. 42. 12).

The impact of 'difference' on the group could be unclear: "**Interviewer** *As a group do you think it made you more together?* 07 *It give us plenty to talk about [laughter]. That was the topic of conversation. We were sort of placing bets with one another, well she probably won't have the neck to turn up next week, if it's harder next week we're just not putting up with it. But thank goodness she didn't come back*" (07p. 26. 28). Here patient 07 appeared to describe how the group consolidated their identity and had a plan about what to do if the 'different' patient returned.

Patient 11 also reported how his group spoke about a group member who they considered to be different: "*I think at the moment the person is probably a bit isolated. Yeah, which is quite sad erm. But while ...[sigh]...I think when people speak to the person they're very nice to the person but when they get into a group it's a different story and it's quite sad really*" (11g. 10. 23). The group had initially talked about this 'different' patient, but as the group evolved had become less focused on her: "*When we get up here [hostel accommodation] the person doesn't mix... I mean I don't know why but it hasn't, I don't think it's effected the group....At the beginning yes it was because the person was I suppose the centre of the conversation and everything like that but as time went on and we all got to know one another that little bit better then I think that person was given their space and they were made, you know, "you know where we are if you want to come" that was it*" (11ac. 28. 01).

Some patients were more tolerant of difference than others. Patient 11 described how he understood this patient: "*They say there's always one bad apple sort of thing but I don't see the person as a bad apple but maybe as someone who I think is hurting inside, who is angry and somehow leaving a little bit of her frustration out in the group*" (11b. 09. 30).

Patient 11 went on to comment that the patient had calmed down since attending the programme, although it was not possible to determine whether this was related to group dynamics: *"I had hoped that this week that, once we'd got the first week over us and we all started to get to know each other's little faults and things like that you know that, and I mean in actual fact this person has calmed down quite a bit you know. Today you wouldn't think it was the same person that we left last Thursday"* (11h. 11. 17). In his comments patient 11 sees himself as part of a group, using "we" and "us" in his conversation.

Patient 11 described how he felt sad that his group was 'breaking up' when he heard that one patient was to move rooms in the hostel accommodation, because she and a fellow group member were not getting on: *"Someone was saying that she's having to move her room or something, so I don't know if that's the fact or not but I just heard someone say it. So, that makes me quite sad because I feel the group is breaking up even though they may not have met with us socially but still part of our group and it's a bit like you know cutting a bit off and isolating that person even more from the group and that, so I do feel a bit sad"* (11f. 11. 25). It seemed as if the identity of the group was challenged, or changed by this member no longer being such a part of it, even though she had not mixed socially with the rest of the group.

Pain and group identity

When asked whether it was the shared pain identity, or the group identity that was helpful on the programme, patient 11 suggested it was a combination of the two: *"Int. What is it that's helpful do you think, is it because you all had the same starting point of chronic pain, or because you're all here and in the same boat..? 11 Yeah. I think a combination of both. You know, we all know where we're coming from and er it's, again it goes back you know, we're all in the same situation and er we're able to relate to each other and that which is something you don't really get when you're at home or at work"* (11n. 12. 16).

SUPPORT

Caring

CARING FOR FELLOW PATIENTS: Patients cared for each other whilst attending the programme: "*P in the wheelchair ... the other day for instance, we hadn't seen him for, he didn't attend one of the sessions because he hadn't been well the night before and that and the other P who is next to me here, he really showed great concern, he kept going knocking to see if he wanted anything and that he was all right you know*" (11s. 13. 16). Similarly another group cared for a patient with flu: "*The lady in the room next door...she really went down, we thought she had real bad flu, I mean we've all knocked to see if she's all right, if she wants drinks and everything. So as I say I think we're all here, you've all got something in common*" (07q. 28. 22).

Patient 10 reported that: "*When somebody didn't feel too well we make the tea for them or the coffee for them, without saying. We just said sit down and one of us brought it. We didn't even have to ask anyone*" (10c. 44. 09). In addition to caring when other felt unwell, patient 03 felt he helped others on the course: "*I mean I'm helping people as well, I mean I take J back home and bring her back. T we go swimming. We have an activity plan. I'm helping one of the ladies walk across the bridge*" (03d. 16. 04).

BEING CARED FOR BY FELLOW PATIENTS: Group members observed other group members caring for one another and hence knew that if they were having a difficult time the group would be supportive to them: "*So we know that there's this, that if we're not well there'll be someone who will come to see how we are and whatever and make sure everything is OK*" (11t. 13. 22). This may have been reassuring for patients who were away from their safe, familiar, home environments. Patient 10 described a thoughtful fellow patient: "*It didn't matter if they came from the second lot or anything. If somebody needed help ... when it was raining I wasn't going to go over to the canteen. I wanted a sandwich and one of the boys said 'okay, I'll get you one'. Without being asked. That kind of relationship. And it makes such a hell of a lot of difference*" (10e. 43.18).

Patient 05 stayed in the hospital, rather than the hostel rooms that most patients stayed in. The hospital was for patients who needed help at night. Patient 05 described how he had been visited in his room by the members of his group when he had had a bad day: *"last week I wasn't too good and one night, 'cos I stayed up here you know, I was reading the paper one night, all of them, not all together, but all come up and see me and then at the end all of 'em come up. And they was in this room and I tell them next morning, they kept me up late"* (05j. 25. 22).

Mutual support and encouragement

WITHIN GROUP: On a day to day basis group members encouraged and supported each other through the programme, as well as through other problems in their lives: *"Being in a group, you know, support. There's a lot of support here, you know. I mean you'll never ever touch this amount of people in pain ever again in one go, not for a month, so the support of everybody to sort of gear you on really sort of helps"* (09d. 13. 29).

Mutual support could be practical, emotional, a listening ear humour: *"We joke. We laugh. And then we call names. We have a good time. And when you have a good time you don't think on your pain any more"* (12a. 07. 01). Similarly: *"The group that we're in I mean we're a great crowd. I mean we sit down at night time and have a good old laugh. You know, take the mickey out of one another, just basically playing around which does make a difference. If you can laugh, you know, it brings you up"* (02h. 14. 40).

Patient 11 described a mutually supportive atmosphere that he had not experienced before: *"If one is feeling down the others do rally round and try to help in any way that they can so it's something that I haven't really experienced before you know so, yeah, a very good group"* (11q. 12. 12). The atmosphere at the programme was one of informal sharing and it seemed that within the group there was sufficient experience of pain or whatever that meant there was always a group member who could help another out: *"Even when we're sitting in there having a cup of tea or a fag, or whatever, you know we talk about our problems with one another and there's always someone you know there who can give a word that'll help the others"* (11y. 24. 20).

The type of support available from fellow patients with chronic pain was something patients had not experienced before: *"You know this is very helpful for each one of us and that. Especially for me, 'cos as I say you know, maybe they've been the same. There's never, we've never been able to find anyone to speak to when you're going through a bad patch and that and because all of us have similar aches and pains, chronic pain and that you know, we're really able to sympathise with one another and to encourage each other"* (11o. 09. 03). Patient 11 thought the support was better than that he received from his family: *"Being with people obviously....I mean that has been a tremendous help and the support that you get from one another as well that has been really really good. I mean there's been a few who have gone through really bad periods of times and that and the support they were given not only from the staff but also you know from fellow patients and that has been tremendous and it's something you know that, OK, with the best will in the world you don't get from your family sort of thing"* (11v. 22. 25). Patients reported that other patients had an understanding of what it was like to have chronic pain that this led to encouragement that was often no longer available to them from their families.

Group members appeared to be sensitive towards individual group members who were having a particularly difficult time. Patient 07 described how her group supported someone who was experiencing a flare up in her pain: *"We all encourage one another, one of the girls today was having quite a bad day and we was sort of you know all supportive towards her. Sort of don't give in, just stick with it, get on with it"* (07c. 13. 21). Patient 11 described an argument between two of the patients and how he and some of their group had helped one of the patients to deal with it: *"They were so angry, tears everywhere and all the rest of it but I think that we got her calmed down a little bit. We got her upstairs and told her to go and practice the relaxation and all that so hopefully she'll be OK"* (11ad. 28. 22).

Similarly, in being supportive group members were understanding and flexible. Patient 07 described how her group had to change their plans for a celebration at the end of their programme: *"Different ones have had flare ups and set backs as I say we've all supported, I mean, tonight the whole idea was we woz all going out for a*

drink but there's 3 of them who can't manage it, so all right if we can't do that we'll go in the lounge and buy some bits and pieces" (07i. 22. 24).

Patient 11 described how his group had supported someone having a difficulty at home: *"One person came back a bit destroyed after the weekend because their husband wasn't very sympathetic towards them, things had been er, she had left some stuff that needed to be washed you know things like that and it was still lying where she'd left it you know so she came back quite, quite destroyed and that so you know we were able to I suppose rally round and give a little word of encouragement to her"* (11p. 09. 13).

Between groups: In addition to supporting fellow patients within their own group, the groups as units appeared to support each other: *"It's helping each other. You moan. You laugh. You help. I've never been in this situation But I thought the way it worked out with us, with both groups, it was fabulous"* (10d. 44. 19).

The more senior groups tended to use their experience of being at the programme to support the more junior group: *"You're the new boy on the block aren't you?....where's this? How's that? It goes on in life generally, I think it's a good idea starting it in two different parts, like anything, if you were to work in a new office, you went in, you'd have to be shown what you're doing and how you're doing it by someone who's already been shown"* (06b. 08. 15). Patient 05 described how the senior group had suggested when he might expect to see changes: *"Those who on their last week or on their 3rd week saying it's really bucked up in the last couple of weeks you know. Most of them have said that the first two weeks you don't notice a lot of difference. You know but they said that in the last 2 weeks you really notice the difference"* (05o. 10. 19). Patient 08 described how the group above him had helped: *"The group that's there 2 weeks before you helps you to settle in, shows you the ropes and all the different things, but they don't give you any advice, which is nice. And they don't tell you, "oh you should do this or you should do that", 'cos you don't need that"* (08a. 03. 08).

Similarly patient 07 described how she felt reassured to hear that being tired was 'normal': *"I mean this week like I've been very, very tired, and they all say "oh that's normal". Like next week it will be a little bit easier. So you think oh well that's OK then I can, this is normal, fine"* (07g. 15. 01). Once patient 07 was in the senior group, she described how her group supported and encouraged the junior group, including telling them about being tired: *"We woz all giving them encouragement you know, "don't worry about the first week you're gonna feel like you don't know what's going on but it will all click at the end of the week" and warned them they woz all going to feel dead tired and all that"* (07k. 23. 17). Information shared between groups could be simply which member of staff to see about particular difficulties such as work experience, or information unrelated to the programme such as applying for disability living allowance. Alternatively it could be to generally try and help another group engage in the programme: *"You get some people who are very sceptical, they put the thing down straight away without even trying it, and you do your best to sort of tell them that it's not as bad as sort of you think it's going to be, and you know, we try and explain what it entails and that, and we show them the ropes"* (02c. 20. 39).

The groups also supported one another if there were particular stressors such as patients who did not fit into the group or get on with their fellow patients: *"We woz all saying to the other group "don't let her wind you up" 'cos we could see them, really, going on the skids. I mean it was bad enough for us and she wasn't in our group....we kept saying to them, you know like, "don't let her wind you up, keep going, don't let her get you all tense and ruin it for you"* (07m. 25. 04). Patient 05 described the support his group had given to another group: *"We helped them with this one bad apple they got. 'Cos we'd been here longer we knew the people, the best ones to talk to. We did our little bit to help them, we talked to our keyworkers about this certain person was upsetting the group"* (05l. 27. 01).

In the context of change, patient 11 had found it difficult being with a more senior group who had been less positive about the programme. However, he described that with time, how this group had become more positive and he felt that the support and attitude in his group had had an influence on that change: *"As the weeks went on, I mean quite a few of us in our group we were saying, you know, we feel that it's done*

this for us, and doing this for us, and that and little by little they started turning round then and saying yeah we've felt a little bit of a change so I don't know if they were feeding off each others' negativity and that and, or they felt like they weren't supposed to turn round and say that things were getting a bit better but by the end, by the time that they left they were speaking more on the positive side" (11aa. 26. 17). He went on to comment: "I hope it doesn't sound big headed, but I think it had a lot to do with the group, our group in that, people coming with a little bit more positive talking about how it was helping them and that you know. It helped them to come out of their shell a wee bit" (11ab. 27. 19).

Additional themes

There were two additional themes concerning making changes, unrelated to staff or group, that emerged from the interviews. The first was of the programme as a 'goldfish bowl', the second referred to the uniqueness of the programme.

"But it's a different world out there you know you're in this goldfish bowl here, you know and you're supervised and but it's going to be another matter when I get out there"(05. 15. 15). Patient 07 called it a bubble: "It is very much a bubble, I mean it's gonna, it's still gonna to be very hard in the outside world to get everything into practice. In a way this has been like a four week holiday, you know you've only got yourself to think about, there's no outside pressures whatsoever" (07. 18. 14).

Patient 07 spoke of how special she felt the programme was: *"I feel really strongly, you know, that every, every hospital should have this type of unit in it. I really do"* (07. 12. 28). Similarly, when describing a 'different' patient she said: *"What annoyed us more than anything, it's so hard to get on this place, we all know people who would benefit from it and they're denied a place for the likes of her" (07. 27. 12).*

CHAPTER 4: DISCUSSION

The study presented a qualitative analysis of the process of change in 13 patients with chronic pain participating in a residential pain management programme. It appeared that non technical aspects of the PMP helped patients make changes. The non technical aspects were the programme staff, and participating in a group. The results of the current study will be described in the context of literature concerning the therapeutic bond, empathy, and group therapeutic factors. The method, ways of determining validity, and study limitations will be discussed, followed by suggestions for further research. The discussion will conclude with the clinical implications of the current research.

CHANGE REPORTED BY PATIENTS

The changes patients reported were categorised into five clusters; physical; pain; behavioural; psychological, and others seeing change in the patient. Eleven patients reported several changes, two patients reported few changes. The eleven patients who reported several changes generally felt better and 'different'. The reported changes were consistent with changes after attending a residential pain management programme (Williams, Richardson et al. 1996).

Physical: Patients reported feeling more flexible and fit, as well as experiencing less physical tension. In addition to reporting physical changes, by the end of the programme most patients were assessed to be able to walk a longer distance and climb more stairs than before attending the programme. Some patients had decreased their achievements on the physical measures taken by the programme. This probably reflected their use of pacing and the realisation that they may have pushed themselves to 'overdo' activities before attending the programme.

Directive groups aim to counteract demoralisation (Frank and Frank 1991). Through direct praise and acknowledgement of success, members' feelings of self-worth and successful coping can be enhanced. The use of stretch and basic exercise allowed patients to achieve change at the beginning of the programme. An achievement could be

as simple as getting down onto the floor for the first time in five years. This initial success provided patients with evidence that change could occur. In addition it provided the basis for staff to encourage patients. In seeing early success, patients may have felt that there was a chance of being able to make changes. This may have increased their feelings of self efficacy and hope.

Pain: It was not anticipated that patients would report changes in their level of pain. None of the patients had expected to see a change in the level of their chronic pain, although most commented that a change would be appreciated. Some reported increases and attributed these to flare-ups, set-backs, or 'rust' pain due to using muscles and joints that had not been used for some time. One patient reported a reduction in his headaches.

Behavioural: The behavioural changes reported were mostly specific aspects of the course such as using a timer, pacing or setting goals. Many patients aimed to reduce medication whilst attending the programme and had made some progress.

Psychological: It may have been early for patients to have made significant changes in the way they monitored their thoughts and feelings. Patients reported more changes to their ways of thinking at the second interview than the physical changes reported mostly at the first interview. Several patients reported using the skills of identifying thoughts and feelings and challenging unhelpful thoughts. Patients appeared to prefer negative and positive terminology rather than helpful and unhelpful. Most patients reported increased pain self efficacy whilst attending the programme.

During the programme over half the patients reported decreases in their depressed mood. Three patients reported increased depressed mood. It may be that coming to the programme had given some patients the opportunity to consider their situation and reflect on how difficult life had become for them. This realisation led them to report increased depressed mood. On leaving the PMP two patients were referred to their local clinical psychology service.

Patients reporting little change: For some patients it may have been too risky to hope that there could be change. Due to prior experience of disappointments, it may have been more adaptive to deny the possibility of change so that they would not be disappointed. One patient appeared to be ambivalent about his chance of seeing changes. He suggested he had no expectation of change, whilst indicating a hope of change in the future. This patient reported having experienced disbelief in his pain from others before arriving at the programme. He may have chosen to disbelieve anything could change for him because he felt that if the situation could change that 'easily' it would have been an indication that his chronic pain could not have been that bad, and that he should have been able to overcome it if he had tried hard enough. This patient reported that others had seen change in him. It may have felt safe to allow others to see change because, if these changes were later unsubstantiated, it could be their mistake and not his.

Patients who feel that others do not 'believe' their pain can become preoccupied with proving the legitimacy of their symptoms and may believe that if their symptoms were acknowledged as 'real' there would be successful attempts to provide relief (Shapiro and Teasell 1997). These patients focus on an appropriate diagnosis and treatment rather than optimising their function despite the pain. This may have been the case for the patient described above.

The effectiveness of directive therapies depends on finding a balance between their rationale and the participants individual experience (Frank and Frank 1991). The lack of fit between an individual's formulation of the problem and a group's rationale is one of the primary reasons for failure of a self help approach. It may be that at the programme those who did not benefit were those whose formulation of their chronic pain did not fit the rationale of the programme. As above, a formulation that there was an organic cause to the pain that had not yet been identified, would not aid patients in making changes whilst attending the programme. Patients who attended the programme were screened to identify the degree of fit between the formulations of the individual and the programme.

Patients attending the programme should no longer actively seek medical treatment or expect a cure for their pain. Screening was not always able to identify those who had differing formulations to the programme. Not all patients who attended the PMP found it helpful. Volunteers for the current study may have under-represented patients who attended the programme with different formulations to that held at the PMP. Such patients may have been reluctant to volunteer for research that assessed changes as they may have made few changes, or felt that the programme was not suitable for them. Hence the sample of the current study may have been biased towards those who found the programme helpful and against those who did not.

STAFF THEMES AND THE THERAPEUTIC ALLIANCE

The themes that emerged from the patients' perceptions of what it was about the staff that helped them make changes fell into two clusters; difference to prior health care professionals (HCPs) and personal qualities with three further themes of expertise; not pushing; and support and encouragement. These themes overlapped considerably and no specific theme appeared to be the most significant. The specific and non specific aspects of the programme in the context of the staff were difficult to 'differentiate'. The staff's expertise was a specific aspect of the programme, yet as perceived by the patients it was the difference in their knowledge compared to other HCPs that helped the patients make changes, not solely their specific skills. Patients reported their prior bad experience and perceived that it was 'different' to the current situation. It was difficult to elicit from the patients specific 'differences', just a sense of general 'difference'. It may be that stronger emotions were attached to prior bad experiences rather than the current experience.

Within the cluster of difference to prior health care professionals there were five themes; patients feeling believed; staff able to help; understanding; time; and availability. Not being believed was a common experience for patients with chronic pain both on the programme and in the literature (Osborn and Smith 1998; Shapiro and Teasell 1997). Patients appeared to find being believed by staff a unique experience. Many had been

told the pain was in their mind so to be accepted, by staff, as having pain was a significant difference. In believing patients, staff may have validated patients' prior difficulties with their pain and hence helped them feel less that they had to 'prove' their suffering.

Patients reported feeling isolated and alienated from a society which held psychogenic attitudes towards chronic pain patients. Societal beliefs about chronic pain (Shapiro and Teasell 1997) were not evident at the programme. Patients on the programme may have previously met doctors and HCPs who had psychogenic pain models. Patients reported how 'different' it was to meet staff who did not have these views and instead were accepting of the patients and their pain experiences. Views such as 'if they tried harder they would be able to get over their pain' were not present at the programme and the difficulty of dealing with chronic pain was acknowledged. Patients reported being believed, accepted, understood, and offered a way to enhance their coping skills. In addition, patients reported feeling that the staff were able to help them rather than dismiss them as had been their prior experience. To find help offered may have been a powerful counterbalance to the patients' prior experience of feeling dismissed.

The strength of the therapeutic alliance has been proposed to be dependent on agreement between the therapist and patient concerning the goals and tasks of therapy, and the therapeutic bond (Bordin, 1979). The structured nature of the pain management programme ensured patients and staff had common tasks and goals provided they shared a formulation concerning the chronic pain. The collaborative design of the programme may have helped strengthen the alliance.

Bordin (1979) suggested that the therapeutic bond was a network of personal attachments between the therapist and their patient which included mutual trust, acceptance and confidence. Mutual trust may have been a combination of two themes reported by the patients in the current study. Patients felt the staff trusted them in that they believed the patients had pain. The patients trusted the staff in believing that the staff were able to

help them deal with the pain. These themes may have been an indication that mutual trust was present and helping patients make changes. Acceptance between the staff and patients may have been a function of patients feeling believed as well as their perception that staff spent time with them. Additionally the themes of understanding, support and encouragement may have helped patients feel acceptance from the staff. Confidence between the patients and staff appeared to be portrayed in the theme of staff expertise. In addition to perceiving the staff as accepting of them and able to help, patients perceived that the staff had the expertise to help them due to their experience of working with patients with chronic pain. This may have enhanced their confidence in the staff.

A specific aspect of the therapeutic bond was mutual affect (Orlinsky, Grawe et al. 1994). In terms of mutual affect, therapist affirmation has been associated with therapeutic outcome (Orlinsky, Grawe et al. 1994). Therapist affirmation comprised acceptance, non possessive warmth and positive regard. Non possessive warmth may be similar to the cluster of personal qualities in the current study. Patients perceived that the staff were friendly, approachable and listened to them. Listening to patients' views and experiences accords them value and indicates that they are worthy of attention and acceptance. Patients attending the programme perceived that their individual needs were addressed, be it in the context of a much broader teaching programme. This may have been due to the personal qualities of the staff, who patients perceived as listening and understanding. There did not seem to be evidence of positive regard between the staff and the patients other than friendliness and encouragement. It may have been some time since the patients had experienced encouragement. Family members may have found that the patient with pain did not respond favourably to encouragement, fearing failure, so family members may have stopped trying to encourage them.

Empathy has been defined as sympathetic identification which promotes understanding of that person's view point and their motivation (Burns, 1996). The themes in the current study of understanding, not pushing, and support and encouragement could be factors associated with sympathetic identification.

The patients' perceptions that they were not being pushed may have been quite 'different' to previous experiences. Physiotherapists, doctors, family members and friends may have had unrealistic expectations concerning the patients ability to do certain activities. Patients may have internalised these expectations or had unrealistic expectations of their own. Such unrealistic expectations would have led patients to believe they should, if the just tried harder, be doing more (Shapiro and Teasell 1997). The theme of not pushing may have had more to do with patients' expectations than staff behaviour. Staff at the programme aimed to encourage patients to achieve as much as was reasonable within the limits of their pain. The patient's perception of not pushing may have been because the staff did not share their unrealistic expectations. The patients may not have felt they had to do 20 sit ups, but they were expected to attempt at least one.

GROUP THEMES AND THERAPEUTIC FACTORS

The current research identified several themes associated with being part of a group whilst attending the PMP that helped patients make changes. These were similar to the group therapeutic factors reported in the literature. The cluster of themes labelled chronic pain identity appeared to be similar to universality, the group identity cluster similar to cohesion. The cluster of support themes included caring for others which appeared to be similar to altruism. This section will outline how the themes in the current study related to the group therapeutic factors of universality; acceptance; cohesion; altruism; hope; vicarious learning; and modelling.

Universality Perceived similarities among group members is considered to be a powerful therapeutic element and has been called "universality" (Yalom 1975; Yalom 1985). Demoralised patients feel isolated and believe their problems are unique. Within the cluster of chronic pain identity the themes of experience, isolation and understanding were key aspects of universality. Group members tended to endorse the value of hearing that other members had similar experiences and feelings. The understanding of chronic pain by fellow patients was a novel experience for most in the group. People who have

not experienced chronic pain may underestimate its constancy. Fellow patients would know exactly what you meant.

Mutual self-revelation can bring enormous relief to the individual (Frank and Frank 1991). When patients met on the Sunday evening, prior to the programme, they began identifying shared experiences due to chronic pain. Patients reported having been anxious about meeting fellow patients but all found it subsequently helpful. Hence a process of change within individual patients, to do with universality, may have begun before the teaching programme started.

Acceptance The themes of understanding and tolerating others with chronic pain seemed similar to the group therapeutic factor of acceptance. Patients reported that they felt able to behave as they wanted within the group, such as losing their temper or withdrawing, because the group would understand and not take offence. It seemed as if due to this understanding and acceptance there would be no repercussions attached to what they perceived as unacceptable behaviour. This highlighted how at ease group members felt. Feeling at ease and accepted may have led patients to have felt more able to take risks without worrying about the repercussions. Hence it felt safe enough to take risks in terms of trying to make changes and seeing what happened.

Acceptance is particularly relevant for patients with chronic pain as many feel alienated from 'normal' life (MacKenzie 1998). In the transcripts there were no specific dialogues concerning patients being accepted into the chronic pain, or programme groups. It was as if there was an assumption that patients were accepted by the group. The theme of difference highlighted the fact that most patients were accepted into the group. Those who were not either tended to alienate themselves or were not perceived as genuine by their fellow patients. Hence the 'different' patients had either not accepted the group, or the group had not accepted them.

Cohesion Group cohesiveness is “the attraction of a group for its members” (p260; Frank and Frank 1991). It develops out of the group member’s shared history of supportive and tension arousing experiences. Group cohesiveness at the programme was based on shared experiences, and mutual support whilst being on the programme. The patients shared two identities; as chronic pain patients and as a group of patients participating in a pain management programme. Themes identified within group identity were anxieties about the programme, experiences at the programme, and difference.

Early development of group cohesion mobilised the sense of being included and accepted. In all the transcripts patient used ‘we’ rather than ‘I’ when talking about changes, activities or sessions. Feelings of being part of a group appeared to ameliorate some initial thoughts patients had had of not coming back for week two of the programme. Specifically, some patients were phoned by other group members over the first weekend and encouraged to come back. Patients felt that not returning would be letting the group down, possibly due to the alliance formed as part of attending the programme and “seeing it through” together.

Research has highlighted that deliberate efforts to speed up the development of cohesion within groups has led to accelerated symptomatic improvement and change in group members (Frank and Frank 1991). On the first Sunday evening the group experienced the tension of arriving and starting the programme. Most patients reported anxiety, but also feelings that everyone was in “the same boat”. By Monday morning and the start of the programme, patients were already a cohesive group rather than individuals. The degree of homogeneity within a group promotes rapid group cohesion. At the programme there was an initial focus on how similar individuals were based on their chronic pain identity, this evolved into group identity. Specific group identity was also salient because at any one time there were two groups going through the programme and although most patients felt part of the larger group, the smaller groups were reported to be most supportive.

Patients have been reported to experience and express angry feelings towards staff more in group than individual treatment settings (Frank and Frank 1991). The presence of other members seemed to provide protection and support. Although no group reported challenging any staff member, groups of patients complained to their keyworkers about specific patients. This may have been because it felt safe to complain because fellow patients were also doing so.

Individuals in groups are given the opportunity to function in an open social system that values authenticity and the open expression of feelings (Bednar and Kaul 1994). At the programme patients were valued for their experience with chronic pain. None of the patients participating in the current research were working hence to be in a group and be valued for their experience with chronic pain may have enhanced self-esteem.

Cohesiveness and shared responsibility for the group's activities appeared to enhance feelings of competence. At the programme there were specific 'activity times' when patients chose what to do. Patients seldom spent activity times on their own. Usually about half the group would arrange a specific venue as well as support around how to get there, helping those who would need extra help and ensuring the plans included as many of the patients as possible. Patients reported the 'success' of their group during the research interviews by describing how well patients got on and how supportive the groups were. Being a participating member of a cohesive group may result in feelings of competence. Particularly as patients were able to show their 'success' to the staff as it was they and not the staff who had 'made' the group.

The degree of cohesion was evident in that patients shared the problems they had whilst attending the programme. This may have been because the patients were away from home and other group members took the place of usual supports. It may also have been a function of the programme because patients shared their experiences with chronic pain, and described difficult emotions during sessions. This may have 'let' people share more

readily than if they were in a less open environment or had not been encouraged to share experiences by the staff.

Difference Patients shared the problems of coping with 'different' patients in their group. This may have fostered group cohesion as group members identified a common 'foe'. During the research interviews patients were asked if having a 'different' patient in their group made them closer. They suggested this was not the case but did identify 'different' patients as a common focus of conversation. It seemed that group members shared the experience of having someone in their group who did not get on with the majority of group members.

It may be that those who were 'different' did not experience the stage of engagement with the group in terms of finding commonality with other group members (universality), and hence a way to relate to other members comfortably. Additionally they may not have considered the group a safe enough place for them to share their experiences. (MacKenzie 1998).

High cohesiveness is associated with high morale, fragmentation associated with a demoralised group (Frank and Frank 1991). The morale of the group being correlated with the morale of its members. At the programme, there appeared to be a 'need' to 'get rid' of the 'different' patients, such as hoping they would not come back after the weekend. Patients may have felt that the 'difference' promoted fragmentation and hence reduced morale as patients felt threatened by the 'different' patient. Examples of feeling threatened were demonstrated by at least two patients who referred to the attention received by 'different' patients from staff. Frank proposed that rivalries could be generated by aspects of the group situation, such as attention from staff (Frank and Frank 1991). In the current study attention from staff to a patient who the group felt should not be at the programme elicited comment and at times anger.

The nature of what made a patient 'different' was difficult to identify. "Group members are likely to fear and dislike others they perceive as similar to themselves" (p 258; Frank and Frank 1991). Conflict in groups at the programme may have been because those who were 'different' were seen to be the embodiment of how chronic pain patients perceived that others perceived them. For example, CP patients can feel that others see them as "putting it on", which they accused the 'different' patient of doing. They did not feel believed yet they in turn did not believe the 'different' patients who were accused of being too able. It may have been that patients felt the 'different' patients were not genuine and thus not worthy of group membership. This may also have given group members a sense of power, being able to exclude another as they had been excluded from groups in the past due to their chronic pain.

Those who were 'different' tended to criticise the staff and the programme. This may have challenged other patient's faith in the helpfulness of the PMP. For patients attending the PMP it was crucial that they had sufficient confidence that the strategies they were learning would help them make changes. The 'different' patients may have been visible reminders of the fragility of the patient's faith in the treatment and hence it was adaptive to alienate such a dissenter.

Altruism Patients with chronic pain tend to report being the recipient, never the giver of help, as well being a burden to others due to their difficulties (Williams 2000). The support cluster of themes was similar to altruism on an individual and group level. The groups reported being mutually supportive. Due to the residential nature of the programme patients had ample opportunities to care for one another. There were examples of both practical and emotional caring as well as mutual support and tenderness. Patients 'looked out' for each other and noticed if someone was having a difficult time. Group members observed other group members caring for one another and hence knew that if they were having a difficult time the group would be supportive to them. This may have been reassuring as patients were away from their safe, familiar, home environments. Opportunities for altruism can reinforce self-esteem and feelings of

self-worth (MacKenzie 1998). Similarly, each member of a therapy group can give as well as receive (Frank and Frank 1991). Participants can aid one another by comparing their experiences or giving useful information, advice or insights. Significantly on the programme, patient's advice was taken seriously which may have increased self esteem and feelings of competence. At the programme patients shared advice about practical and emotional experiences, such as Disability Living Allowance as well as local shops and more distant services.

Hope An important aspect of psychotherapeutic treatment is the mobilisation of hope (Frank and Frank 1991). There were few references to hope in the transcripts of the current study. It may be that for patients with chronic pain hope was too remote an emotion because of previously failed treatments. Although there were no overt references to hope it seemed that witnessing changes in fellow patients may have been a way of thinking and talking about hope. Patients frequently reported seeing the achievements fellow patients had made, at times emphasising how small the changes were. This was reported both as the patient telling others they had changed, and as others telling the patient s/he had changed.

Seeing others succeed has been reported to be associated with a surge of hope and desire to emulate success, rather than jealousy (Frank and Frank 1991). Patients on the programme were proud of how others had made physical and emotional changes. They reported how fellow patients had stopped using sticks or walked over Westminster Bridge. Seeing change in fellow patients appeared to be helpful. It may be that this consolidated patient's own changes, or gave them hope for continued change.

Vicarious learning and modelling In group therapy, unlike individual therapy, group members are sources of feedback, provide models, and guides (Frank and Frank 1991). In the theme of sharing experiences of the programme, patients reported witnessing physical change in others and listening to how others talked about their pain. It seemed that there was behavioural and cognitive vicarious learning at the programme. In the

therapeutic setting it is important that the patient and therapist are on the same wavelength, the therapist not being too ahead of the patient in their interpretations (Orlinsky, Grawe et al. 1994). Modelling in the group was such that patients were able to hear the thought processes of their fellow patients who may have been ahead of them in terms of learning new skills or assimilating their chronic pain experiences. Additionally patients modelled physical behaviour in the gym. Observing others complete exercises, particularly those perceived as of a similar ability, may have encouraged patients to attempt exercises. Change is a sequential process of coming to understand one's maladaptive behaviour and then attempting new and more adaptive behaviours. At the programme patients would have observed others, as well as their own, maladaptive behaviour. This may have enhanced their insight into unhelpful behaviours and hence aided learning.

In summary, group therapeutic factors that appeared to help patients with chronic pain make changes whilst attending a pain management programme were; universality; acceptance; cohesion; altruism; hope; modelling and vicarious learning.

THE PROCESS OF CHANGE

Acceptance was a key theme in patient's perceptions of which staff and group factors had helped them make changes at the programme. Being believed, being given time and encouragement were indications that staff accepted and respected the patients. Similarly patients were accepted into a community of chronic pain patients and were valued.

It may have been that the staff and group themes provided patients with a "safe enough" environment for them to attempt change. Patients described the programme as a "goldfish bowl" or a "bubble". The combination of trust and acceptance with a safe, non pushing, understanding environment may have increased patient's confidence sufficiently for them to attempt change. The observation of fellow patients in "the same boat", attempting the same changes may have been an additional incentive.

In addition to the “bubble”, for a significant proportion of patients participating in the current study, the programme was a space free from stressful home circumstances. Two patients had significant relationship problems, one had a violent home situation and another had difficulty with neighbours. One patient was caring for a parent with Alzheimer’s disease and one patient’s wife had experienced a late miscarriage within the previous 6 months. In addition to the programme being a “bubble”, for these patients it was also an escape from stressful home circumstances.

Faith has been described as an important non technical aspect of therapy (Frank and Frank 1991). Faith in treatment may be particularly important for patients with chronic pain because they have had considerable treatment that has not reduced their pain. Patient’s faith in treatment would be expected to be low and they may feel extremely hopeless and demoralised. The process of coming to the current programme was lengthy and included a screening interview followed by a waiting list. These factors may added to the patient’s faith in the programme in that if it is such a difficult process to get on to, it must be worth it. This was indicated by patients discussion of the “magical”, “specialness” of the programme, it being the ‘only’ one in the country. Hence it was an achievement to have been able to both find out that the programme existed and to actually be on it. Patients may have been reinforcing their own ‘faith’ in the programme’s effectiveness by considering it so special.

Self-efficacy beliefs are influenced by four sources of information; performance and enactment experience; vicarious experience; verbal and social persuasion, and emotional/physiological arousal (Bandura 1977). All these factors were present whilst patients attended the programme and may have been key in the increase reported in self-efficacy. Experiences gained through performance have been suggested to have the greatest impact on expectancies, because they provide recognisable and real information about actual ability (Bandura 1977). At the PMP patients were constantly exposed to experiences of themselves and others thinking about change and making changes.

DISCUSSION OF METHOD

The qualitative method adopted by the current study provided data concerning patient's perceptions of the process of change whilst attending a pain management programme. Due to the increasing use of qualitative research methods there have been discussions reviewing the method and suggesting guidelines for rigorous research (Smith 1996; Yardley 1998; Elliott, Fischer et al. 1999). Recommendations have been made for the conduct of qualitative doctoral theses (Turpin, Barley et al. 1997). Clear descriptions of procedures and the process by which data were collected are essential (Turpin, Barley et al. 1997). Within the limits of the available resources, it is hoped that the current research provided a clear description of its method and process of analysis. The results were written with constant reference to the transcripts. There were periods of reflection, and discussion with research supervisors and fellow clinical psychologists.

Elliott and colleagues (1999) suggested evolving guidelines for the conduct and publication of qualitative research. Specifically they suggested seven "publishability" guidelines for qualitative research; owning one's perspective; situating the sample; grounding in examples; credibility checks; coherence; achieving general vs. specific research tasks, and resonating with readers. The guidelines were suggested for use when reviewing qualitative research in psychology, to balance the use of quantitative standards which Elliott and colleagues (1999) viewed as inappropriate. Detailed below is a discussion of how the 'quality' of qualitative research can be evaluated with reference to the current study.

"Owning one's perspective" as detailed by Elliott and colleagues (1999) involves the researcher specifying theoretical orientations and personal "anticipations", both as identified in advance of the research and as they became apparent during the research. The authors should recognise their values and assumptions, and identify the role these play in their research. The disclosure of these values and assumptions helps readers to interpret the researcher's data and hence consider possible alternatives. The current researcher values cognitive behavioural pain management programmes and their efficacy,

and was interested in assessing what helped patients to make changes. Others may not see PMP's as a valid treatment for patients with chronic pain. An interest in systemic theory influenced the literature review in terms of the way individuals within groups made changes. Additionally, having worked on the unit as a trainee the researcher was aware of how the groups appeared to form an identity, that could be helpful or unhelpful for the individual, as they progressed through the programme. Important friendships and relationships were observed. It is noted that the literature reviewed had an impact on the themes reported. It may be that a different literature review would have led to differing emergent themes.

The emergence of unexpected themes in qualitative research can suggest that the method and analyses are flexible rather than directive. The themes that emerged from the current study were partially anticipated by the literature and partially emergent from the researcher whilst conducting the interviews and reading the transcripts. For example, within the therapeutic alliance literature there was limited discussion of how patients perceived their therapists compared to other therapists. The significance of the staff at the programme being different to the staff patients had previously encountered, and that this may facilitate them make changes, was not anticipated. Similarly, within the group therapeutic literature there was little discussion of difference within groups and hence it was not an anticipated theme. In therapeutic groups, difference and conflict tend to be interpreted rather than taken at face value. Additionally, altruism was a theme that was not anticipated to be as significant as it appeared to be in the current study. This may be due to the unique opportunity for altruism offered by patients living together during the PMP. The emergence of unexpected themes in the current study suggested that the method was used in a flexible manner.

Adequate descriptions of the research participants and their circumstances, in this case the pain management programme, are essential to aid the reader in judging the range of persons and situations in which the findings might be relevant. Elliott and colleagues (1999) label this "situating the sample". The pain management programme was outlined

in the current study and patient characteristics described at the beginning of the chapter 3. Using patient identification numbers it was possible to match each quote to that patient's characteristics and questionnaire data. The characteristics described were chosen with reference to research which had identified the significant factors associated with mood and outcome in chronic pain management programmes. For example, duration that the individual had not worked, and whether the onset of pain was sudden or gradual.

A vital aspect of qualitative reports is the use of interview extracts to highlight the emergent themes or categories. The "grounding in examples" (Elliott, Fischer et al. 1999) or presentation of evidential links (Turpin and colleagues 1997). It is the key way in which the validity of the interpretation is evidenced, as the reader can review the extracts and observe whether they agree with the interpretation made by the researcher. Elliott and colleagues (1999) emphasise the use of data in illustrating both the analytic procedures, and the understandings developed in the light of these procedures. Full descriptions of the "chain of evidence" from extracted themes and interpretations, back to the original transcript, should be accessible to external audit (Turpin, Barley et al. 1997). The inclusion of a single case account of the experience of attending the PMP may have been helpful. This may have given a more complete understanding of what changed for an individual patient and what they perceived influenced their changes.

An excellent validity check for the current study would have been the inclusion of member validation. Member validation involves taking an analysis of the responses back to the original informants, to enable them to comment upon the interpretation (Elliott, Fischer et al. 1999; Smith, 1996; Turpin, Barley et al. 1997). This can be done at different stages in the analysis, the aim being to gain a more complete understanding of the research subject. The current study would have been suited to such a credibility check. The interview during week 4 could have included feedback of the analysis from the interview during week 2. Patients could have been asked whether the analyses reflected what they felt had been discussed during the first interview. This would have been a helpful experience for the researcher, in checking the validity of her interpretations, as

well as possibly giving more of a sense of process. It may have been easier to identify what had been helpful and when for the patients. Smith (1996) adds a note of caution suggesting that there can be difficulties due to the inherent power imbalance in many research settings. Whilst acknowledging the power issues, member validation would have added a significant dimension to the current study.

Using multiple qualitative analysts, a specific analytical auditor (Elliott, Fischer et al. 1999) or a more general independent audit (Turpin, Barley et al. 1997) partially addresses the reliability of the interpretations made in qualitative studies. Reviewing the data for discrepancies, overstatements and errors is an important “verification step” (Elliott, Fischer et al. 1999). Due to the limits of time and facilities, these steps were not applied to the current research. In the clinical training setting it may be a useful exercise for trainees to review fellow trainees qualitative and quantitative research. In the current study it was initially hoped that the two trainees conducting qualitative theses on the PMP could meet and discuss their findings. However, this did not occur. The transcripts were discussed with two supervisors in which the understanding of the transcripts was elaborated and decisions made about the relevant themes. Comparing two or more varied qualitative perspectives can add to the validity of qualitative research (Elliott, Fischer et al. 1999). Within the limits of the current thesis this was not possible.

Triangulation involves assessing the subject of the research from differing perspectives. It can be with external factors (outcome or recovery), quantitative data or alternate individuals (Elliott, Fischer et al. 1999). It is based on the assumption that if a number of different sources of information are used to answer a question, the answer is more likely to be complete (Smith 1996). Hence triangulation strengthens the claims researchers make by providing a more complete story, including multiple “voices”. In the current study quantitative and questionnaire measures of outcome, such as the Beck Depression Inventory and the distance walked in five minutes, could have been linked with the interview data. For three patients the process was related to a worsening in mood. This was interpreted as being because patients were reflecting on their lives whilst at the

programme. Two of these patients were referred for further psychological support. It is hoped that the presentation of the patient characteristics, the questionnaire data, and the interview extracts with common identification numbers allowed readers to reflect on any links. In terms of additional perspectives, the programme staff and family members could have been asked for their views concerning what helped patients make changes whilst at the programme. As the emergent themes demonstrated, others seeing changes in the patients provided them with support and encouragement. To have assessed how others perceived these changes and what they thought influenced these changes would have added richness to the current study. Although a useful source of information, asking family members to participate in such research may have had an impact on their understanding of the family member with chronic pain. Because family members are seldom invited to participate in such research the impact of such an invitation on family dynamics should not be overlooked. This would have to be carefully described in the research process, much like “action research” (Yardley 1998).

In considering the representativeness of qualitative research it can be helpful to review whether the research presented an internally consistent and coherent picture (Smith 1996; Turpin, Barley et al. 1997; Elliott, Fischer et al. 1999). Coherence has been described as whether the interpretations of the data are presented in an integrated manner whilst preserving its “nuances”. Such interpretations should fit together to form a narrative or model (Elliott, Fischer et al. 1999). In the final report of qualitative data there should be sufficient raw data to allow the reader to make their own interpretations in comparison to those made by the researcher. Hence the reader can become part of the interpretative dialogue. Had the current study used membership validation, a more coherent sense of the narrative, and hence the process of change, may have been achieved.

Resonating with readers (Elliott, Fischer et al. 1999) has also been called face validity (Turpin, Barley et al. 1997). This considers whether readers judge the research paper to have accurately represented the subject matter, or to have clarified or expanded their understanding of it. Discussions with fellow clinical psychologists, both working on the

PMP and in other settings with patients with chronic pain, produced recognition of the statements made by the patients and subsequent interpretations about the staff being different, and the group being an important aspect of experience at a PMP. Additionally the current study was a conference poster presentation where both clinical and health psychologists reported familiarity with the patient's statements and understanding of the themes and clusters.

Elliott and colleagues (1999) discussed achieving general research tasks using data from a sufficient range of informants and situations. Research tasks and the conclusions of the current study were fairly general, based on a range of patients completing 26 interviews. However, in discussing general research tasks the limitations of extending the research findings to other settings should be specified. A key limitation of the current research was its unique setting, the residential pain management unit. There are few residential pain management units in the UK and none as big as the one observed. Excellent practical facilities were combined with social opportunities. Patients spent considerable time together during the day and in the evenings. This made the setting unique and different to the treatments most patients with chronic pain experience. Hence this research provided an indication of how staff and group membership may be helpful in a month-long residential programme rather than what would be helpful at an outpatient setting, or for individual therapy.

ADDITIONAL CONSIDERATIONS IN THE CURRENT STUDY

A key limitation to the current study was the degree to which participants were representative of patients attending the PMP, due to its volunteer design. It is likely that patients who were not finding the programme helpful would not have volunteered for the current study. Hence, the process of change reported reflected data from patients who generally found the PMP useful and were making changes. The study did not assess how patients who were unsure of the programme made or did not make changes and what they thought about the staff and being part of a group.

In the current study patients were reported to volunteer that staff, and being part of the group, had helped them make changes whilst attending the PMP. It may be significant to note that these themes were mentioned as possible influences on change during the process of recruitment. Hence, although the interviews were conducted around 48 hours after recruitment, patients may have been primed to think of these factors which may have had an impact on their thinking before the interviews were conducted.

In attempting to reduce the "power" imbalance between participants and the researcher, patients were interviewed in a setting familiar to them, rather than the researcher (Yardley 1998). It was not possible to identify whether this had been helpful in addressing "power" imbalance. Patients perceived the researcher as a staff member, although she no longer worked at the programme. The familiarity of the researcher with staff, as perceived by the patients, may have led patients to under report dissatisfaction. However, having a thorough knowledge of the programme aided the research process as the researcher was able to ask specific questions about the programme.

The chronicity and disabling nature of chronic pain can be associated with patients experiencing depressed mood, anxiety and difficulties with concentration. In interviewing patients for the current research these difficulties were apparent in some cases. A number of patients appeared depressed and despairing, one patient commenting that he did not care what happened to him any more. Once transcribed, some transcripts appeared confused with patients having difficulty telling a coherent story. Patients tended to lose the thread in middle of sentence, changed tack, or forgot the point they wanted to make. In working with patients who have chronic pain it is essential to recognise that patients can have difficulty concentrating, and may get fatigued. It was important not to lead the patients towards the expectations of the researcher. It is hoped that examination of the available transcripts would demonstrate that this was not done.

FUTURE RESEARCH

- The next stage for the current research will be the formulation of statements for use in a pilot questionnaire about the therapeutic alliance as applied to staff and groups at the PMP. The current research has provided an excellent base from which to build a quantitative investigation of staff and group factors pertaining to the therapeutic alliance and the process of change in non psychotherapeutic groups.
- Research investigating how group dynamics relate to programme outcome and the maintenance of change by patients would be helpful. The use of a questionnaire design could include patients who do not feel they have made changes and did not benefit from being part of a group. It may be possible to identify which patients find group membership helpful and which do not. Linking these experiences to the maintenance of change post PMP would be helpful in designing and structuring patient groups at PMP's.

CLINICAL IMPLICATIONS

- The importance of group membership whilst attending a pain management programme has been demonstrated by the current research. Staff involved in PMPs will be aware of the group dynamics that are evident when they work with patients. Staff awareness of how significant the group is to the individual patient may be helpful in fostering group cohesion and group support within pain management programmes.
- In the context of an in-patient programme, the fostering of group cohesion is relatively straight forward. The challenge clinically is to consider ways of fostering cohesion in out-patient, non residential settings.
- In considering the fostering of group cohesion it is useful for staff to be aware that groups are not homogenous. That the majority of patients report helpful group dynamics does not mean that there may be some patients, possibly those who the group see as 'different', for whom the group is not as helpful.

- The helpfulness of group membership may extend to other diseases. There are support groups for most diseases. The current group was specific in that patients shared tasks and goals whilst at the programme. The benefits described by the group in the current research may extend to other areas of health psychology, such as cardiac rehabilitation or programmes for patients recovering from Chronic Fatigue Syndrome.

CONCLUSION

“Any group process that provides members with a coherent system of values and relieves alienation and despair is a form of psychotherapy” (p244, Frank and Frank 1991). This statement was born out by the current study. Although treated in a group to facilitate treatment delivery, it seemed that group membership was an vital factor in helping patients make changes whilst attending a PMP.

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Chairman - Dr G du Mont
Administrator - Ms S Hirsch

21/10/1999

Ms R Allen
INPUT Team
Gassiot House
St Thomas' Hospital

Dear Ms Allen

**EC99/168 A qualitative, prospective study of the process of change in patients
participating in a residential pain management programme**

Thank you for your correspondence dated 13.10.99 and for submitting a revised consent form as requested by the Research Ethics Committee. This is satisfactory and I am happy for the study to commence.

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

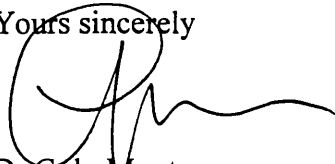
The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

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

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

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

Yours sincerely



Dr G du Mont
Chairman
Research Ethics Committee

September 1999

Dear Patient,

We are conducting a research project during the 4 week INPUT programme. The research involves being interviewed and completing two short questionnaires. We are doing the research to get an impression of what it means for patients to go through programmes at INPUT. We want to explore what is particularly useful for each patient as well as what is helpful and is not helpful in making changes to lifestyles. We are particularly interested in how you find the people at INPUT, both the staff and fellow patients. The research will inform the ongoing development of the programme and help us plan staff training.

The interviews/questionnaires will include questions about:

What has changed/not changed since starting at INPUT.

How you find the staff at INPUT.

What it is like to be part of a group of patients with chronic pain.

The research involves two interviews, one during the second week at INPUT and one during week four. The interviews last about 30 minutes each and will be scheduled either on Mondays, Tuesdays or Wednesdays. The interviews will not coincide with INPUT teaching sessions.

The interviews will be audio-taped so that they can be analysed in detail. There will be no details of patient identity on the tape. All the information gained in the study will be **confidential** to the researcher and the head of research, Dr Amanda C. de C. Williams.

Your participation is entirely voluntary and you can withdraw from this study at any time. Participation (or non participation) will not, in any way, influence the care, support and follow-up you receive at INPUT.

Ruth Allen
Research Psychologist &
Psychologist in Clinical Training

CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS & CLINICAL TRIALS

Title of Project: A qualitative, prospective study of the process of change in patients participating in a residential pain management programme.

Principal Investigator: Dr A. C. de C. Williams Other Investigator/s enrolling patients: Ruth Allen	Ethics Committee Code No:
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Outline explanation:

Dear Patient,

We invite you to participate in a study we are conducting assessing what it is like to take part in the four week residential pain management course.

We are interested to find out how helpful you find specific aspects of the programme. For example, are the staff understanding, or how useful is it to meet other people with chronic pain? We are specifically interested in how useful these aspects of INPUT are in helping you to make the changes you want to. The results from this research will help us with the ongoing development of the service we offer to patients.

Taking part involves two interviews, about 30 minutes long each. There are also two brief questionnaires. The interviews will be in the second and fourth week of the INPUT programme and will not interfere with INPUT activities. The interviews will be audiotaped so that the researcher can transcribe them. The research is strictly confidential and the identity of participants will only be known to the researcher.

Whether or not you decide to participate, this decision will in no way effect the treatment you receive at INPUT, now or in the future.

I (name) _____

of (address) _____

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

SIGNED (Volunteer)	_____	Date	_____
(Doctor)	_____	Date	_____
(Witness, where appropriate)	_____	Date	_____

The Empathy Scale

This questionnaire asks you to consider the staff in general at INPUT. Please tick to show how strongly you agree with each statement.

	Not at all	Somewhat	Moderately	A lot
I felt that I could trust the staff today.				
The staff felt that I was worthwhile.				
The staff were friendly and warm toward me.				
The staff understood what I said during today's sessions.				
The staff were sympathetic and concerned about me.				
Sometimes the staff do not seem to be completely genuine.				
The staff pretend to like me more than they really do.				
Staff do not always seem to care about me.				
The staff do not always understand the way I feel inside.				
The staff were condescending and talked down to me.				

Group Climate Questionnaire

Read each statement carefully and try to think of your group AS A WHOLE. Using the rating scale as a guide, tick what best describes your group during today's sessions. Please mark only one answer for each statement.

Rating Scale: 0 Not at all
 1 A little bit
 2 Somewhat
 3 Moderately
 4 Quite a bit
 5 A great deal
 6 Extremely

	0	1	2	3	4	5	6
The members liked and cared about each other.							
The members tried to understand why they do the things they do, tried to reason it out.							
The members avoided looking at important issues going on between themselves.							
The members felt what was happening was important and there was a sense of participation.							
The members depended on particular people within the group for direction.							
There was friction and anger between the members.							
The members were distant and withdrawn from each other.							
The members challenged and confronted each other in their efforts to sort things out.							
The members appeared to do things the way they thought would be acceptable to the group.							
The members rejected and distrusted each other.							
The members revealed sensitive personal information or feelings.							
The members appeared tense and anxious.							

Appendix VI

Patient. 07

INTERVIEW 1

Int. So the first question is, what has or has not changed since you've been at INPUT?

07 Medication to start with. Today I'm down to one dose of tablets a day (**Int.** ...and that was from?) That was from 3, but they was both tablets that I was really worried about. I was on IBrufen 600 and Gavipentium (??). That one worried me 'cos I didn't really understand it 'cos it was like an epilepsy drug.

Int. So when you say worried you, you didn't really want to be on them?

07 No. I knew with the IBrufen like it can cause ulcers and things like that. I mean I've had things in the past like gastritis, on a different drug, but I seen so many people made ill through drugs. And I did actually work out at one stage, two years into my back problems, I'd taken in excess of three thousand eight hundred tablets and that was like four years ago so you know I was concerned about taking tablets.

Int. So what helped you make the changes in terms of your tablets here?

07 Well basically I was scared to stop them because the pain being so severe and...

Int. When you tried to stop before? Or just it had been so severe..?

07 Well no, the pain had just been so severe and they'd put me on these tablets. My consultant had tried to mix in Amitriptyline with them, but it just made me comatose. I was.. you know the way to stop

the pain was to knock me out cold for days on end and I, that wasn't good you know. And erm so they said they was quite happy here that I come off them so I dropped one dose last week and I've dropped another dose today. Touch wood, I'm OK so far...

Int. And how does that feel?

07 Great. I want, I feel dozy all the time on the tablets and I want to feel like, I mean my senses I mean, you know I'm aware of whatever's going... I mean I'm doing a college course, and I'm sure a lot of things go over my head that I'm not really concentrating on.

Int. What are you doing at college?

07 I'm doing GCSE maths and English and computers.

Int. You'll need to be able to concentrate for that!

07 Yeah, so I really am pleased that, I know it's the first day, but hopefully it'll be OK.

Int. And it feels sort of OK to do that here?.. I guess because you've got someone saying it's OK to do it?

07 Yeah, that's right. I don't know what effects drugs have on you, you know if you just suddenly stop 'em. What are the withdrawals or whatever, whereas here they know what they're talking about so I was quite happy to try it.

Int. Have you talked to other people before about stopping drugs? You know your GP or other hospital doctors?

07 My GP is a total waste of time. He's er, he told me basically, this is as good as it gets, I've got to learn to live with it and that's it. Erm my consultant, he's very sympathetic, but it always seems, well we'll try this, but if not have another operation and I've had three, and if they haven't got it right by now they're not going to get it right next time and the next one he's talking about sounds so horrific I don't want it anyway. So you know, basically I think if they told me I had to stand on

me head on top of the building I'd try it just to see if it worked
(laughter).

Int. So other than medication, is there anything else that's changed since you've been here?

07 I think me stamina's gone up.

Int. Your physical stamina?

07 Yeah. Erm, I'm very tired but I think that's purely, like, I mean I don't sleep very well at home, but I think where you're being bombarded all the time with you know all the different things you're going and hear about and then like Big Ben chiming all the time, I think that's.. and plus I'm doing more, I'm doing, where I might say I go to college I'm doing things mentally, here you're doing much more physical stuff..

Int. ...and four days..

07 Yeah. I mean 8.30 'til 4 yeah. That's right, I mean my full day at college is 9.30 to 2, so it's nothing like this. So, no so I'm really pleased. So far I'm pleased with everything.

Int. So in your stamina increasing, is that because you're stretching and doing exercises you haven't done for a while?

07 I was doing exercises with the physio like back at my local hospital but then the physio department shut down to make way, they're having the accident and emergency revamped. She was moved out to another hospital which meant I could only get to see her once a month so you're sort of given some exercises and stuck with them for a month. Well basically after INDISTINCT. I did my best to keep up with it well then I had a really bad set back and from there on I done no exercises, I just got totally out of the habit of doing it and I've not got back into it until I come here. I must admit working with V did help, when I was at a really low ebb like she sort of egged me on all the time to, you know try and stick with it, erm but as I say I do feel better for doing exercise.

Int. And was it OK to start exercising having ducked out for a while?

07 Well, yeah. I mean you're not expected to jump in and do like a 100 push ups or something are you, it's, if you do one you've achieved something so you just do whatever you can.

Int. So it's helpful is it, that it's actually very much sort of..

07 What you can do, yeah that's fine.

Int. And how about the pacing and stuff has that been helpful? Are you a great driver or actually do you don't overdo? Mind you that sounds like long college days...

07 I do overdo it 'cos I think "oh I can suffer this a bit longer" and I can overdo things but with that on the weekend I was using the timer all the time and that.

Int. Driving everyone mad?

07 Well, it ended up, everyone was so pleased they could all see a difference in me that everyone was helping me with it. We went to friend's for drinks and like all of a sudden it was here goes the buzzer and everybody stood up. It ended up really quite fun and we were sort of toast the queen and it did... They just all said they could see a difference in me which was so much encouragement.

Int. And what difference could they see in you do you think?

07 My husband, he reckoned I was hyperactive. (**Int.** Beforehand or this weekend?) This weekend, there's not been much activity in me for years (laughter). Erm, my son said the "stretch" had gone out of my face. Now what does that mean? But thinking about it where I'm always in pain I've always got a constant frown on me face and I didn't.

Int. Do you feel more relaxed maybe?

07 Yeah.

Int. What's that got to do with do you think? Coming here and going home, and people seeing such a change in you. 'Cos it sounds like a big change that everyone's noticed it..

07 As I say everybody's noticed it and I mean it just makes you feel, you know, I must be on the right thing here if they're all noticing it as well. I just, I really, I'm very very tired as I say and Friday, I had loads of plans but basically it was near enough catch up on sleep and just take it easy. But erm, I did, everything, I did do everything I'd planned, it was in a sort of different order. And er, I mean we went shopping on Saturday morning which normally meant tablets, shopping, erm home again, more tablets, lay down for the afternoon. Well it was shopping, home, lunch, out again, fine. It was just, it was like having a life again, not just having sort of 2 hours to go out on a Saturday and that was me for the week, that was it.

Int. So how have things been "up" so much would you say? 'Cos it sounds as if things have been "up", do you know what I mean, things aren't quite so..?

07 Yeah. Erm. I don't know, perhaps it's having other things to think about, you're not concentrating just on that pain, you're concentrating on doing the pacing and all the other things that the pain, the pain's not building up so much. I mean the pain's still there but it's not getting, where it used to get that unbearable. Another thing, me teeth didn't ache, I'm forever grinding me teeth like with the pain and I suddenly realised that I'm not doing that anymore.

Int. So I guess it might be something to do with actually knowing you can do something...

07 Yeah. I think, as I say Saturday's been, well I got to go shopping, you know at the end of it the afternoon's wiped out. But we did it and you know I was quite capable of doing other things and that just sort of thing, well Sunday you know I can do so and so, it just give you that encouragement to carry on a bit more.

Int. So maybe seeing that you can do something you thought may be more difficult gave you the confidence to then, the encouragement to then try something else?

07 Yeah, to do. Yeah, but you know, as I say, I used the timer all the time and I rested when I was supposed to and just by being on that even keel. You know, the whole pain pattern of up and down that is me all over. On a good day I want to climb Everest and on a bad day I'm on the floor, that's it. So as I say I think Saturday I did meet it, I really did meet it half way.

Int. I've got this lovely picture in my head of this wonderful cocktail party with everyone getting up when the timer goes off. It sounds excellent.

07 It was, it was funny.

Int. Getting other people on board is really helpful, isn't it?

07 Yeah.

Int. Did you spend a lot of time explaining at the weekend, to people, what it was all about?

07 I've had, very supportive, like they're neighbours but they're good friends you know, I mean they've been up to the hospital visiting me every time I've been in hospital and they all know when I've had set backs and whatever and so when I told them about the course they was as enthusiastic for me to come on it as me and my family were. And erm as I say the first thing, Friday it was like "oh come in tomorrow night have a drink" and you know tell us all about it. So it was really nice just that people are there for you.

Int. Yeah. And how about the psychology side of things that you've had over the last week and a half, has that made sense or is it all a bit...

07 It's very logical when you sit and think about it all. I mean, my husband actually, he didn't realise how the pain does effect you. I mean he'd say "you miserable cow" and I'd say I'm not miserable, you know,

but it's the pain that does it. But no, so listening to psychology it is totally logical.

Int. And have you been able to tell him a bit about the links and explain it to him?

07 Yeah. Yeah I say when the pain's bad your mood gets lower and lower and the worse you feel the worse your pain feels and it is it's just a cycle and you go round and round and round, yeah.

Int. And can you identify ways, I mean I don't know how you think but, does it sort of fit in with having thoughts that aren't really that helpful?

07 Yeah. Well basically the whole reason I went to college, I'd reached such a low ebb after the last operation they'd assured me that like this was the one this was going to put it all right and I've always been one, whatever I'm told to do I will do it, so that they can't say, you know, we told you to do that and you haven't done it. I do it. And when I went back in January, well I didn't, I crawled back, I was in such a state and er they more or less told me it was in my mind, and I went mad. I said you know, it's not my mind I'm quite sane this is terrible pain and it's worse than before and in the end I was so fed up of it I went for a second opinion and they told me exactly what was wrong and then it was like well I've had three operations they want me to have this megga one, say it gets worse than this? I couldn't stand it worse than this. So I was going, I really was going on a downward slope that I thought what's the point? And just by chance I got to hear about this college course and that was purely why I enrolled just so I weren't grounded (branded?).

Int. So actually to stop yourself going further down?

07 Yeah. Don't matter what pain I'm in I've got to get up, it's a hard slog, I've got to do it. I mean I had a real bad set back two weeks into the course. They have been so brilliant like, erm setting homework,

and all different er reading and that, that I can do and I've caught up with it. Well I mean now, I mean, I'm doing, it's hard doing homework now that I don't know what the work is and I've got homework here so I feel like I'm always writing but I'm going to stick with it and I'm going to pass them exams. So I did recognise that I had to do something otherwise I was gonna, I was really gonna be on the skids. So thankfully I chose the right thing to do.

Int. Do you find the logicalness (!!) of the psychology stuff useful, I mean do you use it at all at home at the weekends, thinking...or is it something that is easier to see on the board?

07 It is easier to see on the board, I mean, you've basically got to come to the terminology like this cup is not half empty, it's half full. You know you've got to think like that all the time. It definitely makes sense. So it will be interesting when I am in a flare up whether I can think that way but until, I mean we've done our first aid plans today so it's just a matter of, I mean please God I might not get a flare up for ages but it's just then putting it into practice and seeing what does happen.

Int. So you've made loads of changes haven't you..

07 I think my whole attitude has changed... over the last week.

Int. What do you think the most important aspect of INPUT has been in helping you make those changes?

07 Being understood. You know, as I say, the hospital more or less said to me I was imagining it. Me doctor said well this is as good as it gets, like get on with it and that's it and you think, I could, I remember sitting there once saying look I'm 42 I'm not 72, I've got, please God, another 30, 40 years in front of me and if this is as good as it gets what's the point? So, as I say just for people to understand what pain is, understand when you're on a low or whatever, it's, that is the main thing.

Int. And how about the staff at INPUT, how do you find the staff at INPUT?

07 Fine.

Int. Do you see them as a team or more as individuals?

07 Mostly as a team, I think.

Int. And you feel you can ask them...

07 Oh yeah, I wouldn't be worried about asking them anything.

Int. Have you been in a situation before when you've been OK to ask things about your pain?

07 What do you mean here, or outside here?

Int. Outside here.

07 Well no because as I say basically with hospitals it's well you've had your operation that's it. You've got to get over it now and as I say the doctor he hasn't got a clue, he's erm...I can't, I just get cross.

Int. I'm sure you've talked to other people in the group and realised that most people here, don't have great faith in their GP's.

07 No, not at all. But there again I mean they're not specialists but erm I think a sympathetic ear now and again goes a long way. I really do.

Int. And from what you've said particularly in terms of being here and the fact that you're understood...

07 Yeah. When I had that set back, we phoned him and he said well go to hospital. I said I can't get out the bed, get an ambulance and that was it, end of conversation. He didn't want to know any more. We got to hospital and there was a 5 hour wait. I couldn't sit there 5 hours. It ended up, I mean I crawled in and said look you told me I need an injection, when you going to do it. Oh in a minute, in a minute. I stood it for two and a half hours and in the end, in tears, my husband took me home, I said I'd sooner lay in bed and suffer in bed by myself than sitting in the casualty, just waiting for a pain blocker. They weren't

going to find out the reason for the pain. So, as I say there is nowhere to go outside of here, there's no one. Even down to the pain specialist I go to, he's not particularly sympathetic. You know he's given me epidurals, he's given me like the beta blockers and er I actually felt when he sent me here he basically washed his hands of me. He does want to know what happens but erm it was actually his nurse who was so enthusiastic she'd been on the course in Liverpool. And she kept saying to me, get on that course she said, it's the best thing you can do. And er like as I say she, I've gotta let her know how I get on. With him, I see him next March sometime. But er as I say, unless people really understand pain they haven't got a clue, not at all.

Int. So staying on the theme of the staff have you had any keyword sessions yet?

07 Yes, with L.

Int. And have you found those particularly helpful or are they an extension of what you've been doing during the day, or are they space for you to talk about other things?

07 Yesterday, I saw her yesterday that was quite helpful. 'Cos we suddenly realised that I don't rest enough. You know I'm doing all the pacing and the exercising and everything and I forget to rest. We worked it out, out of a, I think a 16 hour day I only rest for about an hour or so, or something silly so she said I must rest 20 minutes every hour. And take it from there. I've never actually looked at my day, or mapped out like that and thought oh right, well I don't really rest. At home I mean, if I was in pain that would be it. I'd be laying down for the afternoon but er, since I've been a bit more active I'm not doing it, no.

Int. At the moment it sounds as if you use keyword for more, very much things to do with INPUT, would it be helpful to talk about more personal stuff?

07 Well yeah. To be honest there's a situation at home, I got these exams coming up, we had a memo come round last week, is there any students who won't be able to sit for two and a half hours. And I thought Oh blimey how am I gong to manage that? So I told her so she said don't worry, I'll, remind me next week and I'll get a letter written out about that. I did actually ask her, I know someone who is in a desperate pain situation and their doctor's never heard of INPUT so I asked for some information. I didn't realise there was some out in the foyer area. Yeah, she told me to go out and get that and I go the information and hopefully it will help someone else out.

Int. Do you know many people with chronic pain? You mentioned someone there that....

07 This is a friend, or er a brother-in-law of a friend of mine. Erm I was telling her last week about everything that had happened and she was saying she was so worried about her brother-in-law, like he's getting to suicidal and er she said it sounds like what you're doing is what would suit him, so I said well, I'll find out for you and see if it can help him. Funnily enough, one of the patients, no, ex patients, there's a letter up on the wall downstairs he wrote. He's running a support group near where I live. He's also doing something else, it must be based on what he's learnt here, I don't know what other counselling he knows or, but he's running some sort of course at the hospital A recommended that I go on. When I phoned him up and told him I was waiting to come in here, well he said you don't need my course, like you're going for the real thing, he said do that but then come and see me once a month as like a back up. So, it's nice to know that there's someone else there, like any problems, you know, I could get in touch with him.

Int. And how about coming here and meeting all these other people with chronic pain, what was that like?

07 That was OK 'cos you realise you're not on your own. You're not the only one. We've all got something in common.

Int. Do you think everyone understands each other?

07 Yeah. Yeah I think we're all sort of sympathetic to one another. Erm in the different situations, as I say one thing we've all got is years of pain behind us. It's just a waste of life isn't it? I feel really strongly, you know, that every, every hospital should have this type of unit in it. I really do. You know, as I say when you think you have an operation and they say oh you need physiotherapy, you wait 6 months to get that, by which time like the damage is done, isn't it. So the more, we had the talk on the healing process, and the more she went into it I thought, well, what a waste, the time I've spent at physio and everything 'cos all the rot had set in so it was just a waste of time then.

Int. And do you feel angry about that, or what feeling do you have about that?

07 Yeah, I mean I'm angry with the whole situation actually as it started because the first operation I had I felt was very successful, 'til 8 weeks into it when one of the bolts fell out. And I've never been right since. They put that back and then they, a nerve got caught up. After another 18 months they said well, we've got to sort this out, and they did that and as I say now I'm worse than I was before. But as I say I am angry, I mean how can a bolt fall out? If they hadn't put it in properly, that's the only way it could fall out. But you know, that's going into years of litigation to try and prove anything like that and I just want to get over it and

Int. So, as a group, the 10 of you, do you feel that you all get on?

07 Yeah, I think we all encourage one another. Erm one of the girls today was having quite a bad day and we was sort of you know all supportive towards her. Sort of don't give in, just stick with it, get on with it.

Int. So would you hope that people would do that to you if you were having...

07 Yeah. And I think everyone feels the same like if, we'd all support one another. And I feel everyone is putting, there was a couple of doubts, different ones I spoke to I think when we first started, but everyone's', I think all the doubts have now diminished and everyone can see the improvements.

Int. Was it OK to hear people talk about doubts initially or was that a bit worrying?

07 First of all I thought to myself oh you know, why come if you've got doubts, if you don't put 100% in you won't get anything at all out. When I went in for my interview I said look I'm totally open minded. If at the end of it I think it's a load of rubbish, well fine but you know, I'm here I want to get better, well not better, I want an improvement in my life and I'm prepared to try anything you tell me to do. And as I say so far, you know I feel like I have improved quite a bit.

Int. And do you think support from people with chronic pain is more helpful than support from other people?

07 Yeah because they know what it, they know how, a stupid little thing to anybody else is such a major step for you. Erm as I say they just understand what it's like and how debilitating it is all the time and you think it's just there you never, you never ever go to bed and think oh I'm comfortable and wake up feeling oh right lovely. It's like aches and pains and pricks and groans and you, and every day it is a slog. (**Int.** It's exhausting) Yeah. But erm, as I say you know, it's nice that the group all actually get on. I think this week we've sort of all settled down we know each other's ways and we're all pretty supportive.

Int. And how about meeting the two weeks above you?

07 The first thing I asked them was well what do you think? Erm all barring one, that was all good feedback. There was only one of them,

not so strong on the idea but as I say all the others, they were all pretty positive.

Int. And is that helpful, to sort of see some people who are two weeks down the line?

07 Yeah. 'Cos you can, I mean this week like I've been very, very tired, and they all say oh that's normal. Like next week it will be a little bit easier. So you think oh well that's OK then I can, this is normal, fine.

Int. Well that's about it, is there anything else you'd like to add about your first two weeks here?

07 I'm just really pleased, I'm going with the flow and I'm just whatever they tell me I'll try. But tomorrow I'm gonna try and walk across Westminster Bridge. If I do that it will be a bloody miracle, but I'm gonna give it, and I got a feeling I'll do it. 'Cos I had a little walk today, the same walk last week I could barely get a foot in front of the other, by the time I got back, I did it today, and I thought oh that was really quite comfortable. So as I say tomorrow it's out activity and I'm going to try my best to get over that bridge.

INTERVIEW 2

Int. So have there been any changes since you came to INPUT?

07 Loads. I'm totally off my medication. I'm getting about, indoors on, not using the stick at all. I still feel I need to take it outside, just really until I'm more confident and people are more aware that, of you. People do barge about and knock you over so I feel happier taking that erm. I feel so much better being off those tablets, I feel like I've come alive. Rather than being fuzzy all the time. So that is the biggest one. I mean I've done a lot, I've been shopping and everything and paced it all and used the timer and it worked. I actually went out Christmas shopping for 6 hours which I, it was too much at the time I thought, but I did keep stopping and resting and everything and I got home and I had a little rest and I was fine.

Int. You were very good I remember when we first met, about using your timer with friends at the weekend.

07 Yeah. It really, you know, it was just amazing really 'cos I really did expect to, oh I thought I've really done too much now that'll be it, but I was as right as rain. Still obviously got the usual pain but whereas it would have gone sky high and that would have been it next day, bed-rest most of the day, I was OK.

Int. And do you feel fitter in yourself?

07 Yeah. A lot fitter. I mean I was having physiotherapy erm from the hospital but that was sort of once a month, you know, and review the exercises and it was the same exercises over and over again and that didn't start until 3 or 4 months after the operation anyway. And then er, 'cos they were doing up our hospital it had been moved to another hospital that was miles away so it wasn't really.. although she was a very

good physio I felt, it wasn't really, you know suitable so.. this I really find, this is brilliant.

Int. And has the stretch been helpful as well?

07 Oh yeah.

Int. And how about the thoughts and feelings, has that been...

07 Yeah. It puts everything into perspective. Actually I think the best one was probably the worst one which was the one where they actually come across that it is like a bereavement and they was going through the seven stages of bereavement or whatever it is. Now, I mean I did go through bereavement counselling when I lost my mum and that so I knew what that was all about and then when you stop and look, at what having chronic pain is like you can tally it all up and that made an awful lot of sense that one. How angry you get, and all the rest of it. So after that one I did actually feel better I think. So it did, it put everything into perspective that did.

Int. So the idea of getting towards acceptance...

07 I think that's the hardest thing 'cos all the time you think oh well next time I go to the hospital perhaps they'll do so and so and you think I'll be all right after that. And it don't, it just goes on and on. So I think now that I've accepted it, I know what me limitations are and just, you know, just get on with it now. Not keep waiting for this miracle cure that's never, ever going to happen.

Int. When you first came here did you think there was a miracle cure?

07 No. (**Int.** So you knew that already) Yeah.

Int. So what is it about INPUT that has helped you to make all these changes, do you think?

07 Erm. I think one thing you're with people, we've all varying degrees of disability but we've all got the same chronic pain. So everyone understands one another. Erm, the staff understand what

you're going through. You know you go to hospital and basically you're a number, if they give you tablets and it makes you go asleep and you don't matter 'cos if you're asleep you're not suffering pain and so they've done their job. That's basically it. But here it's giving you a life not just an existence. So, all supporting one another. It is very much a bubble, I mean it's gonna, it's still gonna to be very hard in the outside world to get everything into practice. In a way this has been like a 4 week holiday, you know you've only got yourself to think about, there's no outside pressures whatsoever. So, I can see it is going to be difficult but I think we've all learnt that it's time we had an hour or so to ourselves every day. You know, the world won't stop if we haven't done the washing and the ironing or whatever. So I think, I think that's it, it's just getting everything into perspective.

Int. So that's what coming here has helped you do?

07 Yeah.

Int. And what's helped you get things into perspective here do you think?

07 Erm. I think the main thing is accepting that this is it. And then building on that and so the exercises and stretches they do, the definitely work and the timer. So by that first shopping trip, that was it, I know I'd cracked it then once, I mean I never intended going out as long as that and to do it and be fine, that was it.

Int. And how about your husband, does he see a change in you?

07 Oh yeah. Every time, you know, each weekend he says you're walking faster, the pain's gone out of your face, you look better. So, all the family has noticed.

Int. And is it just the physical stuff they've noticed or anything...

07 I think a lot of the emotional things is down to tablets, I really do. 'Cos as I say, most of the time you're just fuddled, you know. And I think, you know coming off of them I feel like me old self again. You

know, often like we'd be sitting there and he'd say what's the matter with you you miserable cow and I'd say nothing. But I'm not sort of sitting there laughing all the time, most of the time I'm gritting me teeth thinking oh I wish this bloody pain would go away. But he did come up for the family day, and so he's a lot more, although I mean he's been very strong and he's been very good, he's a lot more aware of, you know, how we feel and everything. I've leaned not to be, to expect them all to be mind readers. Erm there was a stage were I used to, I got sick of hearing myself say look I don't feel so good can you do so and so. I wanted them to volunteer to do it which don't happen. So I've learnt now if I need help I've gotta ask for it not just sit and think oh why aren't you getting up and giving me a hand doing this or whatever and winding myself right up about it which makes the pain all the worse and so you're back on the circle again.

Int. So it's having lots of information while you're here that has helped you to.. such as information about pacing and the timer and stages of bereavement and so on, is there any other aspect of being here, other than being in a bubble and not having other concerns, is there any other aspect of being here that's helped you make the changes, or does that sound to be...

07 I think it's just the whole thing is just so well structured. It really is. I mean the first week, the first day you think God, what is this all about, you're just totally bombarded. But I do think you've gotta come in and be prepared to have a go it's no good coming here and just sitting back and not participating you know, I can't do that, that hurts, you've got to have a go. But if you don't give it 100 percent you won't get anything out of it at all. You have gotta be, definitely a willing party in it. But I mean we've met one lady on the first course who didn't want to be here and she went away with nothing I think. And there's one last week who should never have been here, but she didn't come back so

..We all said the same it was the end of the road, this was the only place we had to come, so we woz all prepared to give it 100 percent and as I was saying if you do you get your reward out of it.

Int. How about, is there anything that hasn't changed having come to INPUT that you had hoped would change?

07 Erm....no, I mean it would be lovely to think the pain levels went down, but they don't, perhaps that does come later, perhaps with relaxation or the fitter you get perhaps they go down, I don't know but as I say my pain level is exactly the same, but I'm not increasing it. You know, going into the overactivity, underactivity cycle so (**Int.** And you're not taking any medication) Well this is it, I feel exactly the same and I'm not taking all that junk. I was first of all, I thought oh say if it gets really bad and I need a tablet, what am I going to do? But now I realise I'm still at the same, I'll probably get the benefit of them paracetamol whereas before I was on like strong stuff that wasn't doing anything so as I say we've got all our set back plans and all the rest of it so if push comes to shove and I have to take a few paracetamol perhaps they would help.

Int. And how long have you been off all your medication?

07 Totally....a week today. I think I had a little bit of withdrawal at the weekend, I had a really funny turn in the supermarket erm, I managed to get through it with the relaxation methods they told us. I mean, I think if I'd have carried on I would have been ill by Christmas with the tablets 'cos I'd got to a stage of really, really bad heartburn. When that happened before, like within the next couple of weeks I got really bad gastritis so I think I would have quite easily been ill over Christmas if I hadn't got off of them.

Int. How about the staff at INPUT, how have you found being with the staff and having them around?

07 Great, they're all so understanding, they...everything you do they encourage you. You know, it's not "you're not doing that", "you're not doing enough" like, I always feel with doctors it, at home, you're not a nuisance, that's not the right word, but they've tried everything and you know there's, what else can we do like... (**Int.** They don't know quite what to do with you?) Yeah. Whereas here, this is just a fresh challenge all the time and as I say I think they're excellent.

Int. And do you think they understand you?

07 Yeah. Different problems I've spoke about they've all been very good.

Int. How about keywork sessions, have you had many?

07 I've had a few, yeah.

Int. And what, do you find them helpful, do you tend to talk about INPUT related stuff, personal stuff or a mixture of the two.

07 A bit of both really. I'm waiting at the moment, L is doing me a letter 'cos I've got some exams to sit so erm they're like 2 and a half hours but I'm not going to be able to sit down for 2 and a half hours so she's going to do a letter so I can have breaks after every 20 minutes. And take it from there. That's going to be a struggle, getting back to that college work. It really is 'cos I've not been able to keep up with it being here, it was too much. I didn't go into college the first week here 'cos I was too tired and I've missed some of the handouts. But I thought it's silly putting myself under pressure here this is the most important thing. If the worse comes to the worse I can just re-sit all that. Plus, I mean now I'm off the tablets perhaps it might all come so much easier when I go back. I was saying today, the notes O write when I read them afterwards I don't remember that, and I don't, so perhaps you know I'll be more observant and everything in the actual lectures. I would sit there yawning, waiting for a break even though I did enjoy it. So as I say, maybe it will be more easier.

Int. How about being part of the group and that, I mean you seem to be a very cohesive group.

07 We get on really well.

Int. Has that been of use when you've been...

07 Very much so, we've all supported one another. Different ones have had flare ups and set backs as I say we've all supported, I mean, tonight the whole idea was we woz all going out for a drink but there's 3 of them who can't manage it, so all right if we can't do that we'll go in the lounge and buy some bits and pieces, we've only got lemonade, which most of us would have drunk in the pub so that's what we're doing. I mean like different times of an evening some of us will go over the canteen and we'll see others in the lounge and that so we have got on quite well.

Int. And has it helped you make the changes at all, having people round who have the same.. position?

07 Yes, as I say, we're all sort of pulling together and you're all trying the same things together, so obviously, it is when you get home that that is going to be when it hits you and you've suddenly got to start fitting your own life round it all. But erm, as I say here it is definitely much easier like that.

Int. Do you think everyone within your group feels very much part of the group, everyone understands each other?

07 Yeah.

Int. And what was it like when the junior group arrived, forgetting the issues that happened with particular people in that group, but just what was it like being the more senior group?

07 At the start we woz all giving them encouragement you know don't, don't worry about the first week you're gonna to feel like you don't know what's going on but it will all click at the end of the week and warned them they woz all going to feel dead tired and all that. So

that was OK. You do feel a bit, erm how can I say, the first two weeks you're so bombarded and then all of a sudden it relaxes and you do feel a little bit sort of lost, I don't if that's the right word lost, erm like you start having circuits and stretch, self-stretch, suddenly like, there's no one there to keep an eye on you, but we all did it! You know, we were sort of taking it in turns to be at the front of the class and we carried on. All right we might have counted, did our counting to whatever number it was, a bit faster then the actual physios and that but as I say we did it. But erm, no I say there was no, you know the problems, but there woz no, any, nothing really to adjust with er, when this other group came in.

Int. Going back to the problems that there were when this other group came in. What do you think the impact was of having particular people in that group, was on your group?

07 We were so tense. Lunch times were terrible, absolutely shocking. (**Int.** That was when of course all 20 of you were together...) That was when everything was going off. Erm, I mean people were getting really angry and you know it was getting to a state where we're not going to hold out tempers any longer, she's gonna get it.

Int. So what was tense about lunch time?

07 Well you just knew that as soon as she walked in she'd want someone to stop and help her, and then do this for her and do that for her and it was just, we're all disabled you know, but nobody had a disability as bad as her (sarcasm) or was as ill as she was and all the rest of it. She would not do a thing. And as I say it got everybody's backs up, it really was an awful atmosphere.

Int. So how soon did that tap in?

07 (laughter) The first morning. I'm not joking she hadn't been here, I don't know if it was the tea break or the lunch, walked up to the kitchen and er "I can't open that" will someone open, what wound us all up was she's so bloody ignorant, there was no please, thank you,

nothing. “Open the door”, so we let her in and we all sat down and we woz chatting and there was bang, bang, bang on the door and she has the strength to bang on the door, not to open it. “I can’t get out”, someone let her out and then it continued and in the end we started ignoring her, or leaving her locked in the kitchen. But I don’t know, she had the strength to do things that suited her. But not, I don’t know perhaps she was used to having servants around, I don’t know. Her whole behaviour, she should have been thrown off that bloody bridge into the water. Oh, she was, really, and it was just so awful, ‘cos we woz all saying to the other group “don’t let her wind you up” ‘cos we could see them, really, going on the skids. I mean it was bad enough for us and she wasn’t in our group. Erm, but oh.

Int. So how did you manage it?

07 Well in the end we all kept saying to everyone “keep calm, keep calm”. At lunch times it was basically eat your meal as fast as you could to get out of there. It was awful. It was, I mean there one day, one of the erm psychologists was trying to get her to put her dinner from the trolley onto, from the food trolley onto a kitchen trolley, well she wouldn’t have that. Then there was another day, four of us was talking to M, and she comes storming in, “the porter didn’t come and get me”. Now she should have started her class at half eight and this was five to nine and not, you know, excuse me. “Well where am I supposed to be” and J said well if you had your folder you’d know where you was supposed to be. And she just sort of looked through you as if, well the only, I think it was purely selfishness because the only person that mattered was her and it didn’t, that was it. But as I say I don’t know, I don’t know how she got here, I don’t know how they stood her, but I think it should have been nipped in the bud, I don’t think it should have been allowed to go a week. I really don’t And er as I say it could have

got, I think if you'd had a weaker group it would have made a lot of difference.

Int. Weaker in the sense of your group or the group..?

07 In both, I think, yeah both of them. And...

Int. Do you think your group gave strength to the other group?

07 I think, because we kept saying to them, you know like, "don't let her wind you up, keep going, don't let her get you all tense and ruin it for you". Erm, but I also think that if there'd been any other people, people more volatile than us there would have been rows galore. There really would and that would have been awful. I mean I can think of a couple of people on the group the week before, they would have wiped the floor with her. They really would. So, so it, it shouldn't have been allowed, she should have been, you know, after that first day if she didn't want to participate she should have been out. We've all got our own theories on why she was here but er no, she should have stayed back. It shouldn't be detrimental to the other 9 people, to have someone like that.

Int. As a group you dealt with it by supporting the other group and telling them not to get wound up. How did you stop it getting you wound up?

07 I just tried to turn off from it in the end. You know I just kept thinking to myself well she's a selfish about herself, I'm selfish, I'm here for me, I'm not bothered about her. But as I say it was getting really difficult. Lunch times was the worst, they really were. You were just waiting for what was going to happen like, who was she going to pick on. Because you daren't make eye contact that was the worst thing, if you made eye contact with her she'd hone in. Nasty piece of work that one.

Int. As a group do you think it made you more together?

07 It give us plenty to talk about (laughter). That was the topic of conversation. We were sort of placing bets with one another, well she probably won't have the neck to turn up next week, if it's harder next week we're just not putting up with it. But thank goodness she didn't come back.

Int. From what other people have said she was quite critical of the programme and staff and stuff like that. What was it like to hear that?

07 It was just so hard to keep me mouth shut. It really was 'cos you really felt like wiping the floor with her. But, it was getting everyone down, I mean one of the fellas in the other group he really had a go at her. He totally lost it. And er although everyone was saying like oh you know keep calm, keep calm I don't blame him, why should you have to put up with it? What annoyed us more than anything, it's so hard to get on this place, we all know people who would benefit from it and they're denied a place for the likes of her. Same with that woman on the last one, I should imagine she's gone back and told everyone what a load of rubbish this was, I cannot imagine her saying a single good word about it. Well to me, they know what we're all like down there (staff at INPUT), and if they pick up on that I think you should be out, I really do. There again I suppose once you've started the course it's had innit, you can't suddenly get someone to come in at the drop of a hat and do it but, it's just not fair, it really isn't. Thank God, she's gone. We haven't got to see her, she'll carry on having her bad neck, every part of her body that hurt. I'd love to see them try and get her off the tablets. (**Int.** Yeah, A was describing a great big bag of tablets..) Yes. It was like, she'd fetch out a plastic bag, like a kid's, you know like the pic' and mix in Woolworth's, it was like that. Oh she was an absolute cow, she really was. In actual fact on the Monday like my husband phoned, he said what's the matter you sound really down, so I said this has driven me mad today, we've got one who's a right stropy cow, thankfully she's

calmed down, she'd all right now, this other one, I said well I can only say she's a raving nutter, can't think of anything else to classify her as. No not a nice piece of work at all that one. As I say, it's awful suffering pain but, I even wondered if she was like a hypochondriac, she quite wallowed in the pain and she didn't want to loose it. We did hear a rumour she was coming back today and we was all ready for her. As I say it's purely the fact that there's some poor soul out there who would get such benefit from this and she's robbed them of that now. That is where it is totally wrong.

Int. We've basically covered everything, but I was going to ask, do you feel anyone in your group didn't feel part of your group?

07 No, we've all got on really well.

Int. Do you think people in the group below you don't feel part of the group at all, are there any people there...?

07 There's one young fella he seems to be a bit of a loaner but I think he's mixing more now. First of all he seemed as if he was on his own all the time but he sits with different ones lunch times and that so I think he is mixing a little bit more now. I mean the lady in the room next door, P, she was, she really went down, we thought she had real bad flu, I mean we've all knocked to see if she's all right, if she wants drinks and everything. So as I say I think we're all here, you've all got something in common, it's, unless you have a real total clash of personalities I think that would be about the only thing but erm, you haven't got, mix with them other than downstairs so...but as I say unless you get a real raving lunatic come in. Oh dear, she should think herself lucky she was in with us and not that last group, there's two of them I think they'd have tied her up and thrown her out the window (laughter). Well, we was positive, one night we saw her hanging our the window upstairs having a cigarette. Now if she could, if it was her, I mean we can't say for certain we was down here and it was up here but it looked

very much like her. Now if she was strong enough to open one of these (windows) and stand there hanging out the window smoking there weren't much wrong with her bloody neck and shoulders. You know she couldn't lift a tray but she could cut, she could lift a cup up, she couldn't put the cup on the tray to, in fact, that annoyed me, the fact that everyone clears away after them but her, every day it was left there. Now she wouldn't make any effort, if she took one piece at a time, no no, it seemed as if it was below her and you know she was expecting someone to wait on her all the time.

Int. Well that's it, I've got the same questionnaires as last time...