THE SOCIAL DIMENSION OF CHRONIC PAIN: PROBLEMS OF MEASUREMENT

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A thesis submitted in partial fulfilment of the
requirements of London Guildhall University for the
degree of Doctor of Philosophy

June 1997

ABSTRACT

The research question investigated was, can chronic pain be measured? Two commonly used pain measurements, the McGill Pain Questionnaire and Visual Analogue Scale were compared to individual accounts of pain obtained by semi-structured interviews with people who had rheumatoid arthritis. The research was part of a wider study of cultural differences in the pain experience. Forty patients (18 men and 22 women) were included in the study. There has been little research into patients own accounts of their pain and in particular how the measurements relate to their experiences. The findings in this study suggest that the pain measurements are both methodologically and theoretically problematic. For the VAS there were problems determining what the score was actually representing. By comparing the scores with the interview data it was found that the scores represented different aspects of the pain experience for each individual. For some it represented the intensity of the pain while for others it represented their unhappiness about the effect of the pain on their lives. For the MPQ, the words appeared to be interpreted differently by each individual and therefore raises questions about the validity of the weightings used.

Theoretically, the pain measurements were found to be problematic for several reasons. The main problem being the narrow definition of 'chronic pain' upon which the measurements were based. Through analysis of the interviews, certain features of the chronic pain experience were identified. The first is the importance of 'context'. On the one hand this includes 'factors' such as attention and expectation but more importantly it refers to the wider social context and its influence on the perception and interpretation of pain. In other words, there are different meaning systems which people draw upon to make sense of their experience. These form the 'lifeworld' - the background stock of knowledge which is used to construct a narrative. It is through constructing a narrative that self-identity is formed. Self-identity and the construction of self is an integral part of the way people make sense of and communicate the experience of chronic pain; the measurement scores and the interviews are not just representations of the pain but representations of 'self' - how the person wants to be seen by others. This is an important element which has been neglected in the construction of pain measurements and it is argued here that by quantifying the pain experience vital elements such as self-identity are lost. The issue then is not how to measure chronic pain but whether chronic pain should be measured at all. The argument of this thesis is that current pain measurements do not assist us in understanding and assisting those who live with chronic pain.

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GLOSSARY OF TERMS

FACES	Delighted-Terrible faces scale used to measure a person's affective evaluation of their quality of life.
MPQ	The McGill Pain Questionnaire
NHP	Part II of the Nottingham Health Profile used to measure the perceived impact of the pain/illness on the person's life.
NWC	The Number of Words Chosen (from the MPQ). One of the scoring systems used in the MPQ.
OFM	Other Family Member
PPI	The Present Pain Intensity Scale. Part of the MPQ; a number-word scale used to measure the overall intensity of the pain.
PRI (T)	The total Pain Rating Intensity score. One of the scoring methods on the MPQ. The sum total of the scale values of the words chosen from the MPQ word list.
PRI (S)	The total pain rating intensity score of the words chosen from the sensory category of the word list on the MPQ only.
PRI (A)	The total pain rating intensity score of the words chosen from the affective category of the word list on the MPQ only.
PRI (E)	The total pain rating intensity score of the words chosen from the evaluative category of the word list on the MPQ only.
PRI (M)	The total pain rating intensity score of the words chosen from the miscellaneous category of the word list on the MPQ only.
VAS	The Visual Analogue Scale

INTRODUCTION

The research question being investigated is, can we measure chronic pain? In order to answer this question, two commonly used pain measurements, the McGill Pain Questionnaire and the Visual Analogue scale will be compared to individual accounts of pain obtained by semi-structured interviews with people who have rheumatoid arthritis. Research into the field of chronic pain measurement means that certain questions will need to be addressed. The first being, obviously, what is pain, and in particular what is chronic pain? Medical and non-medical definitions and theories about the nature of pain will be explored. The next important question is what kind of interest does medicine have in pain? Theories about the relationship between medicine and pain will be discussed. Finally, how do we measure pain and how valid are the measures used? The most commonly used clinical methods of measuring pain will be critically examined in a further chapter, including the two methods being used in this study in order to see how well they measure the complex phenomenon of pain.

Until the 1950's, pain as a medical problem in its own right did not exist. Instead, it was seen as an inevitable accompaniment of disease and considered, as far as research went, as irrelevant. Wall & Jones (1991) suggest that one of the reasons why medicine largely ignored pain is because of the aims and priorities of medicine. In the nineteenth century and up until very recently, the aim was the diagnosis of the proximal cause of disease and treatment to eliminate that cause. As pain was viewed only as a symptom and not a cause of disease it was not considered important in nineteenth century medicine. But recently, medicine has shifted to trying to alleviate symptoms too (Nettleton, 1995). There has been a move in the medical burden from treating predominantly acute, life-threatening infectious diseases to treating chronic, non-life threatening conditions such as heart conditions, circulatory diseases and arthritis. Life expectancy is increasing and these chronic conditions are more prevalent in this ageing population. Chronic conditions are by their nature not amenable to successful intervention and so medicine is limited to ameliorative responses. One of the main symptoms of chronic disease is chronic pain and the focus has turned, therefore, to treating this major symptom.

According to medical science, (see Gracely, 1983), in order to assess the effectiveness of treatments for the relief of pain, numerical measurements have to be used so that comparisons can be made. The search, therefore, is on for a "gold standard" of pain measurement. The various methods that medicine is using in an attempt to measure pain will be discussed in the next chapter, but first it is necessary to see how medicine defines pain. This will then be followed by a discussion of other theories about pain and what constitutes the pain experience. This includes considering arguments that medicine has turned a normal part of human life, pain, into a medical problem with far reaching consequences.

Medical Definitions of Pain

For ease of discussion, the medical definition of pain will be discussed first. Until quite recently the "specificity theory" of pain has dominated much of the medical literature. Developed by Descartes in 1644, this theory explains pain in a straightforwardly sensory way. He conceived of the pain system as a straight-through channel from the skin to the brain, similar to the bell-ringing mechanism in a church. A man pulls a rope from the bottom of the tower and the bell rings at the top and in the same way, the pain signal travels from the site of injury and pain to the brain.

Kotarba (1983) outlines three paradigmatic reasons for the general acceptance of the theory by physicians:

(i) it fits the "one disease/one cause" perspective of traditional western medicine.

(ii) it is conducive to the traditional emphasis on surgical intervention in disease.

(iii) it is strictly physiological

The specificity theory of pain rests on a firm distinction between body and mind. Pain is designated as a bodily event to which the mind reacts. But since the 1960's, Melzack & Wall (1965, 1984, 1988) have challenged this theory, arguing that it does not provide answers to all the problems of pain. For example, the location of pain may be different from the location of damage; extremely serious injuries are sometimes accompanied by no pain sensation; extreme pain can be experienced when only a light stimulus is applied and: pain can sometimes occur when there has been no apparent injury or continues long after healing.

Melzack & Wall introduced the Gate control theory and the concept of "modulation" - the idea that incoming pain signals could be inhibited. Messages would come from other sources, including the spinal cord, the brain or both. The idea of a gate opens up the possibility that the central nervous system has a degree of autonomy from the periphery in creating the perception of pain. Whether pain is experienced or not, and if so to what degree, is influenced by what else is going on in the person's environment. Environment can be interpreted broadly, including both the immediate physical surroundings and the psychological and cultural climate of the individual.

As Melzack and Wall argue:

> "The effects of mood, culture, experience and expectation fall into place as part of a unified and integrated system and not as mysteries to be pushed aside or assigned to a totally separate mechanism of the mind." (Melzack & Wall, 1988: 182-183)

The gate control theory, therefore, includes a social dimension to the understanding of pain. In addition the theory suggests that psychological phenomena are not simply reactions to pain but play an important role in determining the subjective experience of the sensation. This allows for the influence of a large variety of external factors: the immediate physical environment, evaluations of sources of threat and pleasure, personalities, conscious calculations about the consequences of courses of action, and cultural conditions. Medicine has made some attempt to work with this model but it has also created problems for those working within a medical paradigm, as will be discussed further on.

The medical definition of pain has moved from one which defines pain as a purely sensory experience:

> "Pain is that sensory experience evoked by stimuli that injure or threaten to destroy tissue" (V Mountcastle, in Wall & Jones,1991)

to a wider definition incorporating emotional aspects:

> "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. (Pain) is always subjective. Each individual learns the application of the word through experiences related to injury in early life. It is unquestionably a sensation in a part of the body but it is also always unpleasant and therefore also an emotional experience." (Merskey, in Wall & Jones, 1991)

But although the gate-control theory has challenged the mind/body split, the biological still remains dominant over the social (Williams & Bendelow, 1995), which, as shall be seen in the following section, still provides a limited view of the pain experience.

Non-Medical Theories About the Nature of Pain and the Pain Experience

There are many different theories about the nature of pain and subsequently how to deal with it. A review of some of these theories can be found in a study by Vrancken (1989) of pain specialists in the Netherlands. Five ideal typical schools or approaches were identified:

1. The somato-technical approach
2. The dualistic, body-oriented approach
3. The behaviourist approach
4. The phenomenological approach
5. The consciousness approach

Vrancken (1989) summarised the different approaches as follows:

1. The somato-technical approach

Here, pain is seen as essentially organic. "True pain" has an origin in the body and can be traced. The only difference between acute and chronic pain is time. Chronic pain syndromes are classified in the same way as acute pain. Psychological aspects are acknowledged but are seen as disabling. Patients are regarded as cured when the objective signs disappear.

2. The dualistic, body-oriented approach

In this approach, pain is seen as the result of organic, psychological and possibly social factors. Physical pathology is a necessary determinant with other factors being seen as contributory to the final expression of pain. This fits into the gate control theory of Melzack & Wall. Vrancken designates this approach as dualistic not because of its conceptualisation of pain but because of its practice. Although pain in essence is not defined as dualistic, in practice the realms of body and psyche are differentiated. It is seen as being very important to find out the relative contribution of the somatic and the psychic realms as this will determine whether the patient should be treated by a doctor or a psychiatrist, psychologist. The patient is cured when the pain is gone.

3. The behaviourist approach: chronic pain as learned behaviour

Pain should be called pain behaviour as behaviour refers to "overt", observable actions. The subjective experience of pain cannot be known by others. Chronic pain is seen as different from acute pain in that it has become separate from the initial physiological stimulus. The persistence of pain has become largely dependent on behavioural changes, which in their turn are induced, maintained and reinforced by environmental reward responses. Environmental and personality factors play a major role in the genesis of the syndrome which should preferably be treated by a psychologist. The objectives of pain therapy are to minimise pain behaviour. The patient is considered recovered when pain behaviour is replaced by effective "well behaviour".

4. The phenomenological approach: pain as a mode of being

According to this approach, pre-scientifically, pain is that mode of being in which the body becomes the centre of one's lifeworld. The "lifeworld" is a phenomenological concept which refers to the everyday reality or world in which people live. This reality consists of taken-for-granted, common-sense knowledge and forms the basis of understandings about the world. According to this approach, the everyday life is pushed into the background and the body has come to the foreground, separated from the lifeworld. This is painful because people notice the change from their previous experience of their body as "self" and what it is like to perceive and to feel the world in a normal way. Pain is a "breach in the continuity of experience", in that the body is experienced out of its context. The meaning of the "painful event" plays a decisive role in the occurrence of pain. For example, a minor injury, when interpreted as a threat or harm to integrity can give rise to pain. Pain, therefore, is seen as an answer to a certain situation, an interpretation within the framework of existence.

In other words, pain is seen as a complex of reactions and behaviours, triggered off as a physiological self-defence under harmful conditions, but which becomes independent of the initial event. The intrinsic function of living beings, the 'pain function' shows specific phases in relation to specific goals, ranging from survival to recovery and reintegration. Chronic pain arises through the derangement of the pain function where a life crisis that may have been relatively hidden is not brought to light. In short, chronic pain is seen as the result of an interrupted healing process. The pain sufferer has not been able to find his way back to the world and is in an existential need. This can be seen in the way the person talks about the painful part of their body; by showing a great distance from it eg the leg rather than my leg.

Therapy involves looking for the factors that may have impeded healing. This is achieved first of all by reconsidering the complaint from the patient's perspective which may have been different from that of the physician's and which may have caused inner conflict. In addition, the therapist must pay attention to the patient's biography and outlook on life. Finally, the therapist looks at the patient's perception of their own recovery. The objective of therapy is to return the patient human life, to help them become a person again. The encounter is considered the crucial condition for recovery. By 'awakening' the patient through the encounter the patient experiences oneness and the until now rejected part of the body will be assimilated and reunited with the lifeworld.

5. The consciousness approach: pain as consciousness in form and content

This school considers pain as a problem of consciousness. In everyday life we may be conscious of our body but this is a level of consciousness separate from the content of our here-and-now awareness. In pain, a part of our body has entered the here-and-now awareness. Finally, our consciousness is totally filled by pain. When a person is in a state of pain, he/she is hurt in the core of his/her existence. Buytendijk (1973) refers to this when he stresses than in the case of pain, a person is hit in his/her psycho-physical unity - living through something to him/herself, not opposite him/herself. In order to solve the puzzle of pain, therefore, we have to reflect on what it means to be human and question consciousness. In this approach it is argued that humans are inclined to be overwhelmed and led away by pain but a person who is motivated is able to halt it by an act of will.

As pain raises the question of our existence, the pain patient should ask him/herself: who am I? He/she should reflect on his/her life and existence and draw conclusions. In other words, the person should engage in his/herself otherwise things will not alter. Therapy involves the therapist offering the conditions in which the patient can work upon his/her recovery, whatever form this may take. The main prerequisite is establishing an interpersonal relationship. The therapist guides the patient as a fellow human being and by his/her presence evokes self-awareness in the patient. The pain could then fade away as soon as the patient has the insight that pain is an appeal. If the experience of pain does not disappear, it is accepted and becomes manageable.

Vrancken criticises the first three approaches and argues in favour of a phenomenological approach to pain. The first approach, that of the somato-technical approach is criticised because it neglects the person, when in fact it is the person through whom pain can speak. The dualistic approach attempts to fill this gap but is "trapped in the very dilemma, which is brought about by the idea of man being either physical or being a psychosomatic unity" (Vrancken: 440). With this approach the patient is left confused as he/she is passed between the two views. The behaviourist approach is seen as being slightly better as it does look, to a certain extent, at the existential needs of the patient. By viewing the human being as a subject with purposeful activity, in a limited way, they are "respecting the attack of suffering on the coherence of the sufferer's world". One of the main problems of this approach, Vrancken argues, is that it neglect's the patient's definition of his/her situation; they do not ask what pain is and they seem to know what life is. By focusing on behaviour rather than insight or experience, the operant approach separates a person's inner world from the outer world in an attempt to get around the difficulties of mentalism. In other words, the reality of the person is replaced by well-defined definitions and statements derived from this school's need to objectify.

The main problem with current approaches to pain, Vrancken continues, is that neurophysiological explanations cannot explain the "natural impulse to react to pain". The experience of pain, she suggests, is of a different order than electro-chemical impulses. This order involves returning to human existence and its domains such as the "lived" body, feeling, willing and thinking. Phenomenological approaches, therefore, try to understand, rather than explain the experience of pain.

Baszanger (1989, 1992) has also looked at the various approaches to dealing with pain. Her focus is on how medicine operationalises the gate control theory of pain and the consequences it has for the doctor-patient relationship. Chronic pain is seen as problematic in this respect as it cannot be reduced by objectification like other medical conditions eg blood pressure, and more importantly, it cannot be stabilised as an unquestionable fact. Physicians, therefore, have to draw on multiple resources in order to decipher a patient's pain.

Using the example of two pain centres with opposite conceptions and practices, Baszanger explores how physicians try to stabilise the problematic reality of chronic pain and try to hold on to it. In the first pain centre, physicians restricted the description of pain to body sensations with little room for the patient's discourse. When formulating advice, the physician used several resources to make the pain situation visible. These included showing the patient the X-rays or test results and demonstrating a treatment with diagrams. If no physical cause can be found, the physician has to switch to deciphering a case in terms of the patient as a person rather than a body. In this instance, the language changes from body sensations to talk about life circumstances and the whole person. The same resources are used to show that the pain is not physical and that psychiatric treatment is needed. Pain measurement is also used as a way of showing the patient improvement. But, according to Baszanger, the two parties' perceptions often differed because they did not rely on the same criterion to assess progress. The physician reasoned in terms of global improvement since the start of treatment; the patient in terms of the intensity of pain during each crisis. Some patients also found the idea of measuring painful sensations with numbers as unrealistic.

In the second centre, physicians recognised the province of medical knowledge and acknowledged the world of the patient and his/her pain. This does not call for surveying the body as with the centre above, but rather evaluating the patient's pain by weaving it into a medical classification, namely the 'chronic pain syndrome'. Medical work calls for a deciphering that must explain "a set of social, behavioural, psychological and physical manifestations as part of the single category, the chronic pain syndrome" (Baszanger 1992: 197). To determine the patient's pain situation entails breaking this complex phenomenon down into parts to be weighed and working within the patient's subjectivity. By interrelating the medical knowledge and person's thoughts and feelings, the physician integrates the information into a global judgement about the person and pain. Physicians use a pre-established grid for interviews in order to collect systematically the information necessary for evaluating cases. The chronic pain syndrome underlying this grid "opens up a multidimensional space in which a patient's words and thoughts become tools for the eventual diagnosis and therapy" (200). The work of reducing the pain entailed modifying the patient's relation with pain - "by modifying the way of reacting, we modify the pain" summed up this point of view. The explanation often linked pain to life circumstances such as divorce, and the physician tried to convince a patient that this link accounted for the persistence and/or intensity of their pain. In the follow-up, patients and physicians worked on small graphs that the latter used to show the relations between the former's pain, tensions and activities during a typical day. What this centre 'objectified' then, was the links between events and not, as the other centre did, the pain itself.

Baszanger's study is relevant to a study of the measurement of pain as it not only illustrates different approaches to the treatment of pain but how these approaches, although stemming from a single theory can lead to different logics of action. Some of these actions involved using numerical pain measurement in an attempt to make pain "visible". It was found that patients and physicians differed it their assessment of pain relief because of their differing frames of reference. This is an important point, as those who construct pain measurements may also be operating with different frames of reference from those who use them. Finally, the use of pain measurements has an important role in the doctor-patient relationship. Past pain measurements could be used by physicians to discount patients' views that they feel better/worse than before. In these instances, the patient's own experiences could be seen as 'wrong' and the measurement (and hence physician) as 'right'.

Another theory of pain has been proposed by Kleinman (1988), who argues that, in the everyday experience of "local moral worlds", people come up against resistance to their life plans and practical actions. When a person cannot get access to resources, symbolic or instrumental, the idea of control becomes "untenable": "the normal everyday routinization of misery can be experienced as bodily pain" (Kleinman, 1988: 186). In order to resist being overwhelmed by the world of suffering, people develop strategies as a means of resistance. In other words, the development of chronic pain can sanction transformations in experience. For example, for a woman in Kleinman's study, pain became a means of resisting her husband's irresponsibility and her mother's cruel manipulations.

Scarry (1985) takes a quite different approach in describing the experience of pain as leading to the "unmaking of the world". In other words, acute pain "resists" language and thereby resists entry into the world of communication and meaning. It "shatters language" (1985:5). Good (1995) argues that language is not "shattered" in the literal sense but that pain still has a "world-destroying" quality. Drawing on the phenomenological analyses of Schutz (1971), Good (1995) argues that pain, along with other extreme experiences leads to a shift in the "embodied experience of the lifeworld" (1995:118). The lifeworld refers to the everyday common-sense reality, which, through pain, becomes "systematically deformed". In other words, pain threatens the relationship between the person and their taken-for-granted understanding of reality.

Schutz (1971) outlines six features of the lifeworld and Good (1995) uses these to illustrate how pain changes the way they are experienced. The first is that a specific "form of experiencing the self" is typical of common-sense reality. In the everyday world, the self and body are experienced as one, but for those in pain the body becomes an "object", distinct from the acting self. Second, a "form of sociality" is part of the lifeworld. According to Schutz, one of the most fundamental assumptions is that we live in the same world as persons around us. But for many people with chronic illness this becomes doubtful as others cannot share or fully understand their experience. In particular, as there is no objective indicator of pain and no direct relationship between the origin of disease and the felt pain, pain remains ambiguous and unverifiable by others, resisting social validation (Scarry, 1985).

A third feature is having a "common time perspective", one we share with others. Space and time become overwhelmed by pain and the private world loses its relation to the world in which others live (Good, 1995). Pain also leads to a change in consciousness as it distracts and exhausts the person. The everyday world, Schutz argued, is organised in terms of "intentional projects". For many people in pain, everyday life goals are subverted by the prominence of pain with the world of suffering and medicine replacing the prior social world. Finally, in the everyday world, we suspend awareness of our mortality (Schutz). But for those with chronic or life-threatening illness, this suspension of doubt can fail as they realise how vulnerable they are.

Finally, there are some sociologists who also argue for a phenomenological approach which are relevant to the study of pain and pain measurement. Bendelow & Williams (1995), argue that "insights from the newly emerging sociological arenas of emotions and embodiment provide a framework which is able to both transcend the divide between mind and body and to develop a phenomenological approach to pain." (Bendelow & Williams, 1995: 139). Phenomenological approaches to embodiment, as Turner (1992) argues, are important for studying issues such as pain.

One of these approaches which is seen as being important is the work of Merleau-Ponty (1962). He developed a conception of human embodiment which attempted to overcome the mind/body duality by arguing that it is not possible to talk about human perception without a theory of "embodiment" as the "perspective" from which observation occurs. In other words, our perception of everyday reality depends upon a "lived body". Human beings can be seen to have a dual nature, described clearly in the German language by the difference between the terms "Lieb" which refers to the animated living, experiential body (ie the body-for-itself) and "Korper", which refers to the objective, exterior, institutionalised body (ie the body in itself) (Turner 1992). Plessner (1970) and Berger and Luckman (1967) have also suggested a similar argument, namely that each of us is a body and has (ie experiences) a body. For Bendelow and Williams (1995) it is the emphasis upon the body as a "lived experience" ie one in which the objective body is not treated as separate from the inner sensations of the subjective body which has relevance for the sociology of pain.

The sociology of emotions, they argue, is also important for the study of pain as the physical experience is inseparable from its cognitive and emotional significance. As Scheper-Hughes and Lock (1987) argue, emotions affect the ways in which the body, illness and pain are experienced and are projected in images of the well and poorly functioning social and body politic. Emotions, like pain, "lie at the juncture between mind and body, culture and biology and are often considered crucial to our survival by their signal function in relation to danger" (Hochschild, 1983). Hochschild highlights the common practice among social scientists to ignore emotion altogether. But the interactionist model emphasises how emotions take place within a social context and involve both mind and body. Because of this Denzin (1987) insists that scientific study of emotions is not possible and stresses the term "emotionality" which he defines as the process of being emotional. Drawing on the works of Heidegger, Sartre and Merleau-Ponty, he shows how this "lived quality" and intersubjectivity is of paramount importance, locating the person in the world of social interaction in which all emotional experiences involve reflection, feeling, cognition and interpretation. More importantly, no emotional experience is exactly the same and is open to constant reinterpretation and meaning depending upon the particular social and cultural experiences which shape them. In other words, Denzin suggests that the study of emotionality "requires a conception of the human body as a structure of ongoing lived experience" (1987:3). A suggestion which Bendelow and Williams see as being equally relevant to the study of pain as an embodied experience.

Cross-cultural Studies of Pain

Cross-cultural studies of pain show how the experience of pain varies across different cultures (Fabrega & Tyma 1976a, 1976b; Diller 1980). Fabrega & Tyma (1976a, 1976b) have looked at the role of language and culture in shaping how individuals experience pain. They argue that "to the extent that culture and language may actually affect perception, thought and cognition, then to that extent they also may affect the actual experience of pain" (1976b:324). This issue is explored by comparing the description of pain in English, Japanese and Thai. They classified the terms which make up English pain descriptions into three groups: primary, referring directly to a pain experience; secondary terms which do not refer to pain per se but which serve to qualify pain in special ways (eg sharp, pressing); and tertiary, additional terms which can be used to qualify pain but which do not seem to have a special association with pain. Fabrega & Tyma suggest that analysis of the meanings of secondary and tertiary terms can show how people construe and make sense of pain.

In English, Fabrega & Tyma found that the basic terms most frequently used to describe pain are "pain", "hurt", "sore" and "ache". They then progress with an historical analysis of these words. "Pain" derives from the Latin poena, meaning punishment. The original meaning, therefore, had nothing to do with pain per se but the idea of victimisation, penalization and vengeance. The term "hurt" which is probably Frankish, originally meant ram or butt. Secondary pain terms in English include tearing, sharp, dull, pressing. Fabrega & Tyma suggest that we choose these because when nominalized and made to refer to body parts, they still convey the idea of pain. These terms also have a special relation to primary pain terms. Tertiary pain terms eg depressing and tiring, do not appear to be connected to the sensory description of pain per se. Fabrega & Tyma go on to say that the model of pain represented in English language suggests that an observable, natural and physical process is implicated, giving emphasis to things physical and suggesting that the experience itself is being likened to a physical process. Historical analyses of the primary pain terms by Fabrega & Tyma (1976a) revealed that with the exception of intensity, no other feature of the quality of perception was marked for reference. In other words, no relationship could be drawn in English between the pain terms and other attributes of pain such as location, quality, or source. In addition, the processes or consequences of disease were not directly implicated semantically in the English primary terms. English pain terms, therefore, turn pain into an "object", which could be visualised as though it were located in an n-dimension "experience" space with the axes of this space marked by scales such as: stationary-static vs moving-dynamic; temporally-extended vs temporally circumscribed; discrete-materialised vs vague-formless; intense vs non-intense; and complex-differentiated vs simple-undifferentiated.

The description of pain in Thai was found to differ from that of the English. Syntactic and semantic features of Thai pain descriptions suggested that a determinate entity was being delimited but in an "experience" space which seemed to be ordered in dichotomies and scales far different from those of English: internal vs external; visible vs invisible; known cause vs unknown cause; and disease related vs disease unrelated. Pain descriptions in Thai were found to be ambiguous and it appeared that for semantic focus speakers were dependent on context. Thai also appeared to have at least two sharply distinguished conditions of pain, glossed by a general covering term, whereas English had one pain which could be rendered and graduated in various ways. English pain descriptions also drew on semantic units such as activity, intensity and degree of differentiation, whereas the native Thai speaker did not give explicit consideration to these aspects. Fabrega & Tyma suggest that these themes may be already implicit in primary pain terms or may be communicated non-verbally.

In describing pain, as discussed earlier, the English speaker makes reference to pain in an abstract way, where pain is sometimes seen as an object and sometimes a dynamic experience. This objectification process did not appear natural in Thai, except for descriptions in special contexts (eg with a physician where objectivity may be required). In summing up the differences between Thai and English, Fabrega & Tyma suggest that, at a general level, the "biological meaning" of a pain experience and/or description is everywhere the same; a "cultural invariant" in other words. This would mean that "culturally distinctive semantic units are being used to speak about and make sense of these universal biological aspects of pain" (1976b:332). In other words, they are claiming that languages and cultures "apprehend" significant and recurring human problems in the same ways but bring them into focus by means of "different linguistic lenses".

Moving on to the Japanese, Fabrega & Tyma (1976b) suggest that for the Japanese, pain is related almost entirely to the idea of human psychological experience per se. This is supported by analysing what pain can be linked to in addition to the physical apparatus of the person. The qualifiers of pain place emphasis on pure experientiality. Whereas English pain is described through metaphor, Japanese qualities are described more "naturally" through direct symbolisations of the experience. English pain, therefore, could be said to be modelled in terms of events or phenomena which logically are separated from the pain. But for the Japanese, there are no objects or events unrelated to pain to which the secondary pain terms can refer. In rendering the experience more determinate, the Japanese do not model it on other events, instead the qualification seems to stay entirely within the pain experience itself and represent a refinement of that experience. In other words, Japanese words used to describe the pain experience are not used to describe other non-pain related experiences as in English.

It could be argued that the English way of describing pain reflects the empiricist understanding that words and hence language have and they are thus seen as direct representations of reality; ie have a one-to-one relationship with what they are describing. This would explain the limited use of metaphors and the view of pain as an object existing independently of the person experiencing it. This contrasts with the Thai and Japanese pain descriptions which, it could be argued, are more phenomenological in nature. For example, the Thai language tended to use simile and the Japanese used symbolism. In turn this results in models of pain different from that implied by English. In particular, the "psychological" rather than physical experience is more implicit in Thai and Japanese pain description. This also suggests that with the English language it is more difficult to describe the pain experience as there are fewer symbols to draw upon compared to other languages like the Japanese.

Diller (1990) has also examined cross-cultural pain terms, in particular that of Thai pain descriptors and compared them to other languages. He found that, in colloquial reporting of pain, languages differ in the extent to which, on the one hand, pain tends to be reported by a single general term to which specific qualifiers and other descriptors are added to narrow down the general meaning, or on the other hand, pain is dealt with mainly through a set of "pre-differentiated" multiple terms less prone to qualification as specific information is already provided. More importantly, Diller suggests that in some languages, social context of speech may call for linguistic variation of pain terms on grounds other than of physical experience. For example, the Japanese regularly distinguish "formal-literary" and "informal-colloquial" ways of describing the pain of stomach pain and toothache. Also, Diller continues, in languages such as Vietnamese, the choice between two lexical pain terms may be based on or affected by issues such as subjectivity and focus. Hungerland, (1967) and Ornstein, (1972) and other philosophers have been interested in the pain patient's dual cognitive role as experiencer and observer-reporter and Diller argues that it is important to bear in mind the linguistic consequences of this dual role in making cross-language comparisons.

Also, pain terminologies need not be digit-like equally weighted terms in a circumscribed set (Diller, 1990). Contextual constraints again are also important in interpretation (Diller, 1990). For example, if a patient reports his head to be "splitting" in English, it is naturally interpreted as a "metaphorical pain-term surrogate". Several languages also use sound symbolism. These forms symbolise intensity and indicate whether pain is felt to be repetitive in aspect.

Although Diller argues for caution in making cross-cultural semantic comparisons, he does not think it is impossible, especially for researchers who are native speakers of languages. There is some evidence that pain threshold and intensity perceptions vary across cultures (Melzack, 1973). Diller suggests that language-specific differences in pain reporting may be partly an effect, but partly also a cause of culturally-modulated differences in pain perception as language can exert a powerful influence on the different aspects of our conscious attention and on our species' cognitive abilities to deal with meaning.

These studies are important as they not only illustrate the importance of culture and history in shaping the meaning of pain, but also some of the problems of using pain language in measurement. In particular the argument that social context is not only important in helping people make sense of their pain but in interpreting what other people are trying to say about their pain. This issue will be discussed in more detail in the following chapter on pain measurement.

Meaning and the Chronic Pain Experience

The meaning of pain, in other words how people make sense of it is influenced culturally as described above. The importance of meaning has been the focus of many writers. It is important to realise that phenomenologically acute pain differs from chronic pain. Acute pain is usually defined as pain which is short-term, has an identifiable organic pathology and is usually amenable to medical treatment. According to Hilbert (1984), acute pain is the accepted western cultural view of pain from which stems the appropriate behaviour for being in pain. People in acute pain are expected to show their feelings, these are accepted and in turn they are obliged to be given or obtain relief. In contrast, chronic pain is defined as pain which continues for more than three months; often has no known organic pathology and is untreatable by medicine. Saunders (1970) warns that chronic pain is not a "mere extension in time of acute pain". It has, she suggests, a qualitative difference affecting the whole person, physiologically, psychologically, emotionally and spiritually. Twycross (1984) describes chronic pain as a "situation" rather than an event. Its characteristics include: a lack of positive meaning; it grows worse rather than better; it is likely to occupy the person's whole attention and tends to isolate him/her from the world around.

Hilbert (1984) argues that because pain is viewed within the acute pain model, people in chronic pain are "socially suspended in an ongoing experience which makes no sense, that no-one else can share". The pain has no meaning. To cure the social isolation, sufferers are involved in "pain management", in other words they are involved in trying to communicate their pain experience. This involves a balancing act over whether to disclose or reveal the pain. In Hilbert's study, the case for disclosure was most commonly warranted when pain forced people to behave in unusual ways or to change their personal habits in ways subject to misinterpretation. By revealing pain, it is hoped that their behaviour will not be judged as harshly. On the other hand, concealment was used in respect for general social rules against complaining, iniating depressing discussions etc. Hilbert emphasises that this is not simply a lack of public understanding - sufferers know why they are misunderstood - it is part of their cultural understanding of pained and troubled people. Pain management would not be a source of trouble if pain were a familiar cultural object. Visibility would also remove ambiguity over its reality.

Kotarba (1983) suggests that, due to the lack of information from their culture on how to explain their pain, some sufferers have to rely on constructing their own supplemental realities within whose terms pain can be understood. He describes interaction among professional athletes and blue-collar workers. What emerges is a "chronic pain subculture" which often overlaps considerably with occupational subcultures. How to handle it, experience it, express it, how to display it and for what kinds of audience all become apparent through the subculture. For example, for the athletes, the decision whether to disclose pain or not was influenced by the athletes perception of his/her job security. Pain was also seen as an inherent feature of professional sports and was therefore ignored. For the blue-collar workers, the main decisive factor was whether disclosure would threaten their self-esteem.

Kleinman (1988) argues that how people interpret their illness contributes to how it is experienced. When people talk about their illnesses it becomes interwoven with their own biographies into an "illness narrative":

> "a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings ... The personal narrative does not merely reflect illness experience, but rather contributes to the experience

> of symptoms and suffering." (Kleinman, 1988:49)

Williams (1984) asked people suffering from arthritis what they thought caused it. He found that they interpreted this as a question relating to their biography and answered accordingly. In other words, they re-organised their biographies in order to account for the onset of their illness and their changing relationship to the world in which they lived. Identified causes, therefore, represented "not only putative connections between the disease and antecedent factors but also narrative reference points between the individual and society in an unfolding process which becomes profoundly disrupted" (Williams, 1984: 175).

Narrative is also viewed as an important part in "remaking the world" of the person in pain (Good, 1995). According to Good (1995) and Scarry (1985), the "dissolution" of the lifeworld is countered by a human response to find or construct a meaning; "to reverse the deobjectifying work of pain by forcing pain itself into avenues of objectification" (Scarry, 1985:6). Good argues that medical activities as well as traditional forms of healing can be seen as part of the attempt to objectify pain. Constructing narratives of suffering or by developing meaningful lives in spite of illness "can be understood as efforts to counter the unmaking of the lifeworld" (Good, 1995: 128). In other words, narrativization is a

> "process of locating sufferers in history, of placing events in a meaningful order in time. It also has the object of opening the future to a positive ending, of enabling the sufferer to imagine a means of overcoming adversity and the kinds of activities that would allow life experience to mirror the projected story."
> (Good, 1995: 128)

According to Good, narratives are not only important in the "remaking" of the sufferer's world but also in enabling the experience to be understood by others. In other words, the pain experience should be viewed as a phenomenological experience which does not just exist in the body but in life. By the use of narrative, people can describe their experience; make sense of it in a meaningful way and in turn try to moderate the suffering by reconnecting themselves to the world. There are many cross-cultural pain narratives which contrast to the western pain narratives. Using the example of American pain narratives, Good describes how they seem to derive from the "contradictions of mind-body dualism, the highly complex and often delegitimizing language of stress and the quest for affirmation that accompanies the search for relief" (1995: 134). But despite this, he argues, they do bring a certain coherence to events.

Another important point regarding narratives which needs to be acknowledged is that illness is universally experienced as a moral event (Good, 1995). Williams (1984) has highlighted the importance of morality in the development of strategies for dealing with the experience of chronic illness.

> "In articulating the experience of illness in relation to their social milieux, individuals elaborate moral discourses based on their own biographical experiences which often stand counter to the dominant rhetoric of both professionals and politicians." (Williams, 1984:104)

In other words, Williams is arguing that people manage illness within the context of a moral life. Conduct may be recognised in terms of its virtue and a person may recognise themselves in terms of their virtuousness. When people pursue virtue, they are attempting to enact a story about themselves as they wish to be understood, regardless of whether the enactment is the optimum way for them to proceed. This pursuit of virtue does not exist in a social vacuum. The way virtue is displayed, Williams argues, includes the ideologies and belief systems predominant in his/her society.

> "The conflicts and tensions exhibited in the pursuit of virtue can only be understood in relation to the wider social and historical setting through which someone has passed and now lives."
> (Williams, 1984: 105)

Threats to virtue, therefore, come from society and draw people into a process of self-enactment through which potentially damaging evaluations can be resisted. For example, an important virtue in western societies is that of independence. Dependency is viewed as something to be resisted. People with chronic illness, therefore, may continue activities which they perceive to be important in "proving" that they are independent eg by continuing to go to work, even though it may cause them pain and make their condition worse.

To summarise so far, it appears that narrative has an important part to play in the chronic pain experience. In particular, it is argued that the construction and reconstruction of narratives enables people to find some explanation for their suffering. Meaning is important for maintaining a sense of optimism and purpose about continuing in life. Good (1995) suggests that medicine provides narratives to help achieve this and people select from these what they think makes sense in the context of their lives. For example, knowing that the pain is due to a non-life threatening illness can provide some meaning and reduce fear. But medical narratives, according to some writers (Hilbert), are not always adequate for people in chronic pain and these people are therefore left in a state of anomie. Williams (1984), in contrast, has suggested that people do develop strategies for coping with illness which may conflict with those proposed by the doctor and that these enacted stories, or narratives are shaped by the moral context in which the person lives. The search for meaning, therefore, does not just involve a theological search for meaning ie why me? but how should I respond to this? What is the moral order to make sense of it? (Good, 1995).

Medical Sociology and Pain: The 'Social Constructionist' Approach

As has been shown throughout this chapter there are many different views about the nature of pain and the pain experience. We now turn to a further approach in medical sociology which questions the way knowledge about pain arises, particularly medical knowledge. The basic argument is that all medical knowledge is socially constructed and contributes to the shaping of social relations. In addition, the objects of medical science are not stable realities but 'fabrications' or 'inventions' rather than discoveries.

Bury (1986) identified the main propositions to the 'social constructionist' approach. These shall form the basis of the following section which will critically assess the approach in terms of what it means for the study of pain.

1. The 'Problematising' of Reality

The first main strand which Bury (1986) identifies is the 'problematising' of reality. Medical knowledge is treated as problematic and apparently self-evident and stable realities are questioned. Drawing on the work of Foucault (1976) and discourse analysis, the claim is that medicine's objects are created through the language and practices which surround them.

> "familiar objects of the social world, (whether they be death,

> disease, madness, sexuality, sin or even mankind itself) are realised only in and through the discursive elements which surround the objects in question ... As the discourse changes so too do the objects of attention. A discourse, moreover, is not merely a narrow set of linguistic practices which reports on the world, but is composed of a whole assemblage of activities, events, objects, settings and epistemological precepts. The discourse of pathology, for example, is constructed not merely out of statements about diseases, cells and tissues, but out of the whole network of activities and events in which the pathologists become involved, together with the laboratory and the other settings within which they work and in which they analyse the objects of their attention." (Prior, 1989:3)

Foucault (1976) developed this notion of discourse in his study of medicine. He found that it was within the discursive practices of eighteenth century medicine in Paris that the contemporary notion of disease was developed. The body was the prime focus and came to be the main site of disease. Therefore, within the discourse of pathological medicine, disease was formulated as a discrete phenomenon which was located in the workings of the bodily structures. This conceptualisation of disease within the anatomy was the product of what Foucault called the "gaze". This implies a way of seeing and it was through this that things became visible to the doctor and once seen, an object formulated as a discrete entity could be observed and analysed. The medical gaze is also flexible and permits new objects to come into view. For example, Armstrong argues that contemporary medicine is increasingly taking patients' interpretations and their experiences of their symptoms into account rather than just focusing on their anatomy and physiology (Armstrong, 1994; Arney & Bergen, 1984; Nettleton, 1992). But there is also the argument that medicine is not taking patient's interpretations into account. In other words, while medicine may now incorporate the patient's world into its gaze, it does so only to look for known etiological factors. It does not listen to the patients' narrative.

2. Mediating Social Relations

The second proposition argues that rather than standing outside of social relations, medicine both in practice and through its knowledge base mediates social relations in important respects. To call an area of experience 'medical' is to place it in a significant relationship to other areas of social life. Some constructionists have therefore attempted to show the ways in which medicine and medical categories actively engage with specific social groupings and practices.

An example of this is Figlio's (1978) study of the nineteenth century disease of chlorosis. In his paper he argues that far from being an independent natural entity, chlorosis took on a particular shape and meaning depending on which social group was being considered. The explanations concerning aetiology and the recommendations for treatment differed depending on which social class was being addressed.

From this perspective, medical knowledge is also seen as mediating 'changing' social relations (Cooter, 1978/82). Cooter emphasises the flexibility of scientific knowledge under conditions of marked social change. Other sociologists and historians (eg Barnes and Shopin, 1979) insist on a wider 'social interests' perspective and a view of science as culture.

3. Medicine and the Neutrality of Technique

The third proposition is that the technical realm cannot be regarded as neutral. Technical solutions are advanced to a wider range of social problems, a process of 'medicalisation' which, it is claimed, can only contribute "to a growing alienation from genuine social and political debate".

In terms of pain, according to some writers, medicine and the advance of the technical has resulted in the loss of its meaning (Hilbert, 1984; Illich, 1977). Illich (1977) argues that medicalisation has turned pain into a technical matter and deprived it of its meaning. He defines the pain experience as "suffering", "an inevitable part of the conscious coping with reality" and separates it from the sensation. For an experience of pain to constitute suffering it must fit into a cultural framework . This framework enables individuals to transform bodily pain into a personal experience. In other words, culture teaches us how to suffer in the "best way". According to Illich, a culture will provide at least four interrelated "subprograms": words, drugs, myths and models. Pain is shaped by culture into a question that can be expressed in words, cries and gestures. Each culture also provides its own drugs to take with customs that designate when they should be taken. Religious and mythic explanations for pain have featured in all cultures. Finally, cultures have provided an example on which behaviour in pain could be modelled: the Buddha, the saint, the warrior or the victim. The medicalisation of pain has led to the fostering of one of these methods, management by technique and reinforced the "decay" of the others thereby depriving any culture of the integration of its program for dealing with pain.

Illich goes on to argue that this has led to a change in the relationship between the patient and the physician. Previously the doctor had conceived of him/herself as a healer and pain assumed the role of a step towards the restoration of health. Where the doctor could not heal he/she did not mind telling the patient to use analgesics and thereby moderate inevitable suffering. But the doctor in contemporary medicine is in a different position: the goal being treatment not healing. The doctor thereby ignores the existential questions which pain raises in the patient (why must I/ought I/should I suffer?) and "degrades" the pains into a list of complaints.

Historically, in European civilisation pain had a different meaning from that which it has today (Illich). Pain was the experience of a marred universe. The meaning of pain was cosmic and mythic, not individual and technical. Pain was also a sign of corruption in nature and humans were a part of that whole: it could not be thought of as distinct from the ailment. To eliminate the need to suffer would have meant to do away with the patient. Finally, pain was an experience of the soul and this soul was present all over the body. Pain was a non mediated experience of evil. There could be no source of pain distinct from pain that was suffered.

This view, says Illich, changed with Descartes theory of the body as a machine; separating body and soul. This became central to a medical understanding which in turn has influenced lay understandings of pain, although those with chronic pain may find themselves returning to the wider more existential questions. Pain in the medical sense became "a signal with which the body reacts in self-defence to protect its mechanical integrity" and was thereby reduced to a useful learning device. According to Illich, by the end of the nineteenth century, pain had become a regulator of body functions, it needed no more metaphysical explanation. Progress in civilisation became synonymous with the reduction of the sum total of suffering (as previously mentioned by Wall & Jones above). For Illich, the "dulling" of pain has led to the loss of its referential character and generates a "meaningless, questionless residual horror".

Illich, therefore, views pain as an experience which is wider than the physical aspects; the sensation leads to a form of existential suffering which is a "natural" part of being human and a normal part of life. Society used to help the person make sense of this suffering by providing a framework, but now, due to medicine defining pain as a short-term medical problem, this framework no longer exists. People with chronic pain, in a sense are suffering more today because there is no meaning given to pain; no answers are provided for the question of "why am I suffering?".

One interesting aspect of Illich's argument is that it is suggested that people in the West today give in to pain more easily and resort more readily to treatments to anaesthetise the pain. They are, therefore, less able to bear pain than their ancestors. This issue has been explored by de Moulin (1974), although the question was framed slightly differently: "Can modern algophobia be attributed purely and simply to a decreased willingness to endure pain, or are we conceivably observing an increase in the pain experience as such, an increase in the painfulness of pain?" (de Moulin, 1974: 541).

The question is explored through a review of the available historical literature on the experience of pain and medical treatment. His "cautious" conclusion was that, judging by the reaction of the patient and the attitude of the physician, "there is no evidence that pain was once less acutely felt than in our own days" (de Moulin, 1974: 569). The explanation for the decline in ability to accept pain, he suggests, has more to do with a change in mental attitude than a change in the nervous system. Interestingly, he also points to the change in the task of the doctor throughout history. As well as using drugs, the doctor also offered sympathy, removed fear and inspired confidence as much as possible, something which, de Moulin argues, is neglected today.

Toellner (1971), like Illich above, suggests that Cartesianism may have had an important part to play in the current view of pain. His argument is that, Descartes, by conceptually separating the body from the soul, reduced the body to a mechanical apparatus, a conception that led to the modern view that pain is not the inevitable result of the imperfection of creation or of original sin, but a sign of a repairable malfunction of a mechanism. This view, Toellner argues, although useful for maintaining the body, is "senseless" for the person who has to experience it.

From this viewpoint then, medicine is seen to be a central "carrier" of the tendency towards rationalisation in the modern world. This was a central concern of Habermas (1972). He argued that there are fundamental cognitive interests, given a priori in our relation to the world, which underpin the procedural rules of any science and in turn determine what counts as the objects of knowledge. These cognitive interests have shaped the interests of the researcher and the way reality is viewed. Technical interests, therefore, have led to a science of nature with emphasis on observation and control.

Mishler (1984) has conceptualised this argument as that of the 'voice of the lifeworld' being dominated by the 'voice of medicine' (Mishler, 1984). The concept of the 'voice of the lifeworld' is taken from Habermas (1979) and refers to a patient's contextually grounded experiences of everyday events and problems. Whereas the 'voice of medicine' reflects a technical interest where the meaning of events is provided through abstract rules that serve to decontextualize events from their social context (Mishler, 1984: 104). Mishler argues that in the doctor-patient relationship the doctor's attempt to control or dominate communication with the patient has the effect of absorbing and dissolving the patient's self-understanding of his/her problems into the framework of technical medicine. In relation to chronic pain, as mentioned above, this means that the patient's own ideas about what is causing the pain, what makes it worse, better etc, are ignored and medical reasons given instead.

4. The Social Construction of Nature: Abolishing 'Discovery'

The fourth proposition following on from the above is that claims to the discovery of disease are themselves social events and take place in social contexts. Conflict takes place on the margins of science as to what is to be incorporated and what rejected.

According to one of the originators of this argument, Kuhn (1962), scientists work within dominant paradigms or frameworks of knowledge which comprise an accepted set of concepts and theories about the world. Significant changes in scientific knowledge can only occur when the beliefs of a given scientific community can no longer be explained within the existing paradigm. If this occurs, there is a scientific revolution and a new paradigm emerges. This means that the most recent ideas are taken as correct and the old beliefs outdated and incorrect. Fleck (1935b) has shown that these thought styles are not necessarily resistant to "popular" ideas about disease. Thus the emergence of scientific facts is related to both the scientific community and the social context in which the community resides. This may also be linked to the social interests of the scientists themselves. Scientific developments may be linked to their marketability rather than the results of objective experiments.

From the views of the social constructionists outlined above, it could be argued that medicine's interest in pain is part of the extension of the medical gaze. As other writers have mentioned, pain is an experience which could perhaps be called "suffering"; it is a natural part of human existence which is being "taken over" and constructed as pain by medicine. Medical science is therefore trying to "objectify" suffering by reconstructing it into a psycho-biological experience. The development of pain measurements such as the McGill Pain Questionnaire is one way medicine is attempting to "objectify" the pain experience. Through this method, it is hoped that all the different dimensions of the pain experience can be "discovered", analysed and controlled. By doing this, as Illich, Morris and Hilbert have argued (although with differing emphasis), pain and hence suffering has been deprived of its meaning. They argue that, for those in pain, the experience is more than physical. But Bury (1986) argues that social constructionism has exaggerated the hold that medicine has over contemporary experience. There is increasing empirical evidence to show that modern populations do not totally rely on technical or medical explanations in accounting for the cause of disease (Pill & Stott, 1982) or in the management of illness itself (Bury 1982, Cornwell, 1984). These issues will be explored further in the study through examination of the interviews.

Finally, the power of pharmaceutical companies to influence pain research should not be ignored. In other words, pain research may be influenced by more than an objective search for understanding pain, but by interests which have a bias towards pharmaceutical treatments and neurological theories of pain, thereby ignoring other dimensions of the experience.

The social constructionist approach, therefore, is important as it highlights the important role of medical knowledge in the shaping and construction of the pain experience. But, as Bury (1986) has indicated, there are difficulties with the approach, particularly relating to carrying out sociological research. The main difficulty is that if knowledge and methods of enquiry are held to construct rather than disclose reality, the human sciences have to be included as well. When rationality cannot be treated as external to social forms, as a means of understanding reality or judging accounts, what other methods are available? This in turn leads to a further problem of the "dispensability of categories" (Bury 1986: 155). The central thesis of constructionism is that knowledge changes constantly, is relative only to specific contexts, its truth value is suspect and is incapable of progress, suggesting that categories in use are dispensable. "For why should one interpretation or construction prevail over any other if they disclose or discover no aspect of an independent reality?" (Bury, 1986: 156).

The social constructionist approach, therefore, does highlight the important role of medical knowledge in the construction of reality and in terms of this study it does suggest possible ways of conceptualising the relationship between medicine, society and the pain experience. But, as Bury notes, the resistance to the possibility of producing useful and valid knowledge by constructionists will not reduce the suffering of millions of people:

> "Tendencies towards the medicalisation and rationalisation of society are, indeed, serious issues, but resistances and limits to this process should be recognised. So, too should the needs and sufferings which human experience entails and with which all forms of society must deal." (Bury, 1986: 166)

The Experience of Living with Chronic Illness

The main point being made throughout this chapter is that pain is an experience with many dimensions. In other words, apart from a physical experience, pain is also social in that it is made sense of through interaction with others in the society in which the person lives. There have been many sociological studies of the experiences of people with chronic illness and pain (Locker, 1983, Bury, 1982, Charmaz, 1983). Here, the argument is that for the chronically ill, chronic illness has a meaning beyond the diagnosis. It can impact upon sufferers' daily living, their social relationships, their identity and their sense of self. It could be argued that the experience of living with pain extends beyond the physical aspects.

Bury (1982) shows how chronic illness disturbs not only the physical body but the trajectory of one's own life biography. There is the disruption of taken-for-granted assumptions and behaviours - the breaching of common sense boundaries. Second, disruptions occur in explanatory systems and involve a rethinking of a person's self-concept. Third, there is the response to disruption involving the mobilisation of resources.

Chronic illness is characterised by uncertainty over the impact and cause of the condition and the appropriate behaviour in the face of its effects. The emergence of obvious signs of disability eg severe pain and stiffness can become overriding. The individual then has to decide whether to seek legitimacy for his actions. This raises problems about the relationship between the visible disease and self-hood. Medical knowledge, Bury argues, has an important role in this matter. Medicine offers an opportunity to conceptualise the disease as separate from the individual's self. In his study of people with arthritis, Bury found this to be a precarious situation. There exists an uneasy balance between seeing the condition as an outside force and yet feeling its invasion in all aspects of life. Medical knowledge is also limiting in that it does not help the person to "live with it". It is also incomplete knowledge, throwing the individual back onto their own stock of knowledge and biographical experience in order to understand the meaning of the illness. But despite these drawbacks to medicine, in the person's search for cause and their search for meaning, medicine can provide "an objective fixed point on the terrain of uncertainty" (Bury: 179). Lay and medical modes of knowledge also overlap. When searching for meaning, people set incidents from the past against presumed knowledge of the diseased condition. For example, some sufferers saw themselves as having inherited the condition, thereby interrelating moral concerns with scientific knowledge.

So, how does the concept of "biographical disruption" relate to an understanding of the pain experience? First, it highlights the disruptive effect an event such as chronic pain can have on an individual and his/her social life. Secondly, it shows how individuals attempt to attach some meaning to their pain in order to overcome the uncertainty it brings. Part of this process involves using medical knowledge to bring some meaning into the experience. But, at the same time, medicine can be limiting as it does not provide the answer of how to manage the pain in everyday life (see Illich).

Wiener (1975) studied the way people with rheumatoid arthritis responded to the illness. A major characteristic of RA is chronic pain which fluctuates from hour-to-hour and day-to-day. In order to cope with this uncertainty, Wiener found that people were involved in the process of "normalisation". That is

> "the suppression of the physiological imperative and proceeding
> with the activity imperative "as if" normal" (99)

Three main social strategies of normalisation were identified: covering-up; keeping-up; and pacing. These strategies were used not only to cope with the disability but also the pain associated with the arthritis. Turning to the first strategy, that of covering-up disability or pain. An example of this would be denying the amount of felt pain. The main reason cited for this behaviour by people in Wiener's study was to reject the social significance of the disability, not the disability itself. Unsuccessful covering-up invites the risk of interrupted interaction with offers of help or questions and suggestions. This impedes the arthritic's ability to view him/herself as he/she would prefer to be viewed by others. If covering-up is successful, there can also be drawbacks. The strategy can drain already depleted energy making the pain feel worse.

The second strategy is that of keeping-up with what they perceive to be normal activities eg maintaining a job. A problem can occur though for those who have mastered the art of keeping-up by means of raising the threshold of their pain toleration. This may mean they become slow at reading signs of body dysfunction. Some people also engaged in "super-normalising" as a device to distract themselves from pain. This concept involves engaging in frenetic activity or catching-up with perceived normal activities on pain-free days.

An important point Wiener highlights is how successful covering-up and keeping-up can make it harder to justify inaction to others. A paradox also arises. People who are presenting a normal image to the world are perplexed when they are not taken seriously by others. For example, they may be proud that "nobody knows" but wished that "somebody cared".

> "Pain is essentially private - sometimes you wish for someone
> to understand and be patient with your pain. To allow you to
> have it! I do not mean sympathy or pity." (in Wiener, 1975:100)

The third and final strategy is that of pacing - identifying which activities one is able to do, how often and under what circumstances. This is important because the activities allow one to view oneself as normal. Pacing also fluctuates with the monitoring of the physiological imperative. Sometimes when the pain is bad they have no choice but to rest.

The concept of "normalisation", therefore, is useful in understanding how an individual in pain tries to cope with it. A person in pain, particularly pain which is surrounded by uncertainty in its location, duration and intensity, has to try and balance the decision whether or not to disclose the pain against the pressures of a society which demands activity and normality. The fact that pain is invisible makes the strategy of "normalisation" easier to employ but the consequence can be debilitating as Wiener has illustrated.

Another study of people with rheumatoid arthritis by David Locker (1983), illustrates the importance of attaching meaning to pain. The characteristics of arthritis pain have already been mentioned, with the most important being that of uncertainty. Uncertainty over the cause and the duration of pain can leave an individual mystified and confused. Locker identifies some of the ways people in his study tried to discover what excaberated their pain, either by monitoring day to day experience or seeking medical advice. Such advice allowed them to perceive some pattern to their experience and meant explanations could be constructed which tied the pain to some prior activity:

> Mr M: "Today is a bad day, I'm in quite a lot of pain
> actually, but there again, I went out yesterday
> and so I'm suffering for it today."

The individual is then left with the difficult choice of living a restricted life and keeping pain levels down or attempting to do more with the risk that he/she will suffer additional pain. Some people in Locker's study chose to do the activity and pain became the price for indulging in it. Many of the respondents mentioned physical and emotional distress as a cause of additional pain and tried to avoid these situations. Other understanding was derived from observed connections between fluctuations in levels of pain and more mundane matters such as the weather. As Locker argues:

> "These causal theories are of intrinsic and extrinsic value for they offer a solution to the cognitive problem of finding meaning in experience and the practical problem constructed by the symptoms of the disease."
> (Locker, 1983:24)

To summarise so far, there appear to be many different theories about pain and how to conceptualise the pain experience. There does appear to be a consensus though that pain should not be viewed purely as a physical sensation but as an experience with several dimensions. From a sociological viewpoint, the experience is given meaning by the social context in which it emerges and it is, therefore, the relationship between society and the individual in pain which is important, particularly for a study of pain measurements. On a wider level, according to some of the social constructionists above, the measurement of pain should be seen as part of the increasing 'technicising' of life. Evidence for this will be explored in the interviews. Finally, if the experience is to be conceptualised as comprising of a social dimension, it will have implications for the validity of the measurements not only in terms of the influence of social context on the measurements but also in terms of their ability to measure all the relevant dimensions of the experience.

Having discussed the nature of the pain experience, it is necessary to critically examine the way(s) medicine has attempted to measure pain. This will comprise the next chapter.

THE MEASUREMENT OF PAIN - A CRITICAL REVIEW

A vast array of measuring instruments has been developed in an attempt to quantify pain, but as discussed in the previous chapter, pain is a subjective experience which cannot be directly observed or measured. Measurement, therefore, depends wholly on the subjective response of the person experiencing it. The main developments in pain measurement will be reviewed including an evaluation of the two pain measurements used in this study; the McGill Pain Questionnaire and the Visual Analogue Scale.

A critique of some of the major approaches to pain measurement now follows:

a) Behavioural Measurements

It is argued by several researchers that objective measurement in the clinical context can be achieved by quantifying behaviour (Fordyce 1976; Jacox 1980). This form of measurement is based on the conceptualisation of pain as a constellation of acquired behaviours (Fordyce, 1976). More importantly, it is argued that "one cannot measure pain, one can measure only pain behaviour or analogues thereof" (Fordyce, 1983a). Fordyce (1983a) also argues that as pain behaviour is subject to influence by a variety of factors, some of which are unrelated to the tissue damage from which the pain problem originated, it follows that measurements of chronic pain behaviour cannot be relied upon to characterise physical or neurophysiological characteristics of an alleged pain stimulus. In addition, he suggests that measurement should rely more on what people do than on what they say as inaccuracies have been found between what people say they can and cannot do because of the pain and how they actually behave.

Research into these behaviours is carried out in both in-patient and out-patient settings where non-verbal assessment procedures and behavioural data are collected in parallel with subjective pain report. Commonly reported variables include: activity (eg moving in bed) and activity diaries; measures of the amount of time spent standing, sitting or reclining; sleep patterns; sexual activity; performance on specified tasks such as joint movement, stair climbing or situps; medication demand or intake; food intake; normal household activities such as meal preparation; and engagement in recreational activity.

There is, though, a growing literature suggesting that chronic pain patient self-report can be systematically distorted by several variables (Fordyce, 1983b). Ignelzi et al (1980) examined consistency of self-report of pain intensity to different health professionals. They found that in a single clinic visit, 46% of chronic pain patients reported significantly higher pain intensity to a neurosurgeon than to a psychiatrist or a psychologist. Pain reports to the latter two did not differ. Using responses to the McGill Pain Questionnaire as an anchor, this effect appeared to be an exaggeration of intensity to the neurosurgeon rather than a mitigation of intensity to the psychiatrist and psychologist. One implication of this, Fordyce suggests, is that pain patients use self-report to communicate information or requests in addition to their actual pain complaint.

Block et al (1980) examined the effect of perceived presence of spouse on pain intensity report. They found that patients whose spouses were solicitous toward pain complaints reported significantly greater pain intensity under perceived spouse observation than under the neutral observer condition (ward clerk). For nonsolicitous spouses, the opposite effect was found.

Depression has also been found to influence self-reports of activity (Kremer et al, 1981). They found that depression and chronicity of the pain complaint were significantly related to underreporting of activity levels.

b) Observational Data

Attempts have been made to categorise or standardise the measurement of chronic pain behaviour for clinical observation. Frederickson et al (1978) distinguished three categories of pain behaviour: somatic interventions such as the use of medications or seeking surgery; impaired functioning indicated by reduced mobility or range of movement, avoidance of work, or impaired interpersonal relationships; and pain complaints such as moaning or facial expressions. Keefe & Block (1982) introduced an observational system for scoring pain behaviour in chronic back patients in which guarded movement, bracing, rubbing and sighing were assessed. Teske et al (1983) developed a rating instrument designed to assess behaviours generally indicative of pain. While reliability of judgements between nurses was good, the researchers found only modest correlations between patient report and nurse ratings. They cautioned against over interpretation of observational data.

Facial expression has been coded, quantified and used as a behavioural indicator of pain (Izard et al, 1980). Videotape technology makes it possible to record pain expression in the clinical setting and later analyse it in the laboratory.

c) Self-Reported Behaviours

In addition to observing and scoring patient behaviour or expressions, researchers sometimes require patients to fill out activity diaries or pencil and paper test instruments that ask about normal daily activity levels or medication intake. Chapman et al (1985) argues that while these methods may be valuable, they can sometimes lead to over interpretations by the researcher. It is sometimes assumed that the scores obtained are objective, behavioural data free from self-report biases. Patients may be poor or biased self-observers. For example, Ready et al (1982) found that chronic pain patients reported medication usage to health care providers that was 50-60% less than actual drug intake while Kremer et al (1981) observed discrepant reports of patient activity and social behaviour while comparing patient records and staff observations.

Advantages and limitations of behavioural methods

According to Chapman et al (1985) behavioural methods are especially useful for the assessment of pain relief and treatment effect. Another advantage, they argue, is that the variables measured are clinically relevant as opposed to abstract and academic.

Among the disadvantages of behavioural methods is that they do not quantify pain directly. Behaviours may change for a variety of reasons including changes in the amount of pain experienced. Moreover, it is difficult to separate behavioural measurements from the context in which they are collected and this, according to Chapman et al (1985) limits the ability of investigators to generalise findings of treatment effect.

d) Subjective Pain Reports

These indices, the most commonly employed procedures in clinical pain research, are used to scale both pain and pain relief following treatment. In the first case, the patient is asked to report the intensity (or some other feature) of the pain by using a standardised judgement procedure. In the second case, he/she is told to report the amount of relief afforded by an analgesic treatment. The simplest report instruments are pain category ratings and VAS judgements.

(i) The Visual Analogue Scale

Huskisson (1974, 1982) applied the scales (which had long been used in psychological measurement) to the problem of rating pain. Visual Analogue Scales (VAS) comprise of a 10 cm line that is usually labelled "no pain" at one end and "worst pain" at the other. Subjects are asked to mark the intensity of their pain on this line. The distance of the respondent's mark from the lower end of the scale, measured in millimetres, forms the basic score. Huskisson summarized the advantages of visual analogue scales as follows:

> "Visual Analogue scales provide the patients with a robust, sensitive, reproducible method of expressing pain severity. Results correlate well with other methods of measuring pain. The method is applicable to all patients regardless of language and can be used by children aged 5 or more years."
> (Huskisson, 768:1982)

Reliability

Assessing the reliability of pain measurements is difficult due to the characteristic nature of pain, ie it fluctuates and is dependent on the memory of the person in pain. Scott and Huskisson (1979) studied the repeatability of visual analogue scales and also compared scales printed vertically and horizontally. One hundred rheumatology patients were given a vertical and a horizontal scale in random order. The correlation was 0.99 between the scores, although scores on the horizontal scale were slightly, but not significantly, lower than on the vertical scale.

Carlsson (1983) assessed the reliability and validity of the VAS, in particular its ability to assess pain relief. The finding was that patients appeared to differ considerably in their ability to use the VAS reliably. Changes in pain intensity induced by electrical stimulation were assessed by "absolute" and "comparative" forms of VAS. The mean correlation between the two types of analogue scales was significant but unsatisfactory as a coefficient of reliability. The difference between the two forms of the scale was most prominent when pain was indicated as spontaneously decreased. One main cause suggested for the low reliability was the difficulty in recalling a previous pain experience, which is required for the direct estimation of changes of pain by the comparative scale. According to Carlsson (1983), this means that the reliability of the scale measured in this way is "particularly unsatisfactory for the estimation of changes which are of clinical interest, that is the assessment of pain relief" (1983:99). These results are in line with a study by Reading

(1980), who found that the sensitivity of VAS to changes in acute pain was generally low.

Validity

High correlations have been reported between VAS and verbal and numerical rating scales (Downie et al, 1978; Elton et al, 1979; Kremer et al, 1981; Ohnhaus & Adler, 1975; Scott & Huskisson, 1976; Woodforde & Merskey, 1972). As the validity of estimates of chronic pain cannot be assessed directly, the properties of VAS have been studied predominantly in connection with pharmacological treatment of pain. Ohnhaus & Adler (1975), and Scott & Huskisson (1976) have concluded that the VAS is no less valid than verbal rating scales.

The accuracy of VAS results has also been questioned (Bird & Dixon, 1987). Downie et al (1978b) showed a poor correlation between measured grip strength, using a sphygmomanometer cuff inflated to 30 mmHg, and estimated grip strength using a 9 cm vertical VAS with ends marked as 30 mmHg (the initial level) and 300 mmHg (the highest possible level). In addition, Maxwell (1978) showed marked intersubject differences when volunteers were exposed to ordinally related sound volumes which they assessed using a VAS. The maximum volume was sometimes recorded less than 50% of the way along the VAS from the "no sound" end. However, as Bird & Dixon (1987) have argued, it is not possible to determine the accuracy of VAS when used for pain assessment, because it is necessary to have the measurement of a standard amount of pain to which VAS results can be related (accuracy = observed result x 100/'true' result).

The precision of results along a VAS can be determined more strictly than accuracy (Bird & Dixon, 1987). Studies using normal volunteers attempting to duplicate a set of marked 10 cm vertical and horizontal VAS showed that the most precise results were obtained near the ends of the VAS and the least precise were near the golden section (Bird & Dixon, 1981; Sitton et al, 1982). A further study of 30 patients with rheumatoid arthritis where two VAS, one vertical and one horizontal, were presented on four occasions over two consecutive days with a 1-hour interval between assessments on each day, showed a similar pattern in precision in pain measurements along the VAS though results were higher than for normal volunteers (Hinchcliffe et al, 1985). This variation in precision with the distance along the VAS, it is said, adds a complex built-in error to VAS results, particularly when VAS are used to assess serial changes in pain (Bird & Dixon, 1987). But Huskisson (1983), argues that "expressing pain on a VAS may not be the same as remembering a point on a line and trying to reproduce it" (1983:36).

There is also debate over whether patients should have access to their previous scores when serial estimations of pain are being made using the VAS, as such access does lead to different results (Bird & Dixon, 1987). Huskisson (1979a) suggested that patients should be shown their previous results when asked to complete a new VAS, having indicated an apparent over-estimation of pain severity when previous scores were unavailable. In Carlsson's (1983) study mentioned earlier, comparing an absolute VAS with a comparative one, the absolute seemed to be preferable to the comparative because the latter seemed to be influenced more by effects of expectancy and deficient memory of pain. In particular, she argues, this is also the case when comparative estimates are derived from two absolute scales, when the patient has access to his/her preceding estimates. The patients should, therefore, "complete each scale without having the possibility of comparing with previous estimates" (1983:100).

Bias can also arise in the serial use of the VAS when a patient marks an initial VAS close to the end of the line (Bird & Dixon, 1987). If the initial assessment by the patient is close to "worst pain possible" and then a notable worsening of pain severity occurs, there is little room for manoeuvre. A similar situation can arise near the "no pain" end.

It has also been suggested that the psychological status of the patient can affect his or her perception and use of the VAS. In particular, it has been shown that the level of depression results in different VAS results (Peet et al, 1981).

A number of sources of error in the use of the VAS, which are not inherent in the structure of the VAS, are also important. Patients may interpret one end of a VAS to represent morning and the other to represent evening, hence marking the time of day that their pain is at its worst (Bird & Dixon, 1987).

The context of the interview situation may also affect the results as Gaston-Johansson (1983) and Burckhardt (1984) suggest. The former study found that patients reported their usual pain to be twice as intense as their present pain. Burckhardt also found that patients are apt to acknowledge only mild or no pain during the interview, but when asked to recall their usual or worse pain, they scored their pain intensity higher.

Finally, another limitation of the VAS is that it only yields estimates with a unidimensional character, usually estimates of pain intensity. Several authors (Chapman, 1976; Gracely, 1979; Petrie, 1967) have argued, therefore, in favour of a multidimensional method, the McGill Pain Questionnaire (Melzack, 1975) for the measurement of pain. However, being a verbal method, the MPQ requires translation and renewed scaling in order to be useful outside the English speaking countries. The VAS, therefore, still remains one of the most frequently used methods for the measurement of clinical pain.

More recently, visual analogue scales have been drawn up which attempt to measure the sensory and affective dimensions of the experience separately (Gramling & Elliot 1992; Price & Harkins 1983 & 1987). The affective scale usually contains the words, "not unpleasant" and "most unpleasant experience imaginable" at either end. Evidence for the validity of affective scales has been cited in the selective response to manipulations assumed to alter pain affect (Price & Harkins). Selective affective responses were demonstrated in early psychophysical studies of the thermal and chemical senses; hunger or satiety altered ratings of the unpleasantness of taste without changing intensity ratings (Gracely et al, 1978). In addition, raising or lowering body temperature altered unpleasantness-pleasantness ratings of thermal stimuli without altering intensity ratings.

Price & Harkins (1983), devised a VAS to measure the sensory intensity and one to measure the affective magnitude of pain. To assess their validity as ratio scale measures they tested them with chronic and experimental pain by asking chronic pain patients and healthy volunteers to make VAS responses to 6 noxious thermal stimuli. They then asked the pain patients to match their own pain to the experimental pain. Power functions were derived which can "accurately predict pain intensity and pain affect along ratio, not interval scales" (1987:53). But although sensory intensity of experimental pain could be compared with that of clinical pain, comparisons of affective magnitude were difficult to make as the situational context of experimental pain is very different from that of chronic pain. Affective responses to pain are more sensitive to contextual factors than are sensory responses (Johnson, 1973; Price et al, 1980). In particular, the study by Price et al (1980) found that affective responses to skin temperatures can be altered by lowering an individual's expectation of avoiding pain or by changing the manner in which the person evaluated the sensation.

Price & Harkins (1987) also tested the measures on people with different pain complaints. They found that the overall magnitudes of VAS responses to the range of temperatures employed did not differ for these three groups. More importantly, they argue that the higher exponent values for unpleasantness compared to pain sensation intensity provides support that these measures can separately measure two dimensions of pain experience. Further evidence for separate measures is given by studies which show that psychological factors can selectively alter VAS-affect ratings of this type of experimental pain (Gracely, 1979; Price, 1983 and Price et al, 1980) and that specific influences on the affective dimension of clinical pain can be demonstrated (Price et al, 1987). For example, Price et al (1987) found cancer pain to be characterised by higher VAS-affect ratings than VAS-sensory ratings, whereas labour pain and experimental pain are characterised by lower VAS-affect ratings than VAS sensory ratings.

In a study by Harkins et al (1989) visual analogue scales were also used to measure the "emotional suffering" related to a person's pain. Five VAS's associated with emotions (depression, fear, frustration, anger and anxiety) were anchored at each end with the words, "none at all", and "the most severe imaginable". In a comparison of neurotics and extroverts, they found that higher neurotic scorers not only reported greater unpleasantness than lower scorers, but they also gave higher VAS emotion ratings. They conclude that neuroticism "selectively augments affective responses, the second stage of pain processing, associated with both clinical and experimental pain" (1989:217).

There has also been recognition that there may be a pain-independent component of the experience such as fear of death which may be related to psychological variables directly without an immediate relation to pain sensation (Price & Harkins). The next step is how to measure this component.

Finally, Price et al suggest that these VASs are simpler to use and more valid than verbal descriptor scales, ie VASs with words of increasing intensity along them, as the verbal scales may often refer to several different emotional responses or meanings which are unlikely to lie on single continuum. Affective verbal descriptors imply that as pain increases beyond "discomforting" it becomes "distressing". This is possible but pain may become frustrating or depressing rather than distressing.

(ii) McGill Pain Questionnaire

Another paper and pencil instrument which incorporates a scale is the McGill Pain Questionnaire. Designed by Melzack & Torgerson (1975) it is based on an earlier study they made in 1971 on the language of pain. They argued that there was more to pain than overall intensity. Pain has several qualities, each unique to a physiological change. For example, the pain of a toothache is obviously different from that of a pin prick. In this study they asked 20 subjects (14 men and 6 women) with university educations to classify 102 words, obtained from the clinical literature relating to pain, into smaller groups that describe different aspects of pain experience. The words were categorised into three major classes and 16 subclasses. The classes are: (1) words that describe the sensory qualities of the experience in terms of temporal, spatial, pressure etc; (2) words that describe affective qualities, in terms of tension, fear and autonomic properties that are part of the pain experience; and (3) evaluative words that describe the subjective overall intensity of the total pain experience. Each subclass consists of words that were considered by most subjects to be qualitatively similar.

The second part of the study was an attempt to determine the pain intensities implied by the words within each subclass. Groups of doctors, patients and students were asked to assign an intensity value to each word using a numerical scale ranging from least (or mild) pain to worst (or excruciating) pain.

Melzack & Torgerson claim that there was a high degree of agreement on the intensity relationships among pain descriptors by subjects who had different cultural, socio-economic and educational backgrounds. A closer look at the subjects reveals how unrepresentative the subjects actually were. For example, 140 of the subjects were psychology students (90% were male, with an average age of 20 years); 20 were physicians of multi-ethnic origin, most had middle- and upper-class backgrounds; and 20 were patients (white, English-speaking Protestants belonging to the lower-class income group). No further studies have challenged this assumption, and as shall be seen during the remainder of this chapter, many have followed their method by relying on unrepresentative samples.

In addition to the list of descriptors, additional information was requested of the subject: medical information (diagnosis and drug intake), line drawings of the body to indicate the spatial distribution of the pain; words that describe temporal properties of pain, and the overall present pain intensity (PPI). Four supplementary subclasses were added to the word lists when patients found certain words to be absent.

Four types of data can be obtained from the questionnaire:

(1) Pain rating index based on the patients' mean scale values, PRI(S). This consists of the sum total of the scale values of all the words chosen in a given category (sensory, affective etc) or for all the categories.

(2) Pain rating index based on the rank values of the words PRI(R). The word in each subclass implying the least pain is given a value of 1, the next word is given a value of 2 etc. The values of the words chosen are then added up to obtain a score for each category, and a total score for all categories.

(3) The number of words chosen (NWC). The assumption being that the higher the number of words chosen, the greater the pain.

(4) The present pain intensity (PPI). The number-word combination chosen as the indicator of overall pain intensity at the time of administration of the questionnaire.

The study of 1975 analysed the word descriptor information and found the following. First, there is a high correlation between the scale and rank value methods for determining the PRI scores for each category, suggesting that either method could be used. Second, the PPI correlation with the PRI and NWC was significant but low. The reasons found for this were that the PPI fluctuates considerably as a function of psychological factors at the moment eg mood, anxiety level, attention and so forth. This means that the social context in which the measurement is taking place may influence the perception of pain. For example, it may represent an implicit communication requesting help from the physician.

Validity and Reliability of the MPQ

Reliability

Assessing the reliability of pain measures is particularly problematic because the variable under study is subject to variation across time. It is also confounded by memory capacity (Reading, 1983) because the patient may recall the pattern of responses of an earlier occasion and by the inherent fluctuating quality of the pain experience. If it is accepted that the term "pain" refers to a number of dimensions of experience, a problem with rating scales may be that they ensure that one aspect of the experience is responded to consistently. It is argued that scales that require a number of judgements for each dimension will increase reliability of scores obtained.

Similarly, the complexity of the task is seen as influencing reliability; when it is simple, reliability will be enhanced.

Melzack (1975) reported a small test-retest study in which ten patients completed the questionnaire three times at intervals ranging from three to seven days, with an average consistency of response of 70.3%. Repeated administrations of the questionnaire to cancer patients have yielded a consistency index of 75% between the first two administrations, which decreased to 66% and then increased to 80% over the course of weekly assessments. Finally, Hunter et al (1979) studied the ability of patients to remember their pain and to report it consistently. The MPQ was administered to 16 patients experiencing pain resulting from a neurosurgical procedure. Pain recall was assessed after an interval of 1 or 5 days. The results indicated high consistency in score profiles among the three occasions.

Validity

i) face validity:- Reading (1983) suggests that the increase in the number of studies from a variety of clinical settings that include the MPQ as a dependent measure "testifies to its acceptability in this setting" (1983:56). As Melzack argued (1975), supplying the patient with pain adjectives may overcome the language barriers that exist in the free-report situation. Moreover, the inclusion of emotional-affective words sanctions their use if they are indicated. Finally, a preference for verbal scales emerged from a comparison of verbal, visual analogue and numerical rating scales (Kremer et al, 1981).

ii) construct validity:- Several reviewers of the MPQ have addressed the question of whether Melzack's selection and grouping of words do indeed reflect the three dimensions he proposed. Studies in Canada (Crockett et al, 1985), the United States (Prieto et al, 1980) and in Britain (Reading, 1979), each using different types of pain patient have reviewed the factor structure of the MPQ. The general aim of the studies was "to empirically determine the nature and minimum number of dimensions necessary to describe responses to the MPQ" (Crockett et al, 1985). The three studies applied principal component analyses to the MPQ, using the scale values of the words chosen from each group as the scores for 20 variables in the analysis. Two of the studies (Reading and Prieto) extracted four factors and Crockett et al found five. According to Reading (1983) the results of these studies "confirm the distinction between sensory and affective subgroups and lend support to the practice of deriving representative scale scores." (1983:57). An evaluative dimension was distinguished but less consistently.

Despite these results, there are several methodological problems in examining how closely the MPQ reflects Melzack's theory of pain. In particular, there are conceptual difficulties in using factor analysis to assess the validity of the questionnaire. Melzack & Torgerson (1971) recognised that words from different components (eg affective, evaluative) may correlate with one another, while different subclasses in each component will not necessarily intercorrelate. If this is the case, it would necessarily be expected that words in say the sensory component would load on a single factor. Because the respondent selects only one word in each subclass, the correlations among words in each subclass will be zero and so the grouping of words into subclasses cannot be tested empirically. Furthermore, because each word reflects both a type and an intensity of pain, factor analysis may extract type of pain or intensity of pain factors, or both. This was illustrated by a study which departed from normal usage and presented the MPQ words in random order, asking subjects to check every word that described their pain (Leavitt et al, 1978). The seven factors that were interpretable cut across Melzack's groupings and took words at similar levels of intensity from a wide range of subclasses.

Gracely (1992) argues that factor-analytic methods may be inappropriate for assessing the factor structure of the MPQ. Torgerson (1988) distinguished between *semantic* meaning (how the MPQ descriptors are arranged) and *associate* meaning (how patients arrange the MPQ descriptors) to emphasise that factor analysis provides a context-dependent structure of the latter. In other words, the outcome will depend on how specific patient samples make use of the MPQ descriptors. Factor-analytic techniques, therefore, do not directly evaluate the semantic structure of the questionnaire.

Another argument put forward by reviewers is that the high correlation between dimensions suggests that they are not distinct. But, according to Gracely (1992), high correlations amongst variables does not necessarily imply a lack of discriminant validity. Using the example of vision, ie that increasing the intensity of light produces increased capacity to discriminate colour, contours, texture and distance, Gracely argues that high intercorrelations between these variables does not mean we should forget about the different components of vision as it would lead to "a loss of valuable, meaningful data." (1992: 55).

High correlations between the different dimensions of the pain experience would be expected as they are interrelated (Holdroyd et al, 1992). In other words, as the intensity of pain sensations increases, the amount of affect (or distress) generally goes up. However, if the given level of sensory intensity is fixed, there is considerable meaning to the amount of affect associated with it. In other words, the affective component of pain can be assessed as "how much a given sensation bothers you". It can be thought of as a separate amplifier with its own gain control. Adjusting the affective gain changes the amount of affect associated with a specific intensity of a pain sensation. The overall amount of sensory intensity and affect will usually be correlated. The important point is that the amount of affective gain can vary independently. With regard to the MPQ, its ability to measure the amount of affective gain and in particular changes in the amount ie after treatment, should be of central concern (Gracely, 1992).

Studies investigating the "placebo" response and pain (Gracely et al, 1978; Gracely, 1979) have been used to further reinforce the theory of different dimensions of the pain experience and the MPQ's ability to reflect these dimensions. Volunteer experimental subjects received gradually random shocks to the teeth or skin. The subjects were asked to rate separately the intensity of the pain and the unpleasantness of the pain. The subjects were then given a saline injection with the assurance that they were being given a powerful analgesic. The results were that the intensity of the pain was completely unaffected by that at low-shock levels the unpleasantness was markedly reduced but at higher intensities it was unaffected. Gracely et al (1978) then went on to show that diazepam, a tranquilliser, could produce exactly the same effect. However, in 1979, Gracely investigated the effect of fentanyl, a narcotic on the same type of pain and found a different result - it reduced the intensity but not the unpleasantness.

Construct validity has also been addressed by investigating the relationship between MPQ scores and concomitant assessments of psychological state. Elevations on the affective scale in oncology patients have been related to increased scores on depression inventories (Kremer et al, 1981).

(iii) Concurrent validity:- Correlations between MPQ-derived scores and verbal rating and visual analogue rating scales have been examined. Correlations of 0.39 and 0.10 between the total rank score for the MPQ and verbal and visual analogue rating scales have been reported (Reading, 1982). Similarly, Hunter and Philips (1981) found significant correlations between MPQ scores and diary card ratings of headache intensity and duration but not frequency.

(iv) Discriminant validity:- The efficiency of the questionnaire in distinguishing among patient groups has been examined. This is said to reflect the diagnostic potential of the MPQ and is consistent with clinical observations that patients display distinctive score profiles according to the nature of the pain (Reading, 1983). A comparison of MPQ profiles of women experiencing pelvic pain showed that acute pain patients displayed greater use of sensory word groups. In contrast, chronic pain patients used affective and evaluative groups with greater frequency (Reading, 1982).

Dubisson & Melzack (1976), compared responses to the MPQ given by 95 patients suffering from one of eight distinct pain syndromes. Discriminant function analyses showed that 77% of patients could be correctly classified into diagnostic groups on the basis of their verbal description of pain.

Internal Structure

The internal structure of the questionnaire (the grouping of adjectives into word sets) has also been examined. Reading et al (1982) used a different methodology and statistical technique and found support for the grouping of words into semantically homogenous groups. Less consensus though was found over the scaling of the words. Overall, their results indicated "large individual differences amongst subjects over how the adjectives within a group describe the intensity of pain" (1982:347). Bailey & Davidson (1976) suggested that intensity may be more appropriate for affective-evaluative aspects of pain than for sensations. While the latter may have utility in understanding the nature of the pain and reaching a diagnosis, the intensity may be defined by emotive-evaluative words. Because of this, Reading et al (1982) suggest that "the practice of deriving scale score values may be inadvisable until further work has been conducted to determine realistic intensity values for descriptor groups" (1982:143).

Chapman et al (1985) outlines some further limitations of the MPQ. One is that the MPQ is sometimes found to be too complex by some patients in terms of vocabulary. Even if the patient is conscientious, the test may reflect, in part, the vocabulary limitations of the patient as well as the nature of the pain. Although the authors suggest that their methodology is applicable to other cultures, considerable variation in pain vocabulary has been documented (Fabrega & Tyma, 1976). For example, some words may have different meanings in different cultures as found with a Finnish translation of the MPQ where the word "punishing" was not viewed as being associated with pain (Ketovuori & Pontinen, 1981).

A further limitation is that the MPQ weights sensory aspects of the MPQ more heavily than affective and evaluative. Patients are forced to give more consideration to the sensory aspect of pain than to the affective or evaluative aspects in the testing process. This may bias the outcome obtained.

There are also concerns over the validity and reliabilty of using pain language, and in particular the MPQ, for measuring chronic pain syndromes (Kremer & Hampton Atkinson Jr, 1983). Patients with chronic pain are considered problematic as they are characterised by a high incidence of anxiety and depression (Sternbach, 1974) and this affective distress is reported to disrupt cognitive tasks pertinent to responding to the MPQ (Ellis, 1978). In review of the literature up until 1983, Kremer & Atkinson concluded that

> "... affective distress influences pain language in a systematic fashion. It appears that, when intensity is controlled, patients with high levels of affective distress select more pain descriptors and spread their choices among more word categories than less disturbed individuals."
> (Kremer & Atkinson, 1983:124)

In particular, an earlier study by Kremer & Atkinson (1981) showed that patients who reported a high affective component (indicated by a greater use of affective descriptors) were significantly more depressed and anxious and complained of significantly greater physical and psychosocial disability and reliably more intense pain. This group also used significantly more sensory and evaluative descriptors. Hunter & Philips (1981) used the Wakefield Depression Scale to measure depression in chronic tension headache patients recruited from a psychiatric population. Pain intensity, affective language and evaluative language were significantly correlated with level of depression.

One way of exploring the effect of affective distress has been to compare the pain language of those with cancer pain and benign pain. Kremer et al (1982) compared responses to the MPQ for patients suffering chronic pain secondary to malignancy and patients with chronic benign pain. The groups were divided by sex and by pain intensity report (high versus low) on a scale of 0 to 100. The comparison indicated that cancer pain patients who complained of low intensity pain used more affective language to describe their pain than their counterparts with benign pain of the same intensity. Patients complaining of high-intensity pain did not differ by diagnostic category in their use of affective language, but did use reliably more affective language than patients complaining of low-intensity pain. Finally, women tended to use greater affective and evaluative language than men.

These findings, Kremer & Atkinson, (1983), argue, have implications for the use of pain language in clinical care. First, although, affective descriptors might be useful in communicating the patient's urgency in desiring relief, they are of little use in identifying the likely etiology of the pain. This conflicts with the findings earlier that the MPQ can discriminate between pain syndromes. In particular, Fordyce et al, (1978) failed to detect any systematic relationship between medical diagnostic category and pain language and suggested the possibility that pain language could be influenced by so many variables that it is likely to be highly idiosyncratic. The MPQ, therefore, should perhaps be used as a measure of the degree of affective distress that the patient is suffering (Kremer & Atkinson, 1983).

This issue will explored in this study too; as a measure of depression, the FACES scale will be used to see if similar results to those above arise ie that those who score higher on the FACES scale will choose more affective words than those who score lower.

The MPQ is one example of the two main methods of pain measurement currently being used (that of category-scaled measurements or 'domain sampling'). The other method is that of psychophysical scaling (mentioned earlier in relation to the VAS). It is argued that the data provided by the latter method is less susceptible to the 'bias effects' associated with category scales. They also enable clinical responses on these scales to be compared directly with patient responses to ratio-scaled physical stimuli (eg thermal stimulation). The major drawback to using these approaches is that they usually involve single-item analogue scales that may be less stable estimates of a clinical pain sensation than a scale composed of multiple items (Doctor et al, 1995). These scales also presume that people can directly scale their sensations.

There has been a move, therefore, towards combining the method of domain sampling and psychophysical techniques. One method has been through the development of the Descriptor Differential Scale (DDS) (Gracely and Kwilosz, 1988); an instrument that applies psychophysical scaling principles to clinical pain assessment and measures both the sensory and affective components of pain (Gracely et al, 1979). With this scale, subjects are asked to estimate the magnitude of their clinical pain relative to 12 graded descriptors of pain intensity (sensory dimension) and 12 graded descriptors of pain unpleasantness (affective dimension). Patients pain ratings relative to each of the twelve descriptors are averaged within each dimension of pain (intensity and unpleasantness) to produce a total score for pain intensity and for unpleasantness. The measure is still being tested and the results of studies so far are mixed.

In the first DDS validation study, Gracely and Kwilosz (1988) found that some subjects had difficulty scaling their pain consistently in a clinical sample. A similar result was found by Good et al (1991) in a sample of 18 chronic pain patients. However, in a separate sample of 12 chronic pain patients given more detailed instructions and feedback, 100% consistency in responding was observed.

In a recent study by Doctor et al (1995) of the sensory DDS, it was found that the DDS of Pain Intensity "is sensitive to small changes in electrocutaneous stimulation; has consistent ratio-scale properties across two different psychophysical methods and demonstrates similar item-response patterns across divergent experimental and clinical samples" (1995: 251). But as yet, there have been no studies evaluating the DDS affective scale. It would be expected though, that the problems found in relation to the affective VAS mentioned earlier (Price & Harkins, 1987); (ie that the situational context of clinical pain is difficult to control), might also make interpretation of the results problematic.

Additional Problems of Using Subjective Methods

A common (and serious problem according to Bird & Dixon, 1987), arises from pain at several sites. A patient with pain at many joints can be asked to represent their "global pain" insofar as this makes sense. This may cause problems for patients who perceive pain of varying quality at several joints (such as those with rheumatoid arthritis). If asked to complete a scale in relation to the "worst joint", it has to be ensured that this remains the worst joint throughout the period of intervention under study.

A more serious problem may be that patients, grateful for their treatment and attention received, reproduce on the scales what they think their doctor (researcher etc) would like them to say rather than what they actually feel. This may contribute in part to the placebo response, mentioned above, which is seen in one-third of all patients undergoing serial assessment in analgesic trials (Beecher, 1955).

It may also have to be specified whether the scale refers to pain at night, pain by day, pain on movement or pain at rest. Some patients may find "pain" hard to distinguish from "stiffness" and it has been argued that these are indistinguishable (Steinberg, 1978).

Clinical Measures Used To Assess The Pain Of Rheumatoid Arthritis

As this study will be looking at the problems of measuring pain in people with rheumatoid arthritis, it is important to examine other methods used specifically for the measurement of this type of pain, and in particular how they relate to the measures discussed above.

As pain is closely linked with inflammation, composite assessments that reflect inflammation are seen as relevant in the monitoring of pain, particularly if patients have difficulty separating this from stiffness (Bird & Dixon, 1987).

(i) Early morning stiffness:- although commonly used as a diagnostic criteria for rheumatoid arthritis, this symptom is relatively non-specific and is also hard for patients to quantify. The stiffness wears off gradually with no demonstrable end-point and may then recur later in the same morning. Patients also experience difficulty in recalling its duration.

(ii) Grip strength:- this has been used for two decades in arthritic patients (Bird & Dixon, 1987). Various instruments are described, but the sphygmomanometer cuff is usually the method of choice (de Choisy, 1973; Ann et al, 1980). The patient squeezes the pressure bag already inflated to 30 mmHg three times for each hand, alternating hands, to minimise discomfort. Intraobserver error is reasonable but interobserver error may be large (Lee et al, 1971). The main problem is that it could only rationally be used as an assessment of pain if it was always pain alone that limited the development of grip. Factors such as muscle strength and fatigue play a part so this is not always the case.

Poor correlations have also been found between measures of grip strength and patients VAS scores (Downie et al, 1978).

(iii) Joint tenderness:- there are several indices in which manual pressure is applied to a large number of arthritic joints and the patient's discomfort or pain recorded on a summated scale. The Ritchie Articular Index (Ritchie et al, 1968) is the most frequently employed in Europe. In the Ritchie Index, firm pressure is applied to a majority of the joints in the body. Response is graded on a 0-3 scale: 0 = no pain; 1 = slight pain; 2 = pain with wincing; 3 = pain with wincing and withdrawal of the joint. The responses are summated and the maximum possible score is 78. Intraobserver error is low but interobserver error is high and observations need to be made by the same observer. Most of the variation in the use of the scale occurs in the interpretation of the scores 1 and 2 which are less well defined than the scores 0 and 3.

A study by Gaston-Johansson and Gustafsson (1990) examined the relationship between the outcome of the Ritchie Index and pain intensity as measured by the VAS. A high correlation was found (.86) between the scores of RAI and present pain on the VAS. They suggest, therefore, that the pain in rheumatoid arthritis is associated with the hyperalgesic state induced by the inflammatory condition associated with RA. More importantly, it suggests that the VAS and RAI are measuring the same component of the disease. In contrast to their results, Dequeker & Wuestenraed (1986), only found significant correlations between outcomes of RAI and VAS in 2 of their 19 patients. The reasons for this is put down to their using the average rating of pain intensity on the VAS 4 times/day from 9 am to 9 pm, whereas Gaston-Johansson et al used ratings taken once in the morning.

Conclusion

The most commonly used methods of measuring pain have been discussed, in particular the VAS and MPQ. Despite their widespread use there is still concern regarding their validity and reliability. For the VAS, there is concern over concentrating purely on intensity, as pain, it has been suggested (Melzack, 1975) has other dimensions. Other concerns centre on technical issues ie how people use the VAS; should the VAS be horizontal/vertical?; should there be words along it or no words? While for the MPQ, there is concern over the weighting/scaling of the words, in particular, the argument that sensory words should not be scaled but that evaluative ones should. There are also concerns over the relationship between the dimensions with high correlations being taken as a sign of a lack of discriminant validity. While others argue (Gracely et al, 1992) that the dimensions are related and are therefore bound to correlate. In addition there are methodological concerns, ie that education may influence word selection. Also, Melzack (1975) found with one of the scoring methods, the PPI, that it can be affected by the mood and expectations of the person doing the measurement and may therefore not be an accurate reflection of their pain. Mood has also been shown to have an influence on the words chosen from the MPQ (Kremer & Atkinson, 1983), with the argument that the MPQ would perhaps be more useful as a measure of affective distress. In addition, the social context can have an important influence on the words used to describe pain as the Fabrega & Tyma studies illustrated.

Due to the problems associated with using pain language, some researchers have argued in favour of using VASs without words for each dimension of the pain experience (Price et al, 1987). While others are still in favour of using language and are using methods such as cross modality matching to make the weighting of words more "accurate" (Doctor et al, 1995). Despite the lack of agreement over how to measure pain, the inherent problem that pain cannot be viewed objectively, and "contamination" by the subject's expectations and mood etc (the social context), pain researchers (see Gracely, 1983) are still confident that they can develop a "gold standard" of pain measurement which will be free from the problems discussed above. The aim of this research will be to see if this is possible by exploring the nature of chronic pain and the ability of the VAS and MPQ to measure it.

METHODOLOGY

a) The Research Problem

The methodology was designed in order to investigate the following research problem. This was to assess the validity of two pain measurements by comparing them to the findings of in-depth interviews with people in chronic pain. The reasons for choosing this approach and the problems encountered in assessing validity will form the basis of this chapter.

Validity is one of the key components of the Positivist epistemology (Hughes, 1990). This branch of the philosophy of science assumes that there is an external world which can be understood independent of the process or circumstances of knowing it (objectivity). The aim is to construct general laws or theories which express relationships between phenomena. Observation and experimentation will then show that the phenomena do or do not fit the theory. The process of verification is therefore an important part of positivism and relies on the methods used being both valid and reliable. Validity refers to the verification of the conceptual categories that organise the observation. A measurement is considered valid if it is shown to measure correctly what it is designed to measure.

In practice, the research process entails translating the concepts in the theory into observational concepts. For example, the act of measuring heart disease begins with a concept of what constitutes the condition. This concept is then operationalised. In other words, what will count as the indicators or signs of heart disease are decided so that it can be measured, such as chest pain, narrowed arteries etc. The concept then, precedes and guides the observation. Therefore, both symptoms and signs of disease are in fact interpretations which are shaped by the conceptual categories used to observe (Kleinman, 1994). Verification of these concepts, the validity, therefore, is a crucial aspect of measurement.

Validity in pain measurement, in other words what are the measurements measuring? was the problem to be researched. As mentioned above, measurement relies on observation. Pain, in this case is problematic as it cannot be observed like other bodily changes such as blood pressure. Measurements have to rely on what the person says. This is where Kleinman's (1994) comments about operationalised concepts being constructions becomes important. Does the person constructing the pain measurements use the same concept of pain as the person being given the measurement? As discussed previously in the Introduction, it has been argued that the medical definition of pain is not valid as it neglects certain aspects of the pain experience (Illich, Morris, Hilbert). This leads onto the important point that there are several dimensions of the concept of validity. For example, a pain measurement could be considered valid if it is shown to be measuring the construct of pain conceptualised by the researcher (construct validity). The construct validity would be determined by comparing the measurement with other measurements of the same construct (ie comparing the results of the MPQ with the VAS). But there is also the point above about whether the actual construct itself is valid, in other words, does the researcher's definition of pain relate to the experience of pain in "reality". Both of these aspects of validity needed to be explored. In order to explore the latter point, the results of the two pain measurements were compared with the way pain was defined in a person's own words from in-depth interviews. How this was achieved will be discussed further on.

The next important point to discuss then, is, why is it important to find out how people define pain in their own words? As Kleinman (1994) argues, positivists would see such knowledge as "epistemologically unsound" (132) as "patients do not have privileged access to objective knowledge about their underlying conditions that can be verified through measurement with a high degree of probability" (Kleinman, 1994:132). The patient's subjective knowledge is seen as less reliable than the medical researcher's objective knowledge and doubt is cast on their constructions. But, as Kleinman highlights, it could be argued that the researcher's knowledge is a construction which differs very little from that of the patient. As shown in the previous chapter, medical concepts of pain are historically derived categories which have to be learned in the same way as lay ones.

More importantly, Kleinman (1994) questions the reasons behind the assumption that positivistic measurement should be considered more authentic than human experience and expression. What is important, he argues is the person's interpretation of their experience, the *meaning* they have given to it. This meaning is important because people interpret stimuli and these interpretations, continually under revision as events unfold, shape their actions. The same physical stimulus can mean different things to different people and indeed to the same person at different times.

> "The sufferer's interpretation of suffering needs to be taken
> into account in the assessment of pain, distress or dysfunction
> in order for such assessments to have validity in the
> experience of real people in real worlds." (Kleinman, 1994:135)

What is being argued above is that pain is an experience which is interpreted and given different meaning at different times by different people. These multiple responses to pain, it is argued will influence measurement because they do not reflect an automatic, objective response to the sensation but an interpretation which is socially constructed and constantly shifting (see Illich, Morris in the Introduction).

The epistemology which is concerned with the interpretation of meaning is that of hermeneutics. Hermeneutics arose as a reaction to positivism in the social sciences. Whereas positivism sees reality as a reality of external things and forces, the interpretive alternative views reality as being "intersubjectively constituted by persons relating to each other through practices identified and given meaning by the language used to describe them, invoke them and carry them out" (Hughes, 1990:118). In this approach, emphasis is given to the meanings that humans use to make sense of the world around them. With regard to pain, therefore, it can be argued, as Kleinman (1994) illustrates that the meaning people give to their pain, how they make sense of it is, in essence, a more valid account of their experiences than the positivistic measurements which force people's experiences into categories constructed by the medical researchers and separates them from the social context in which they live. Pain, as mentioned earlier should be viewed as an experience located in and influenced by the society in which it emerges. Meaning therefore is fluid, not fixed.

To try and understand the meanings people give to their experiences of pain involves using different methods than those advocated by positivism. As stressed so far, in order to understand why persons act and think as they do requires an understanding of the meaning they give to their actions. The in-depth interview is one way of doing this. By asking people in a way that they can talk about it in their own words allows access to these meanings, rather than fitting what they say into terms generated a priori by the researcher.

To summarise so far, it would appear that in looking at the problem of validity in pain measurements there are two differing views of reality (and therefore pain) and how knowledge of it can be obtained. On the one hand there is the positivistic approach which sees pain as something separate from the meanings, beliefs etc that the person has about it and this attempts to reduce "biases" or "errors" in its search for a "gold standard" of pain measurement. On the other there is the more qualitative approach which, rather than ignoring the "subjective" pain experience, sees the meaning, or response to the pain as the essential feature of the experience. For the person in pain, the experience does not just consist of a reaction to a pain stimulus. Being in pain involves a much wider experiential dimension, which as argued in the last chapter, should perhaps be called 'suffering'.

In order to investigate the way pain was conceptualised in the measurements and to see whether they did relate to the everyday experience led to the development of the following methodology. First, two well-known and supposedly "valid" pain measurements were chosen, the Visual Analogue Scale (VAS) and the McGill Pain Questionnaire (MPQ). The construction, validity and reliability of these measurements was discussed in the previous chapter. To summarise, it appears that both measurements, although widely used, are still problematic as regards validity and reliability. Some of these areas of concern will be explored in this research.

In the empirical work carried out for this study it was planned to compare the results obtained from the MPQ and VAS measures to the person's own account of their pain obtained in the interview. How this was carried out is discussed in the next section.

Having discussed the conceptualisation of the issues, I now turn to the methods chosen to carry out the research and reflections on this process.

b) Methods

i) Sample

As the research is part of a wider research project into the cultural dimensions of the pain experience, the sample was obtained from the Rheumatology Department of the London Hospital, Whitechapel who were involved in this wider project. The consultants were concerned about the problems of assessing pain in people from different cultures, particularly the Bangladesh community who appeared to rate their pain on the VAS at both ends of the scale. They were therefore interested in finding out why this occurred. The work on which this dissertation is based, however, was concerned with the experience of measuring a sample of English patients who were the comparative group for the larger study.

Forty patients, twenty two women and eighteen men were chosen from those attending the Rheumatology Outpatients Department at the above mentioned hospital. It was decided to select only those white people whose parents were born in England for the reason that it would provide some control over the definition of who was English and this would be relevant for comparative purposes in the larger study. The ages ranged from 37 to 75, with the average age being 62. People over the age of 75 were excluded as it was felt that memory could be affected in those over this age. It was also decided to choose those who had had rheumatoid arthritis diagnosed for at least one year. This would mean that the sample would consist of people who had experience of living with rheumatoid arthritis and not those who had just been diagnosed. In other words, they would have lived with pain for a while. The average length of time since diagnosis in this sample was 18 years (range = 2-55).

As it was recognised that it is difficult to measure pain, for the reasons discussed earlier, it was decided to use triangulation. A family relative, in most cases the spouse was interviewed and given a VAS to complete as well. This provided another view of the pain being experienced and a possible way of increasing the validity of our understanding of the pain being experienced if a method could be found of relating the degree of pain experienced by the person with RA to the degree of pain observed by their partner. As it turned out, having two measurements instead of one simply provided another problem to be understood as not all partners did confirm that people were experiencing the degree of pain they said they were experiencing. This will be discussed further in the results section. Sixteen of the men and eleven of the women lived with a spouse or other close relative such as a daughter. The purpose of administering the relative a VAS was to see if they recorded a similar level of pain to that of the patient. The interview it was felt would also provide a check too. For example, some of those interviewed had forgotten the different kinds of medical treatment they had received in the past but their relative remembered. In addition, some of the patients said they never talked about their pain but their relative said they did. Finally, talking to the relatives provided some interesting insights into how pain affected the person's life and the importance of others in dealing with it.

In selecting the sample, representativeness, in terms of the sample being representative of all people with RA, was not a crucial issue. In attempting to understand the meanings people give to their pain, the approach does not imply that everyone sees their pain as this sample did. What is important is the influence of meaning on attempts to measure pain. This, it is being argued, is a problem faced when attempting to measure pain with any group of people and it is the process by which meaning affects measurement which is of interest, not just the measurements themselves.

ii) Rheumatoid arthritis

Rheumatoid arthritis is a common and chronic disease. In the United Kingdom as many as two to three per 100 people (ARC handbook) have some evidence of the disease although in many cases it may be extremely mild. It is an inflammatory disease occurring more often in females than males (3:1), except in the elderly where incidence is more equal (Office of Health Economics, 1992). It is characterised by inflammation of the joints which can result in joint weakness, damage and changes in shape. The most commonly reported symptom is pain.

At present it is not possible to prevent the onset of RA, so minimising symptoms, such as pain and inflammation with medication and in serious cases surgery, are the main forms of treatment. The effectiveness of treatment is varied and this variation is largely due to the problem of knowing which medication to prescribe when a symptom such as pain cannot be directly observed but known only by the patients' reports. In particular, there is no correlation between amount of joint inflammation and reported pain. But despite this, some consultants do use other measures such as the ESR (the erythrocyte sedimentation rate), a blood test which indicates the presence and extent of inflammation as a means of guaging how much pain a person has. In observations carried out for this study, it was noted that consultants spoke of this as confirming that patients must have a great deal of pain even though no correlation has been found between the ESR and patients' reports of their pain (see measurement chapter).

iii) Administering the Measurements

It was decided in consultation with the consultants and because of Ethics Committee guidelines that the hospital doctor would introduce the patients to me in person. I therefore attended the department regularly and in some instances was able to sit in on the consultations which gave me some useful insights. The patients and their relatives (if they were with them at the hospital) were given a protocol outlining what the research was about and then given a VAS to complete. Those who did not have a relative with them at the hospital were asked to discuss it with their partner at home. A follow-up call was then made to see if they were agreeable and a time for an interview was arranged.

Finally, it was decided to conduct the interviews and to administer the majority of the measurements in the person's own home. It was felt that this would provide a context in which the person would feel more in control in the sense that the interview was being conducted in their own, familiar, everyday environment and also to remind them of their daily experience. This meant that the interviews had to be conducted after the consultation when they agreed to participate. The interviews were conducted within one week of seeing the person at the hospital. Before the interviews began, the patient and relative were given a consent form to sign. Further details of the interview procedure are discussed later.

iv) Administering the Visual Analogue Scale

The VAS was administered at the hospital and at home. This was to investigate the influence of social context on the reported level of pain. For example, it was thought that in the hospital setting a person may record a score to indicate the meaning they give to the situation at the time. For instance, they may want to put a high score if they think it will lead to them receiving more medication or less if they wanted to avoid a new procedure which had been mentioned to them. Subjects were asked to place a mark on the line which represented their worst pain at that time (in the hospital) and over the past week (when administered at home). The reason for this being that it would keep it to one specific time period over which the measurements could be compared.

The VAS seemed to be understood fairly well although there were a few comments about its inappropriateness; that the sensation was more like an ache than a pain and a few tried to put a score according to how their pain changed throughout the day. These problems will be discussed further on in the findings.

v) Administering the McGill Pain Questionnaire

The MPQ was administered at home only. The researcher sat beside the person with RA and this allowed them to see as well as hear the details of the measurement. The instructions were read out and results recorded by the researcher. In the word list section, the subject was asked to select the word in each subclass that most accurately described their pain at that time. If none of the words in that subclass applied, then none were chosen. Education may have been an important factor affecting a person's ability to complete the questionnaire. The majority of those in the sample were from a mainly working class background.

A problem encountered in the survey and interview methods is one of respondents trying to please the researcher by giving answers which they think the researcher wants. In the MPQ, this situation arose a few times whereby on completion of the MPQ, respondents stressed a concern with having given the "right" answers. This may have occurred on the MPQ word list section, where respondents may have felt compelled to select a word from every category even though they were reminded that they did not have to. The fact that the interview data revealed fewer words to describe pain than the MPQ may have been partly due to this.

vi) Administering the non-pain measurements: The Nottingham Health Profile and The FACES Scale

In addition to the MPQ and VAS, two other measures were given to the patients. One was one page of the Nottingham Health Profile (see Appendix, 1.1). The questions asked them to record whether their present state of health had caused them any problems in the following areas: home life (doing tasks around the house such as housework and DIY); social life (can they get out and socialise); hobbies and interests; sex life; relationships in the home and going on holiday. This was included as it was felt to be a useful summary of some of the main areas of a person's life which may have been affected by their pain. The NHP has been tested for face, content and criterion validity and has been reported to be a satisfactory measure of subjective health status in physical, emotional and social spheres.

As well as this a Faces scale was included (Andrews & Withey, 1976, see Appendix 1.2). This is an affective evaluation of quality of life which involves a cognitive evaluation and some degree of positive/negative feeling (affect). The authors of the scale compared it with other similar scales and presented evidence that it was a more valid measure than most other scales assessed. But apart from original work by the authors which reported good reliability and validity, there have been few published studies reporting usage of this scale.

A study of 662 people aged 85+ in the East End of London by Bowling and Brown (1991) reported that the FACES scale was fairly skewed with about a quarter of respondents choosing the terrible faces, while over half selected a delighted face. Research on stroke patients in the UK by Anderson (1988) also found the measure to be skewed, with 19 per cent of respondents choosing a terrible face and two-thirds choosing a delighted face. A similar result was found in this study in that the majority of the sample chose a happy face. One possible reason for this is that people may be trying to portray a picture of how they would like to be seen. It could be argued (as will be discussed in later chapters) that people want to be seen to be happy and able to cope with life.

Respondents were shown five faces ranging from wide smiles to turned-down mouths. They were told, "Here are some faces expressing various feelings. Which face comes closest to expressing how you feel about your life as a whole?". Below each is a number which was circled accordingly. Other sociological work on quality of life measures (Fitzpatrick et al, 1992) has found pain to be a good indicator of quality of life. Including the Faces scale was therefore one way of assessing whether this relationship existed in our sample. There appeared to be no problems for people in using this scale.

vii) Developing the Interview Questions

Semi-structured interviews were conducted for reasons discussed earlier. This involved asking the same major questions to every respondent but having the freedom to change the order and probe further according to respondents answers. The questions covered seven based on other studies of chronic illness as discussed in the Introduction. The main areas were:

a) *living with arthritis*: - this included questions on the duration of the illness and its effect on the person's life eg has having arthritis affected your life in any way? Although these questions do not at first appear relevant to the issue of pain, they were important as they provided details of the context in which the pain experience arose.

b) *description of pain*:- these questions referred directly to the pain itself eg how would you describe your pain over the past week? They were important in providing information which could be directly compared to the pain measurements. For example, the words a person used to describe their pain in the interview (such as unbearable) could be compared to those chosen from the McGill Pain Questionnaire.

c) *treatment*:- this section covered the area of medical and non-medical treatments the person in pain had used and their effectiveness eg does the medication relieve your pain? These questions were important as they indicated whether the person was able to relieve their pain or not and the extent to which they had tried alternative treatments when traditional ones had failed and in turn whether these alternatives were effective or not.

d) *coping with the pain*:- As well as finding out what the pain was like in specific terms normally used by the doctor eg location/duration, it was also important to understand how the person tried to cope with the pain in their day-to-day lives. Being able to control the pain, even to a limited extent, was seen as important as it may have meant the person's life was less affected by it than someone who could not find a way of controlling their pain. In turn this may have lead to the former person scoring lower on the affective dimension of the McGill Pain Questionnaire.

e) *relationships with others*:- there is a growing literature on the influence of family relationships on a person's ability to cope with their pain (Revenson et al, 1991; Jamison & Virts, 1990). The findings are mixed, but it appears that people who perceive they have 'supportive' spouses (there remains disagreement over what counts as 'supportive') report a lower intensity of pain. It was therefore felt important to examine this area in more detail. Questions included: do you think your (husband/wife/daughter etc) understands your pain? Would you say they are supportive? In what ways are they supportive? This area also provided insight into who the person was willing to talk about their pain to and who they were not. This is important in terms of measurement as it shows how the relationship between the person in pain and the person who wants to know about it could lead to different accounts of the experience.

f) *relationship with medical staff*:- in relation to the latter point about the importance of the social context in which the measurement was taken, it was important to find out whether people held back from telling the doctor about their pain and if they did, why? For example, if the person felt that the doctor did not understand their pain they may be inclined not to bother telling him/her how it really felt. In terms of measurement, this could mean that the person may underplay their pain. Alternatively, if the person always received stronger medication if they said their pain was worse, they may deliberately overplay their pain and score higher accordingly so that they would receive the medication they required.

g) *pain and identity*:- the final area which was investigated was to do with the perceived impact of the pain on the person's sense of self. As illustrated in the Introduction, chronic illness can have a major impact on what the person can and cannot do. More importantly, these restrictions influence the person's sense of self as it is through these activities that a positive self-identity is maintained. For example, when a husband and father who prides himself on his ability to provide for the family finds he has to give up work because it is too painful, this can lead to a loss of self (esteem). Restrictions can lead to frustration and changes in mood which the person may also find hard to cope with and can also affect their sense of self.

The full list of questions can be found in the Appendix (2.0). The questions were piloted on five patients and minor changes were made. In particular, the area of sex and how living with pain caused problems with this part of people's relationships arose during the pilot stage. Several respondents mentioned it without being prompted and it was therefore added to interview questions as well as being included in the NHP, although it was asked in such a way as to be sensitive to people's feelings as not all them wanted to talk about it.

In terms of understanding the questions, there appeared to be few problems. The use of a semi-structured format allowed the interviewer to prompt people who were less verbal in their answers and to expand on areas that arose during the interview itself.

iv) Conducting the Interviews

The interviews were conducted by myself and my supervisor, David Kelleher. It was decided that the patient and the relative be interviewed separately so that they would not influence each others answers. In addition, the presence of a partner has been found to influence the pain measurement scores. A study by Block et al (1980) found that patient's pain scores changed when they perceived their spouse was watching them compared to when they were told the hospital clerk (a neutral observer) was watching. The interviews were also tape-recorded. None of the subjects objected to this being done. The average length of time of the interviews was one hour.

The interview, as a research method, and in particular the effect of the interviewer on the information obtained in the interview is an important issue in research methodology. There are many differing views on the role of the interviewer and how the interview should be conducted. According to Oakley (in Roberts, 1987), the common paradigm of the social research interview emphasises the following characterisitics: that it is a "mechanical instrument of data collection"; that it functions as a "specialised form of conversation in which one person asks the questions and another gives the answers"; that it characterises the interviewees as "essentially passive individuals" and its reduction of interviewers to a "question asking and rapport-promoting role" (Oakley, 1987:37). The main concern is the reduction of interviewer 'bias'. 'Bias' occurs when there are systematic differences between interviewers in the way interviews are conducted, with resulting differences in the data produced. Such bias would invalidate the scientific claims of the research, since "the question of which information might be coloured by interviewees' responses to interviewers' attitudinal stances and which is independent of this 'contamination' cannot be settled in any decisive way" (Oakley, 1987:36).

This concern with controlling for interviewer 'bias' has been criticised by those from a more interpretive (ethnographic) perspective. They argue that the interview is a social process between two individual human beings which can never be replicated exactly. As the interview is an example of social interaction, the meanings that the interviewees give to the situation are complex and their influence on the information obtained cannot be easily assessed. Interviewee's interpretations of the researcher's interests, attitudes, values and reactions to them are fundamental to their perception of the research situation. For example, as in all social interactions, people use 'stereotypes' with which to base their assumptions on. Many of these are based on external criteria such as sex, age, race, social role etc. The conclusions people draw from their impressions will affect what they themselves want out of the interview and the type of person they choose to present to achieve this end and how they manage the impressions that the researchers have of them. In the giving of accounts to others, people are not just concerned with making their actions comprehensible but also "warrantable" - the legitimation of action and the presentation of a credible and legitimate self (Harre and Secord, 1972 in Jones, 1985).

It could be argued, therefore, that the search for an objective 'truth' in the interview situation is misconceived. As Hammersley and Atkinson (1983) point out, social research is 'reflexive' in that we are part of the social world we study and therefore cannot avoid having an effect on the phenomena we study. Rather than trying to eliminate the effects, they should be understood.

> "We should consider what the informants statements reveal about his/her feelings and perceptions and what inferences can be made from these about the actual environment or events he or she has experienced. The aim is not to gather 'pure' data that are free from potential bias ... rather the goal must be to discover the correct manner of interpreting whatever data we have". (Dean & Whyte, 1958)

Bearing these points in mind, attempts were made to conduct the interviews in a systematic and reflective manner. The questions were semi-structured as indicated earlier which allowed for a degree for flexibility. In the majority of the interviews, whether it be the patient being interviewed or the relative, a female researcher interviewed the women and a male researcher interviewed the men. As Warren (1988) highlights, there is a 'myth' in qualitative research that women are "better" at qualitative work due to their "unthreatening" demeanour and better communication skills, hence they are more likely to get people to "open up" to them. This, I would argue oversimplifies the issue. First, same-sex interviews imply that "gender" is neutralised but this may not be the case. Men-only interviews may differ from women-only ones, although it was difficult to assess in this study. In terms of the respondents, there did seem to be a tendency for women to be more talkative, but this did not appear to be due to the gender of the researcher only.

More importantly, there are other factors such as power. In this particular interview situation, it could be argued that there is an unequal power relationship between the researcher and the respondent. For a start, the majority of the respondents were from a working-class background. Although it was repeatedly stressed to them that we were not medical professionals, but interested in the social aspects of their illness, how they perceived our role and our motives is hard to ascertain. On reflection, some of them seemed pleased that there was someone taking an interest in them rather than just in their disease. Others, particularly those living alone, appeared to enjoy the company. We were always given tea and biscuits which indicated a good rapport had been achieved.

The potential for the semi-structured interview method to allow the understanding of how people make sense of their pain is also important. As discussed above, the data produced by the interview method (and any research method for that matter) is shaped by the interaction between the researcher and the person being interviewed. This cannot be controlled by the interviewer but the relationships achieved must be considered during analysis. How the interview data was analysed will be discussed further on but how the interview method was used to gain understanding and its ability to do this will be the focus here. The interview method, first of all, allowed the person to describe their pain and to talk about their experiences in their own words. As with any social interaction, some people will talk more than others. With the interviews in this study, it appeared that many people did not think about their pain to a great extent in their daily lives. This was largely because it was a taken-for-granted part of their lives which they did not think about or want to really think about. One way of coping with pain, for instance, was to not think about it. The interview situation along with attending the doctor's clinic were the main occasions where they were asked to describe their pain.

This leads on to a further problem that the way the questions were structured could have led to a description of their experience in the form that the researcher wanted. For example, asking questions about pain as a bodily experience ie where is the pain? will lead to pain descriptions along bodily lines. To overcome this, other questions were included such as, how has your pain been over the past week? This elicited responses along both bodily and emotional lines ie "it's in my legs", "it's miserable". Questions were then further asked to find out why the pain was miserable. Obviously, the people being interviewed do not know why they use certain words to describe their pain and not others or why they feel annoyed and frustrated when they cannot do things because of the pain. But the comments made in the interviews have common themes which can be linked to wider social/cultural beliefs about the way to respond to pain and illness and the relationship between the individual and society (see Introduction).

Finally, there is the point that the method of administering the MPQ and VAS could have influenced the subsequent interviews. It was decided to administer them after the interviews so that the words on the MPQ would not influence the words people would use in the interview. In other words, as the aim was to see how people described their pain in their own words, providing them with a list could lead to people using the MPQ words rather than the words they use normally. But there is the contrasting view, advocated by Melzack that providing people with a list of words will lead to more 'accurate' descriptions of their pain. The theory behind this argument is that some people find it difficult to describe their pain because they have a limited vocabulary. Melzack found that people using the MPQ appeared to be "relieved" at being able to describe their pain.

c) Analysis

i) Comparing the Interview Data with the Measurements

In order to assess the validity of the measurements, several questions were explored. The first question was, could the measurements distinguish those who were in great pain from those who were not. In order to test this, the test scores were compared with patients accounts. The reason for doing this was because, as mentioned at the beginning of the chapter, the patients' accounts were taken to be the most valid account of their pain.

The first step in doing this was to see if the subjects used the same words in the interview to describe their pain as they chose on the MPQ. To assist in this process and for further analysis of the interviews, the qualitative computer program, Ethnograph was used. This allows the coded data to be extracted and sorted quicker than by the traditional paper and scissors method.
This proved straightforward as people did tend to use distinct pain words which could be identified easily.

The next step was to develop a way of comparing the scores with the interviews to see if the subjects reported a similar level of pain in the interviews as they did on the measurements. It was decided that two people, myself and my supervisor would independently rate the interviews and place them into one of three pain groups: high pain; medium pain and low pain. Three benchmark interviews were selected upon which the others were compared. The criteria upon which this was based was as follows:

(1) pain words:- the words people used to describe their pain ie mild (not much pain) would be placed in the low group; excruciating in the high pain group. Obviously, our own cultural understanding of the intensity of pain implied by the words would be guiding this choice.

(2) pain descriptions:- this included sentences people used to describe their pain which did not
contain specific pain words ie "burning" but described the experience ie "it's not too bad", "it's reasonable".

But deciding which pain group to place people in was not just based on pain descriptions alone. It was felt difficult to ignore the fact that we had seen the people we had spoken to and heard their descriptions in their *social context.* In other words, we had knowledge of their experiences in the past and their thoughts about how to respond to pain ie whether they were likely to be stoic or not. This context also included the effect pain had had on their lives. Descriptions of pain tended to be expressed in terms of how it had affected their lives and how they felt about the effects. This differs from the doctor-patient context where the focus in on a physical description of pain and the patient's own interpretations and experiences ignored. In other words, as social researchers and by interviewing the person in a non-medical context, the interview process, it could be argued, allowed insights to be gained into the "suffering" rather than the narrow medical "pain".

The benchmark interviews were rated by a group of MSc students at the University and agreement was found ie all 15 students rated high benchmark case as high and medium as medium and the low as low. The independent ratings were then statistically compared to the VAS scores. This was achieved by first dividing the VAS scores into the same three groups (high, medium or low) and then using SPSS to compare them for agreement.

ii) Analysing the Measurements

The second question proposed to assess validity was to see whether there was any correspondence between an individual's scores on the McGill Pain Questionnaire and the Visual Analogue Scale. If there was, it would mean that they were measuring something similar. The MPQ contains the notion of intensity, with words used to describe pain located along a scale of intensity, similar to the VAS. It was therefore possible to statistically compare the scores obtained on the MPQ with those obtained from the VAS using SPSS.

As discussed in the measurement chapter, another way of assessing validity is to see if there is any relationship between the scores on the pain measurement and other factors said to be related to pain such as quality of life or depression. The scores from the NHP and FACES were therefore also correlated against the pain measurements to see if any relationship existed between them.

The literature review revealed another area which could have an important impact on the validity of the measurements. This is concerned with the mixed findings over whether there are any gender differences in the use of the measurements (see Measurement chapter). The measurement scores of men and women were therefore compared statistically ie to see if their scores differed and also through the use of qualitative methods, ie content analysis. This enabled the analysis and comparison of the frequency and type of words men and women used when describing their pain in the interviews.

The final question to be explored was whether the other family members could tell how much pain their partner was in and hence score the VAS in a similar manner. This was tested by statistically comparing the two sets of scores.

iii) Analysis of the Interviews

The interviews were also used to explore the experience of living with chronic pain. As discussed in the Introduction, chronic illness and pain, is more than a physical experience - it has social implications too. More importantly, the social impact of pain is considered worse than the physical, leading to the suggestion that the chronic pain experience should perhaps be called "suffering". It was also suggested in the measurement chapter that the MPQ may actually be a measure of the affective distress, or "suffering" that the person is experiencing. It was therefore felt necessary to explore the nature of "suffering" of the people in this sample by using previous studies of chronic illness as a framework to guide analysis.

FINDINGS

As previously outlined in the methods chapter, the aim of the research was to assess the validity of two pain measures; the Visual Analogue Scale and the McGill Pain Questionnaire and to see whether social factors influenced pain scores. In order to do this, the following questions were explored:

1. Can the pain measures distinguish those who are in great pain from those who are not? In order to test this, the test scores were compared with patients accounts.

2. Can they validate each other? Is there a degree of correspondence between an individual's scores on the two measures?

3. Do the results show differences between men and women? Past research into gender differences and pain have shown mixed results. Factors such as age, class or ethnicity have been ignored and findings are controversial, either revealing no gender differences (Hardy et al, 1954; Lawliss et al, 1984; Neri and Agazzani, 1984) or lower thresholds in women (Woodrow et al, 1977, Otto and Dougher, 1985, Dubriel and Kohn, 1986). It was therefore felt necessary to see whether there were any differences between the pain scores for men and women as any differences found could also be due to other factors apart from pain tolerance. In other words, women may choose more words on the MPQ because they are used to verbalising their illnesses more than men. If this is found to be the case, then it will have important implications for the validity of the measurement.

4. Do the scores for those living alone differ from those living with others? Social support has been shown to have an important influence on the quality of life of people with chronic illness (see Introduction). It was therefore felt important to see whether social support also influenced the pain experience. In order to test this the scores from the different measurements were compared between the two groups. The relationship between quality of life (as measured by the NHP), depression (as measured by the FACES) and the pain measurements was also explored to see if this differed for the two groups.

5. Can others tell how much pain a person is in? This was felt to be a further important test of validity in that the comments other family members (OFM) made in the interviews about the patients' pain, the OFM's VAS scores and the patients' VAS scores and interview comments could be compared. In other words, if the OFM's

comments suggested a similar picture of the experience as that of the patients' VAS scores but the OFM's VAS scores differed, then this would have important implications for the validity of the VAS.

In order to investigate the first question, do the pain measures validate each other, the following methods of analysis were employed. The results of the measurements were statistically analysed to ascertain whether there was any significant relationship between them. It was expected that as they are supposed to be representing the same construct, pain, a significant relationship would exist.

1) The VAS and the Interviews

The VAS was compared to the interview first. The interview was taken as a form of measurement of pain by people using their own words and their own ways of measuring pain. Content-analysis of the words revealed that people used an average of two words each to describe their pain (range = 0-6). In five cases no specific pain words were used. The ratings were therefore based also on the ways people talked about their pain such as "I have very little pain", or "the pain is reasonable" as this appeared to be the most frequent way of talking about pain rather than the use of specific words. The inter-rater agreement was high (0.68).

Table 1: Comparison of Interviewer Ratings with Patient VAS; Relative VAS; Patient's Living Alone and Patient's Living with Others

	T-test	Significance
Interviewer Ratings and Patient VAS	1.75	.088
Interviewer Ratings and Relative's VAS	4.56	.000*
Relative's VAS and Patient's VAS	3.21	.004*
Interviewer Ratings and Those Living Alone	1.00	.336
Interviewer Ratings and Those Living with Others	1.41	.170

When the interviews were compared to the VAS scores, the t-test revealed no significant difference between the scores (t=1.75, p=.088, Table 1) suggesting that the VAS was discriminating between those people with low pain from those with medium or high levels of pain. But the words that the interview ratings were based on do suggest that it is not necessarily pain intensity that is being measured and it may therefore be too simplistic to say that the VAS is a valid measure of pain sensation. People frequently spoke about their pain in terms of evaluative words ie how the pain made them feel. These included words like "unbearable", "excruciating", "annoying" or longer sentences such as those described above, although sensory type words were used as well. The interview data suggests that people may conflate/link together the intensity of their pain with how they feel about it and this may also be reflected in the VAS measurement; they may not be simply measurements of the intensity of the pain but include people's feelings about the pain.

In order to provide a further check on whether the VAS was measuring the evaluative dimension or the sensory, the words most frequently used by those interviewed were compared to the VAS scores. In other words, it would be expected that if the VAS was measuring the intensity of the pain sensation, there would be similar VAS scores for certain sensory words. The most frequently used word in the interviews was "ache" (43%) followed by "hurts" (35%). But the VAS scores for "ache" ranged from 12-100, suggesting otherwise. Another possible explanation is that "ache" could vary in intensity; some people may experience a lot of ache, while others experience a little. The VAS may be measuring the amount of ache the person is experiencing.

For the evaluative words, there does appear to be some relationship between the VAS scores and these type of words. For those in the low pain group, the following evaluative words were used: reasonable; miserable; annoying; irritable. For the medium group; tired and for the high group; killing; unbearable; excruciating; uncomfortable; disturbing; severe; overwhelming; bad; acute; and terrific. What is interesting is that those with a high VAS score tended to use more evaluative type words than those in the other groups suggesting that those with a high VAS are those who are affected more by the pain. In other words they are finding the pain more difficult to cope with. This does not necessarily mean that they are in *more* pain than the other two groups. The way people respond to pain does not always relate equally to the sensory experience as previously discussed in the introduction.

To summarise so far it would appear that interpreting the VAS scores is not as straightforward as previously expected. More importantly, at this stage it seems to lack construct validity and rather than measuring pain intensity it would appear to be measuring how the person feels about their pain (or how it makes them feel). In order to investigate this further, the VAS needs to be compared to the other pain measurement used, the McGill Pain Questionnaire. This comprises the next section.

2) The McGill Pain Questionnaire and the Visual Analogue Scale

As mentioned earlier, comparing the results of the VAS and MPQ is another way of assessing the validity of both measurements. It was expected that if they were both measuring pain, when someone scored low on the VAS they would also score low on the MPQ. In order to compare the two sets of scores, as with the interview ratings, the MPQ and VAS scores were divided into three groups. The MPQ scores used were the Pain Rating Index totals (PRI), that is the total score for the all the words selected from the MPQ for each person. These were then compared to see if there was any difference between the two sets of scores. The t-value was 3.67, p=.001, indicating that there was a significant difference between them.

Table 2: Summary of Correlations Between Measurements

	vas (p)	vas (s)	vas (h)	PRI (T)	ppi (now)	ppi (w)	PRI (s)	PRI (a)	PRI (e)	PRI (m)	nhp	faces
									.360 (.047) *	.157 (.508)	.230 (.175)	.371 (.080)
vas (p)	-	.387 (.08)	.678 (.000) *	.158 (.328)	.658 (.000) *	.496 (.001) *	.055 (.736)	.034 (.851)	-.096 (.701)	.027 (.911)	-.007 (.973)	.127 (.580)
vas (s)	-	-	.400 (.072)	.016 (.944)	-.054 (.813)	-.233 (.307)	-.072 (.755)	-.514 (.034)	.291 (.112)	.040 (.832)	.300 (.074)	.537 (.000)
vas (h)	-	-	-	.153 (.957)	.597 (.000) *	.251 (.117)	.153 (.344)	-.047 (.794)	.245 (.183)	.723 (.000) *	.328 (.050) *	.265 (.117)
PRI (T)	-	-	-	-	.106 (.514)	.059 (.714)	.913 (.000) *	.845 (.000) *	.438 (.013) *	.127 (.502)	.120 (.485)	.362 (.029) *
ppi (now)	-	-	-	-	-	.500 (.001) *	.044 (.784)	.195 (.276)	.285 (.119)	.179 (.341)	-.040 (.816)	.199 (.244)
ppi (w)	-	-	-	-	-	-	-.096 (.555)	.303 (.085)	.169 (.363)	.561 (.001) *	.217 (.202)	.156 (.362)
PRI (s)	-	-	-	-	-	-	-	.662 (.000) *	.195 (.310)	.526 (.005) *	.134 (.477)	.080 (.670)
PRI (a)	-	-	-	-	-	-	-	-	-	.166 (.417)	.078 (.693)	.137 (.486)
PRI (e)									-	-	.337 (.072)	.420 (.023) *
NHP									-	-	-	.527 (.000) *
faces									-	-	-	-

But this result alone does not mean that they lack validity. The difference could arise due to the different scoring methods. Correlations need to be calculated as well. Table 2 contains a summary of the correlations between the VAS and the various scoring methods of the MPQ.

The first comparison to be made is between the PRI (T), mentioned above, which is said to represent the overall pain intensity. As the VAS and the MPQ are supposed to be measuring pain intensity it was expected that the two results would correlate significantly. They did not (r=.158, p=.328). This suggests that they are measuring different pain constructs. The MPQ is based on a theory of pain which argues that there is more than one dimension to the pain experience and therefore has a score for each of the three dimensions (as well as a miscellaneous one).

The only dimension to significantly correlate with the VAS is the evaluative dimension (r=.360, p=.047). This is interesting considering there appeared to be a relationship between the VAS and evaluative words from the interview. Again, this could imply that the VAS is measuring the degree to which someone is bothered by the pain, rather than the amount of sensory experience per se as well as the amount of pain.

The second scoring method is the present pain intensity (PPI). This is said to be an overall measure of pain intensity and it was expected that the PPI and VAS would correlate. They did (see Table 2, r=.658, p=.000). Again, this could be further evidence that the VAS is measuring evaluative aspects of the pain experience as the PPI is based on evaluative words.

The number of words chosen (NWC) is another scoring method with the assumption that the more pain someone has the more words they will choose. As with the PRI scores, the NWC did not correlate with the VAS either (r=.157, p=.345).

c) The McGill Pain Questionnaire

A further way of assessing the validity of the MPQ is to compare the relationship between the different scoring methods. It is expected that the scores would correlate significantly as they are all said to be measuring the pain experience, albeit different parts of it. In other words it was expected that the three different dimensions would correlate with each other.

The only dimension not to correlate with any of the others was the evaluative dimension (see Table 2). This would imply that the evaluative dimension is distinct from the others. As discussed earlier, it is known that the response differs from the sensation in magnitude and may explain the poor correlation between it and the sensory and affective dimensions. To some extent, it could be argued that the MPQ is measuring the pain experience as theorised by Melzack as it can identify the distinct dimensions. But it is still not clear whether these dimensions are being adequately measured by the MPQ ie do the words adequately capture the different dimensions of the pain experience? Are they reflecting something else? or are they omitting to represent some of the aspects of the pain experience?

One way is to see whether people chose a word from at least one of all three of the dimensions, if they did not, then it could mean the MPQ is invalid. All 40 chose at least one word from the sensory dimension, 33 out of 40 chose at least one from the affective, 31 out of 40 chose at least one from the evaluative dimension and 30 out of 40 chose at least one from the miscellaneous category. One possible reason for this distribution could be that compared to the sensory dimension the evaluative comprises only one sub-category (a total of 5 words) which may bias people's choice, particularly if the choice of words is not relevant. It does not necessarily mean that this dimension does not exist but that the measurement instrument is constructed in such a way that it does not adequately capture all aspects of it. For example, one man only chose two sensory words from the MPQ, but in the interview used five, including two evaluative words.

As the PRI score is based on the individual's choice of words, the meaning of the words will have an important bearing on the result. In the interviews people used far fewer words than they chose from the MPQ. This was partly expected as people do not use their full vocabulary when discussing their pain. In other words, although they may know the words listed on the MPQ they may not use them in everyday use. It could be argued therefore that the MPQ is useful in this respect as it enables people to express their pain more clearly. But it could also be argued that the words chosen are a reflection of the words the person understands or recognises and that better educated people are therefore likely to choose more words than less well educated people who may refrain from choosing words such as excruciating.

There did appear to be some similarity between the words used in the interviews and those chosen from the MPQ. As mentioned earlier, ache was used most frequently in the interviews and it was also the most frequently chosen word from the MPQ (63%). But hurt was only chosen by 8% (3 people).

The method of scaling the words will also have an important bearing on the scores. The VAS scores were compared to the most frequently chosen words from the MPQ to see if people who chose similar words also had similar VAS scores. As the VAS scores of those who used ache in the interviews varied, it was expected that these would too.

Dimension	Word	Mean VAS	SD	Range
Sensory	Aching	54	1.41	12-100
Affective	Exhausting	60	3.00	20-100
Evaluative	Annoying	40	10.00	5-82
Misc.	Nagging	55	1.41	12-96

As shown above the VAS scores of people who chose the same words varied widely. These findings suggest that the way the words are scaled on the MPQ is questionable. In other words, the intensity implied by each word may not be the same for everyone. For example, someone may find the ache worse than others. Perhaps words such as ache should be measured on an intensity scale ie no ache - lots of ache.

The word "annoying" was the most frequently chosen word from the evaluative dimension and as shown above was chosen by people with varying VAS scores. This is important if, as previously discussed, the VAS is measuring the evaluative dimension. The wide range in scores could be taken to mean that like ache, annoying may vary in intensity too. Pain may be a little bit annoying or very annoying. Another possible explanation could be that as the evaluative dimension only comprises five words, the choice may be restricted.

To further explore these points, the interviews need to be studied. It appears that those who chose the word annoying from the MPQ, varied in their definition and experience of the annoying aspects of pain. More importantly, it wasn't the pain itself which was annoying but the effect it had on their lives:

> ".. when you get it to the stage when it's bad, it does limit you
> but it's more, it's not the pain so much, but I get annoyed when
> it limits you in what you can do." (woman, no. 33: 498-500)

Some of those who used the word annoying and some of those who did not, frequently used the word, "frustrating" to describe how they felt about the pain. What appears to be important is how the person copes with the limitations. Some of those interviewed used the words annoying/frustrating along with words like "miserable", while others who used it, had accepted the limitations and did not describe themselves as feeling like this.

> "It (pain) makes you feel miserable, because you can't .. you want to do something and you can't." (woman, no.10:555-556)

> "... when you can't do things and you want to you get frustrated don't you? Then you just accept it, you have good days and bad days. ... As long as I can do things, albeit not as much as I could, but as long as I can do things, you just accept it. That way it doesn't worry me." (woman, no. 22: 97-101).

This illustrates that for some people the pain was a little annoying while for others it was very annoying. This cannot be interpreted from the MPQ word list. Also, having the word annoying and miserable in the same group could lead to problems; as described above, some may find the experience both annoying and miserable, while others find it annoying but not miserable.

Another method of establishing the intensity of the MPQ words was to see whether those in the three pain groups, low, medium and high used similar words. As already discussed, ache went across the range of VAS scores and there was no significant difference in the number of people who used the word in each group. In fact, there was only one word, throbbing, which was chosen more frequently by those in the high pain group (50%) compared to only 25% in the low and medium groups. Perhaps the throbbing sensation is harder to cope with.

More importantly, ache may be different from pain. Several of those interviewed talked of the ache being different from the pain. Ache in some cases was worse as it could not be relieved totally. There also appear to be certain words which distinguish ache from pain. For ache these are: burning, cramping; gnawing, whereas the pain tended to be sharp or shooting. This difference is not detectable on the MPQ and could give a misleading picture of the experience.

So far then it would appear that the MPQ may not be as valid as it might at first appear. The score is determined by the individual's choice of words and it has been shown that this choice may be affected by factors such as the person's pain vocabulary. The scoring method, ie the scaling of the words is also questionable as the words chosen do not appear to be able to differentiate between those who are in a lot of pain and those who are not. The problem appears to lie in interpreting the scores. For example, how are we to interpret the score of someone who scores highly on the sensory dimension but low on the evaluative? Are they in more pain than someone who scores lower on the sensory dimension but higher on the evaluative? The words on the evaluative dimension do not appear to provide the full picture either.

d) Comparing the VAS, MPQ and Interviews: Qualitative Analysis

So far the three pain measurements have been compared statistically and this has shown that the interviews and VAS correlate significantly but not the MPQ (pain rating index scores). In other words, at this stage they do not appear to be able to validate each other. In order to determine why this should be, qualitative analysis and interpretation is needed. Looking down the results, there would appear to be no relationship between the PRI scores and the VAS. In order to try and explain the poor correlation between the two, the MPQ scores were divided into the three groups used by the interview raters, namely low, medium and high pain. This was achieved by dividing the maximum possible MPQ score by three (low = 0-22.34; medium = 22.35-44.68; high = 44.69-67.03). The original VAS scores were also divided into three groups in a similar manner ie the three groups consisted of VAS scores of 0-33; 34-67 and 68-100. It was felt that this would enable the scores to be compared more easily.

There appeared to be quite a few people with high VAS scores but low MPQ scores (9/40, 23%). Their scores were as follows:

No.	VAS	MPQ	Interview Rating
2p	97 (H)	5.18 (L)	High
3p	82 (H)	18.65 (L)	High
3	62 (H)	10.09 (L)	Medium
10	100 (H)	19.82 (L)	High
23	68 (H)	14.26 (L)	High
27	100 (H)	14.46 (L)	High
29	72 (H)	16.78 (L)	High
31	70 (H)	7.98 (L)	High
32	63 (H)	16.10 (L)	Low

(H) = high pain group; (L) = low pain group

Taking each person separately, the three measurements were compared qualitatively. For example, if someone used similar words in the interview to those chosen from the MPQ, then this could mean that the weighting of the words on the MPQ is incorrect. This method could also serve as a check on the validity of the three dimensions of the MPQ as some people may use words or phrases covering all the dimensions in the interview but not choose words from each of the dimensions of the MPQ.

i) The first person above is number 2p. This gentleman scored 97 on the VAS but his MPQ (PRI (T)) score was very low (8.60). These scores give a different picture of his pain; if just taking the VAS it would appear that he is in a lot of pain, but the MPQ score could be interpreted as showing that he is not in a lot of pain. In fact, on the MPQ he only chose two words (10%); throbbing and aching. He did use these two words in the interview but he also used other words such as "unbearable" and "excruciating". Unbearable is included in the list of MPQ words but he did not choose it. Excruciating on the other hand is part of the MPQ and he did choose it. Apart from individual words, he also described his pain as "constant" and used a metaphor too in which he said it felt like he was "walking on his kneecaps" (301). The metaphor plus the words above would seem to imply that he is in a lot of pain which was why he was placed in the high group by both of the raters. This high group rating correlated with his high VAS score and PPI too, but the MPQ (PRI (T)) score appears to "underplay" the pain he is in.

The important question then is why should this be? Why did he not choose more words to describe his pain and hence have a higher MPQ score? One possible explanation could be, as suggested earlier, education, ie that he did not understand all of the words on the MPQ. But unbearable was in the list of words but he did not choose it. Another possible explanation could be that as he was in a lot of pain, he found it difficult to concentrate on the long list of words which comprise the MPQ. He had just been interviewed for almost an hour and being in constant pain may have affected his attention.

Finally, in terms of the three dimensions, in the interview he did use words from each of the three dimensions but did not when choosing from the MPQ word list. Just using the PRI therefore would have given a misleading picture.

ii) Turning to the second person, 3p. This woman had a high VAS score (82) and an MPQ score in the low group (18.65). The words she chose from the MPQ were: throbbing; gnawing; hot; itchy; aching; exhausting; annoying; and nagging. A total of 8 out of a possible 20 (40%). Although she did not use exactly the same words in the interview, she did describe her pain in such a way that the words would describe a similar experience. For example, she described the pain as being like "a raging toothache all over your body". Words like throbbing; nagging; aching and gnawing it could be argued describe a toothache. She also said the pain made her feel "terrible" and "fagged out", in other words, very tired, (she chose exhausted from the MPQ).

The high VAS score and interview rating correlate significantly, but not the MPQ. As seen above the words and metaphor seem to give a similar description but the total score gives a different picture. Her PPI was 3, distressing, which would appear to correlate with the VAS and rating too. From the evaluative dimension she chose the word "annoying" which implies a lower pain intensity than the PPI or VAS would indicate. In the interview she did describe the frustration caused by being in pain and not being able to do things. The low weighting value of "annoying", therefore would appear to understate this aspect of the experience. In other words, it is not that she is underplaying her pain by choosing "annoying" but that its weighting may be misleading.

iii) The next person's score (3), again the VAS is quite high (62) and the MPQ is low (10.09). She chose only four words (20%): stabbing; aching; annoying; and nagging. In the interview she did use two similar words, annoying and nagging but she did not use aching and stabbing. She also used the word "miserable", which is on the MPQ but as it is in the same category as annoying, both could not be chosen at the same time.

This is an important point as it could be argued that miserable and annoying should perhaps be in separate sub-categories as other people who used both words in their interviews too but could not choose both from the MPQ. Also, it was not always the case that those who found the pain annoying also found it miserable. Pain may be annoying as it makes certain things difficult to do, but some people may be able to cope better with these problems than others and so not become miserable.

To continue, No. 3 said that her pain "has not been very bad this week" but it was the week before and that it was "nothing serious". This would seem to explain why the VAS was not higher, in other words, the pain was not as bad as she had previously experienced. Although the VAS was classed in the high pain group, the score is actually on the border and her comments would seem to suggest this, as she was put into the medium group by the raters. But the MPQ score would still suggest someone with very little pain.

iv) Turning to the fourth one on the list above (no. 10), this woman scored the highest possible on the VAS (100) but quite low on the MPQ (19.82). From the list of words she chose 7 (35%): throbbing; hurting; tender; tiring; unbearable; spreading; and agonising. In the interview her description was not so detailed, she described the pain as being constant and severe. It also made her feel miserable and she often felt annoyed and frustrated because she could not do things as she was wheelchair bound and in too much pain. When talking about her pain she tended to talk about it in terms of what she could or could not do for herself e.g. cook hot meals and the loneliness she felt being trapped in the house. In determining which pain group she was to go in, these other ways of talking about the experience in the interview were taken into account as they appear to capture the effect of the pain on her life even though she did not describe it in specific words like aching etc.

The words she chose from the MPQ would appear to describe someone in a lot of pain, particularly the evaluative word unbearable and the misc. word agonising. More importantly, they appear to describe a similar experience to that portrayed by the interview and the VAS (ie both are high). Again, the problem appears to lie in the scoring method of the MPQ. Finally, as found statistically, there appears to be a relationship between the VAS and the evaluative aspects of the experience as the evaluative words from the MPQ, PPI and interview correlate with the high VAS score.

v) The fifth person number 23, had a VAS of 68, and a low MPQ score of 14.26. She only chose five words (25%) from the MPQ: throbbing; burning; exhausting; intense and nagging. In the interview she said her pain was "not too bad", but it had been bad the week before. The pain was still "very bad" at night though when it felt like "red hot needles" being stuck into her legs. This pain made her "cry out". Usually she doesn't like to complain about the pain so for it to make her cry out means that she must experience a lot of pain at night. Her description in the interview led to her being put into the high pain group which correlated with her high VAS score. The words chosen from the MPQ do appear to give a similar picture of the experience for example burning, nagging and throbbing seem to relate to her metaphor about the red hot needles. The evaluative word, "intense" is also one of the high scoring words in the category and would seem to imply a lot of pain. As with the earlier people, the MPQ words do appear to be valid in that they describe a similar experience but the way they are weighted appears to give a different picture.

vi) The sixth person scored very highly on the VAS (100), but scored low on the MPQ (PRI(T)), 14.46. As with the others, she chose few words (5, 25%): throbbing; hurting; exhausting; punishing and agonising. She did not use exactly the same words in the interview, but as with the others above, she did describe the pain in such a way that it would suggest a relationship between the measurements. For example, she described the pain in her knee as being so bad that she wished they would "take me leg off, the pain is so bad". Also, further on she said the pain was "blinkin' painful". Her use of the word, "punishing" perhaps reflects her being a Catholic and sometimes wondering what she's done to "deserve it". Therefore, like the cases above, taking the words alone without the scores, and in particular the evaluative ones, they appear to imply that the person is in a lot of pain.

vii) The seventh person has a VAS of 72, and a PRI (T) of 16.78. She chose seven out of a possible 20 words (35%): shooting; sharp; aching; tender; tiring; annoying and nagging. These words were similar to her description in the interview. For example she said the pain "makes you feel tired". Tiring was chosen from the MPQ. She also described it as being like toothache, the words shooting, aching and nagging could be used to describe a toothache. Apart from individual words, she also said she was "going through a painful period at the moment" (a flare-up) and in particular she had a "bad day" on Thursday (a few days before the interview). She also said she found the pain annoying as it made certain things difficult ie using her hands properly etc. Finally, when the pain is bad she finds it "overwhelming". Her MPQ sensory words are similar to those in the interview but the evaluative word does not seem to capture the "overwhelming" aspects which she mentioned.

viii) Moving onto the eighth person, this man had a VAS of 70, and a low MPQ score of 7.98. As his low score indicates, he chose only three words (15%): aching; exhausting and miserable. A word was chosen from each of the three dimensions confirming Melzack's theory. In the interview he spoke about the pain in the following way: "yesterday it was very bad (knee), very, very painful, ... the knee was very painful yesterday" (260). The words he used included,"very severe", "very acute". These comments would imply that the pain is very intense leading to him being put in the high pain group. But again his MPQ score is very low and taking the total score could be taken to mean he is not in much pain. The words exhausting and miserable are quite high intensity words on the MPQ, but do not achieve as high a score as would have been expected.

The low number of words chosen does not seem to reflect poor education level, in fact he was quite articulate in the interview. It would appear that another problem with the MPQ is the idea that those in more pain will choose more words. The evidence so far does not show this. What appears more important is not the quantity but the meaning of the words.

ix) The final person in this list of people with seemingly incompatible VAS and MPQ scores, also had quite a high VAS (63) and a low MPQ (16.10), but he also differed from the others in that the independent raters put him into the low pain group, correlating more with the low MPQ score. He chose seven words from the MPQ (boring; pressing; aching; taut; exhausting; annoying and nagging). In the interview he only used one word to describe his pain, ache, which he felt after painting the fence one day during the past week. To be more specific he said his hands "ached something terrible". Usually though he says he gets "very, very little pain". He had experienced worst pain in the past but recently he had hardly any pain. It was based on his account of experiencing very little pain recently that he was put into the low pain group. His words chosen from the MPQ are high scoring when taken individually and would seem to imply quite a lot of pain, particularly the word exhausting. But they do seem to be related to the episode when he painted the fence which he found quite painful. His VAS also seems to be related to this too.

This is important as it shows the different meaning that "worst pain" can have for people. Many of those with a high scoring VAS seemed to be in constant pain, their worst pain would therefore not be too different from their usual pain (as shown with the correlation between the PPI and VAS). But there may be some people like the man above, who only experience bad pain occasionally after overexerting themselves for example. To them, this pain is probably quite bad compared to what they usually experience and would lead to them scoring highly on the VAS and choosing high scoring words on the MPQ. So to compare this man with the woman before based on their VAS scores would give a distorted picture. Their scores are quite similar both on the VAS and the MPQ, but their description in the interview differs quite dramatically. Someone who is currently going through a flare-up, will have a different experience from someone who has bad pain occasionally after overexerting themselves. More importantly, in terms of treatment, just basing the amount of medication on the person's worst pain score over the past week hides the fact that it may be referring to either to a one-off episode or pain that is constant.

So far the results show that to a certain extent the measurements do validate each other, but only in specific ways. Statistically the PRI (T) did not correlate significantly with the VAS and interview ratings. The reason for this may be due to the construction and scoring method of the MPQ as has been suggested. For example, the MPQ scoring method is based on the assumption that those in more pain will score higher on the MPQ than those who are in less pain because they choose more words. But the analysis above shows that this is not always the case with 23% of the sample who had high VAS scores also having low MPQ scores. The possible reasons for this have been discussed above and it would appear that the problem lies in the scoring method of the MPQ, and in particular the scale intensity weightings. The words on the MPQ are taken out of context and without interviewing the person it is difficult to tell how they interpret the words. This is not to say that they are not understood (ie poor education) but rather that words like "annoying" may mean different things to different people.

The time period to which people are asked to refer also appears to be an important factor, particularly for interpreting the VAS. Asking someone to rate their worst pain over the past week may cause problems in terms of treatment as there is no way of telling whether the worst pain refers to a one-off incident caused by overexertion or whether someone is in a lot of pain all the time. Also, although not discussed above, it became apparent that different levels of pain were experienced in different joints, so when asking someone to rate their worst pain it is difficult to know which joint they are referring to. It may also be difficult for the person to rate it as well as different joints may be affected on different days. A similar problem arose with the MPQ as the words chosen may be referring to different joints ie the shoulders feel sore and the knees ache.

Finally, there appear to be other, more technical problems with the MPQ. As indicated by number 2p, factors such as a person's level of concentration may affect the words chosen. Those in a lot of pain at the time of administering the MPQ may find it difficult to give it their full attention. Also, some people might not understand some of the words and may feel too embarrassed to say so thereby only choosing the words that they recognise and understand rather than those reflecting how bad their pain is.

e) Comparing the MPQ and VAS with other measures

i) The FACES scale

Another way of checking the validity of the two measures in to see how they relate to the Nottingham Health Profile and FACES scale. It was expected that the amount of pain (ie intensity) would be related to the number of problems they reported as recorded on the NHP and also to how they felt about life as a whole. In other words, the higher the intensity the higher the number of reported difficulties and unhappiness.

For the VAS there was a significant correlation between the FACES scale and the patient's VAS scores (r=.405, p=.01, see Table 2) indicating a relationship between the two. But, on closer inspection of the results this relationship does not appear to be straightforward (see below).

	% of each face chosen on Faces Scale				
VAS group	No.1 smiling	No.2	No.3	No.4	No.5 sad
Low VAS group (n=9)	6%	17%	3%	0%	0%
Medium VAS group (n=12)	0%	22%	3%	8%	0%
High VAS group (n=15)	6%	14%	11%	6%	6%
Total	12%	53%	17%	14%	6%

The most frequently chosen face was No.2. This is quite a happy face and was chosen by people in all three VAS groups. The only instance where a high VAS leads to a "high" face (or unhappy face) is for some of those in the high VAS group. To be more specific, half of those in this group chose an unhappy face. This confirms that there is some relationship between the faces scale and VAS but it is not very strong as the figures above show.

The important question then is why should people, even those supposedly in a lot of pain, choose a happy face? One possible explanation is that for several people there appeared to be a contradiction between how they really felt and the way they presented themselves to other people. One woman in particular who scored 100 on the VAS and 5 (maximum) on the PPI, spoke about "always having a smile" on her face. It would have been expected that she would have chosen face number 5, but she chose face number 3 instead.

Turning to the MPQ, none of the three dimensions correlated significantly with the faces scale. The only score that did was the miscellaneous category (r=.420, p=.023). This comprises a mixture of words from all three dimensions. The most frequently chosen word from this category was "nagging" (see previous section on MPQ) so this may explain the result. Nagging could be seen as an evaluative word because although nobody used it in the interviews, a similar word, "niggling" did appear a few times. In the thesaurus, other words given for nagging include: continuous; distressing; irritating; painful; persistent and worrying. These words could also be taken to be evaluative words and several of them were used by people in the interviews. Nagging or even niggling should perhaps be included in the evaluative category as well as the other words.

If the correlation between the miscellaneous category and the faces was to be interpreted as a significant relationship between the evaluative dimension instead, this could mean that they are both measuring the response to the pain, how they feel about it, but it still doesn't explain why the original evaluative category did not correlate too. There is another scoring method on the MPQ yet to be correlated with the faces. The PPI was found to correlate significantly with the face's scale (r=.362, p=.029). Again this contains evaluative words and further adds evidence that the significant correlations between the PPI, faces, miscellaneous category and VAS mean they are all measuring the same construct, namely the person's suffering.

Finally, the influence of affective distress on the use of the MPQ needs to be explored as it has been suggested (see Kremer & Atkinson, 1983) that people who are depressed choose more words from the MPQ and sometimes words of a higher intensity. As the FACES is taken to be a measure of depression, it was expected that those who scored high on the FACES scale (ie were more depressed) would choose more words from the MPQ and words of a higher intensity than those who scored low on the FACES scale. The finding was that there was no difference in the number of words chosen from any of the categories or in the intensity scores of the different dimensions. The only difference was that those who reported being unhappy about their lives had significantly higher VAS scores than those who chose a happy face. They also scored significantly higher on the PPI. This would suggest that those who were more depressed were also experiencing more pain than those who were less depressed. But as the PPI contained evaluative type words, this does not necessarily mean that the sensory intensity was higher, but that the combined sensory and emotional intensity were higher. In other words, as previously suggested, the VAS is a measure of the sensory and emotional elements of the pain experience.

ii) The Nottingham Health Profile (NHP)

Turning to the Nottingham Health Profile (NHP), there was no significant correlation found between it and the VAS. This could be interpreted to mean that if the VAS is said to represent pain intensity, it is not related to what the person can or cannot do, which was what the section of the NHP used was measuring.

As for the MPQ, the NHP only correlated significantly with the PRI (T), r=.328, p=050 (Table 2), the total score for all the dimensions, but not any individual dimension. Nor did it correlate significantly with the PPI. It would have been expected that if the VAS and MPQ were measuring the same construct then the results would have been similar. The correlation between the PRI (T) and the faces could partly be explained by there being a stronger correlation between the miscellaneous category and the faces than any of the other 3. But this was not found to be significant (r=.337, p=.072).

The fact that the VAS did not correlate significantly with the NHP raises another question about the construct validity of the VAS. All of those interviewed said that it was pain that prevented them from doing certain activities or made them more problematic, a correlation between the two would therefore have been expected. Perhaps the VAS correlating with the faces means that the VAS is measuring the response to the difficulties faced by the pain rather than measuring the amount of pain itself. This appears to be the case for the MPQ too with the scores relating to the evaluative dimension being correlated with the faces scale.

This leads to the question of whether a relationship does exist between how the person feels about their life (as measured by the faces) and the difficulties they are experiencing (NHP). Statistically, a significant correlation was found between the two measures (r=.527, p=.000) confirming that such a relationship does exist. In other words, the problems they face affect how they feel about their life as a whole. This is not surprising as keeping independent was an important issue for many of those interviewed, with dependence on others being their greatest fear and threat to self-identity.

At this stage, the measures only appear to validate each other to a certain extent. The VAS appears to correlate significantly with measures of the evaluative dimension of the pain experience (the interview words, the PRI (E), the PPI and the faces) rather than measures of the sensory dimension (PRI (S) and sensory words used in the interviews). This suggests that the VAS lacks construct validity in that it is not measuring pain intensity per se, but their response to the pain ie whether it is bothering them or not, interferes with their lives etc.

3) Do the results differ between men and women?

Another hypothesis which was felt important to investigate was whether any differences existed on the measurement scores between men (n=18) and women (n=22). If differences are found then this may raise further questions relating to the validity of the pain measurements; differences may not necessarily mean that one sex experiences pain more than another but that they may be interpreting the measurements differently. Women are often viewed as being more verbal than men so they may choose more words on the MPQ for example, or talk about their pain in a different way in the interviews. It is these questions which provide a focus for following section.

Table 3 contains the scores for men and women on the VAS and MPQ with the t-test and test for significance for each one. There were no significant differences on any of the pain measures listed in the Table, but a difference was found between the VAS scores obtained at the hospital and home for men only. A mean difference of 6.61. Twelve out of the 18 men had higher scores at home and one was the same in both places. There was no such clear overall difference in the women's scores: their mean score in the hospital setting was 53.5 and at home it was 53.31. Ten of the women scored higher at the hospital and 10 scored higher at home, with two scoring the same in both places.

Table 3: Comparison of Results Between Men and Women

	Men (mean)	Women (mean)	T-value	Significance
Age	61	63	.67	.508
Duration of RA	15	22	1.56	.126
VAS	52.16	53.31	-.12	.902
VAS (hospital)	45.55	53.50	-.76	.450
PPI (now)	2	2.13	-.35	.732
PPI (worst)	3.77	4.09	-.83	.409
PRI(T)	24.94	22.48	.57	.570
PRI(S)	13.29	12.01	.58	.568
PRI(A)	6.17	5.85	.24	.816
PRI(E)	2.50	2.80	-1.13	.267
PRI(M)	6.20	4.43	1.68	.104
FACES	2.50	2.50	.00	1.00
NHP	3.81	3.25	1.09	.283
NWC	9.72	8.22	.99	.329

NB: IN ORDER TO COMPARE THE PPI WITH THE VAS, THE PPI SCORES WERE MULTIPLIED BY 20, THE SCORES IN THE TABLE REPRESENT THE ORIGINAL SCORE.

i) The faces scale and the other measurements

The findings discussed in the previous section would seem to suggest that a relationship exists between the faces scale and the following; the VAS; the PPI and the miscellaneous category of the MPQ. It was felt necessary to see if this relationship occurred when controlling for gender.

First, for the men (see Table 4a), the only significant correlation with the faces scale was with the VAS score taken at the hospital only (r=.577, p=.019). This can be explained by the difference in VAS scores for men at the hospital and home reported above. The faces was also administered at home and as it correlated with the home VAS it suggests that men may be 'understating' their pain in the hospital.

Table 4a: Summary of Correlations Between the FACES scale and the other measurements: Men Only

Measurements	Correlation	Significance
VAS (HOME)	.227	.399
VAS (HOSP)	.578	.019*
PPI (NOW)	.241	.368
PPI (WORST)	.352	.181
PRI (T)	.364	.165
PRI (S)	.209	.438
PRI (A)	.259	.370
PRI (E)	-.230	.428
PRI (M)	.462	.129

Table 4b: Summary of Correlations Between FACES scale and other measurements: Women Only

Measurements	Correlations	Significance
VAS (HOME)	.546	.012*
VAS (HOSP)	.509	.021*
PPI (NOW)	.462	.040*
PPI (WORST)	.026	.911
PRI (T)	.196	.405
PRI (S)	.129	.586
PRI (A)	-.094	.727
PRI (E)	.543	.044*
PRI (M)	.386	.125

For the women, (see Table 4b), there was a significant correlation between the faces and four other scores. The first is with the VAS taken at home (r=.546, p=.012); the second is with the VAS taken at the hospital (r=.509, p=.021); the third with the PPI (r=.462, p=.040) and the fourth with the PRI (E) (r=.543, p=.044). The women's scores therefore are very similar to the combined results and it would suggest that it is their scores which influenced these results.

The important question then is why should these differences occur? Why should there be a relationship between the faces scale and the measurements mentioned above for the women but only with the hospital VAS for the men? There were more women in the sample but this does not explain the results. The findings seem to suggest that for the women in this sample there is a significant relationship between the faces scale (ie how they feel about their life as a whole); the VAS and the evaluative dimension of the MPQ (the PRI (E) and the PPI). As previously discussed, the VAS may be measuring the evaluative dimension too because of the correlation between it and the evaluative aspects of the MPQ and the faces scale. For the men, this relationship may still exist as the hospital VAS did correlate significantly with the faces scale.

ii) The NHP and other measurements

Turning to the NHP, the results differ again. For the women (see Table 5a), the NHP correlates significantly with the PRI (E), (r=.694, p=.005) and the faces scale (r=.441, p=.051). But for the men (see Table 5b), significant correlations exist between the NHP and the PRI (T) (r=.585, p=.017); the PRI (M) (r=.573, p=.051); and the faces scale (r=.613, p=.011).

Table 5a: Summary of Correlations Between the NHP and other measurements: Women Only

Measurement:	Correlation	Significance
PRI (T)	.048	.837
PRI (S)	-.003	.989
PRI (A)	-.275	.302
PRI (E)	.694	.005*
PRI (M)	-.024	.925
PPI (N)	.200	.395
PPI (W)	.053	.823
VAS (HOME)	.422	.063
VAS (HOSP)	.414	.069
FACES	.441	.051*

Table 5b: Summary of Correlations Between the NHP and other measurements: Men Only

Measurements	Correlation	Significance
PRI (T)	.585	.017*
PRI (S)	.444	.084
PRI (A)	.420	.134
PRI (E)	-.269	.351
PRI (M)	.573	.051
PPI (N)	.044	.873
PPI (W)	-.031	.908
VAS (HOME)	.068	.799
VAS (HOSP)	.277	.297
FACES	.613	.011*

These scores differ from the combined scores. With the combined scores, there was only a significant correlation between the NHP and the PRI(T). This relationship was also found for the men but not the women, with the correlation for the men being influenced by the correlation between the NHP and the miscellaneous category. For the women there appears to be a relationship between the NHP, the faces and the evaluative dimension of the MPQ but for the men a relationship only occurs between the NHP and the PRI (M) and the faces scale.

A significant correlation was found between the NHP and faces scale when controlling for gender too and would suggest there is a relationship between the two. But what is interesting is why the NHP does not correlate with the same measurements as the faces scale. If the VAS were measuring the response too then it would have been expected to correlate with the NHP as well as the faces scale. The same could be said for the PPI as it contains evaluative words.

iii) The VAS and MPQ

So far the difference between men and women on the faces and NHP scales has been discussed but the correlations between the pain measurements themselves are important too as a check on the hypothesis. For example, although no significant correlation was found between the PRI (T) and the VAS for the combined scores, a correlation may exist when controlling for gender.

For men (see Table 6a), no significant correlation was found between the VAS and the three dimensions of the MPQ. A similar result to that found for the combined scores. The same result was found for women too (see Table 6b).

The PPI did correlate significantly with the VAS for both men and women. As discussed earlier the PPI uses evaluative words so the correlation between it and the VAS even when controlling for gender could suggest that the VAS is measuring the evaluative dimension. For men, the PPI also correlated significantly with the evaluative dimension (r=.547, p=.042) but not for women (r=.335, p=.203). This was also found for the combined scores and would suggest that it was for the men only that this relationship existed. In other words for the men their pain at the time of the interview, or how they felt about the pain was the same as how they felt about their worst pain over the past week.

Table 6a: Summary of Correlations Between Measurements: Men Only; VAS (home), VAS (hospital), PRI (T), PRI (S), PRI (A), PRI (E), PRI (M), PPI (home), PPI (worst)

	VAS HOME	VAS HOSP	PRI (T)	PRI (S)	PRI (A)	PRI (E)	PRI (M)	PPI (NOW)	PPI WORST
VAS HOME	-	.598 p=.008 *	.122 p=.627	.068 p=.787	.188 p=.501	.462 p=.082	-.010 p=.974	.699 p=.001 *	.516 p=.028 *
VAS HOSP	-	-	.260 p=.296	.317 p=.199	.064 p=.820	.260 p=.348	.351 p=.262	.449 p=.070	.357 p=.145
PRI (T)	-	-	-	.905 p=.000 *	.858 p=.000 *	.289 p=.294	.554 p=.061	.054 p=.834	.098 p=.697
PRI (S)	-	-	-	-	.666 p=.006 *	.243 p=382	.327 p=298	.059 p=.820	-.094 p=.709
PRI (A)	-	-	-	-	-	.405 p=.150	.327 p=.298	.439 p=.116	.381 p=.161
PRI (E)	-	-	-	-	-	-	.167 p=.601	.547 p=.042 *	.566 p=.027 *
PRI (M)	-	-	-	-	-	-	-	-.238 p=.480	.202 p=.528
PPI NOW	-	-	-	-	-	-	-	-	.542 p=.024 *
PPI WORST	-	-	-	-	-	-	-	-	-

Table 6b: Summary of Correlations Between Measurements, Women Only, (n=22): VAS(home), VAS(hosp), PRI(T), PRI(S), PRI(A), PRI(E), PRI(M), PPI (now), PPI (worst).

	VAS HOME	VAS HOSP	PRI (T)	PRI (S)	PRI (A)	PRI (E)	PRI (M)	PPI (NOW)	PPI WORST
VAS HOME	-	.747 p=.000 *	.187 p=.403	.050 p=.822	-.063 p=.801	.313 p=.236	.243 p=.329	.703 p=.000 *	.497 p=.018 *
VAS HOSP	-	-	.089 p=.692	-.015 p=.944	-.138 p=.582	.277 p=.298	-.096 p=.702	.658 p=.000 *	.117 p=.603
PRI (T)	-	-	-	.923 p=.000 *	.837 p=.000 *	.249 p=.351	.794 p=000*	.106 p=.635	.049 p=.827
PRI (S)	-	-	-	-	.671 p=.002 *	.136 p=.614	.647 p=.003 *	.007 p=.974	-.079 p=.723
PRI (A)	-	-	-	-	-	.037 p=.893	.545 p=.028 *	.037 p=.882	.237 p=.342
PRI (E)	-	-	-	-	-	-	.299 p=.297	.335 p=.203	-.016 p=.951
PRI (M)	-	-	-	-	-	-	-	.253 p=.310	.352 p=.151
PPI (NOW)	-	-	-	-	-	-	-	-	.408 p=.059
PPI WORST	-	-	-	-	-	-	-	-	-

A check also needs to be made on the relationship between the dimensions on the MPQ. It was found with the combined scores that the evaluative dimension did not correlate significantly with any of the other dimensions. The same result was found for both men and women but there was one slight difference. For the men, the miscellaneous dimension did not correlate with any of the other dimensions either. What is needed is a content analysis of the kind of words men and women chose from the MPQ. For example, the misc. dimension contains evaluative words and the men may have chosen more of these than women leading to the lack of correlation between it and the other dimensions.

As shown in Table 2, men and women did not differ in the total number of words chosen from the MPQ. But they did differ for the number of words chosen from the miscellaneous category (t-value = 2.53, p=0.17) with men choosing a mean of 2.33 words and women choosing a mean of 1.55 words. For the other dimensions there was no significant difference in the number of words chosen. But although men and women differed in the number of words chosen from the misc. category, their scores for this category were not found to be significantly different, although the scores were slightly higher for men. The difference may therefore be due to the small number of men choosing from the miscellaneous category (12/18). A larger sample size may lead to different results.

In terms of differences in the type of words chosen, ie whether men chose different words more frequently than women will also be important in determining the validity of the measurements. But as the scores were similar on the MPQ for men and women it was expected that there would be no significant difference in the type of words chosen from the MPQ.

The most frequently chosen words in each of the categories for men and women are listed below:

Women (n=22)	Men (n=18)
Sensory: throbbing/aching (54%)	throbbing (22%)/aching (72%)
Affective: exhausting (36%)	exhausting (50%)
Evaluative: annoying (27%)	annoying (33%)
Miscellaneous: nagging (45%)	nagging (39%)

The main difference appears to be in the sensory dimension where 54% of the women chose the word throbbing (12/22) compared to only 22% of the men (4/18). The proportion of men choosing the word ache is also greater (72% (13/18) compared to 54% (12/22) of the women. For the other dimensions there does not appear to be any significant difference in the words chosen from the MPQ.

As discussed earlier in the MPQ section, the people choosing the word throbbing most frequently were in the high pain group. This would suggest that there were more women in the high pain group too. 45% of the women (10/22) were in the high pain group, compared to 27% in the lower pain groups. 39% of the men (7/18) were in the high pain group, with 28% in the low group and 33% in the medium group. Again these differences are not significant.

In terms of the kind of words chosen from the MPQ word list, there appear to be no significant differences between the men and women in this sample. This suggests that men and women do not differ in their use of the MPQ and that gender does not affect the scoring of the MPQ.

iv) The Interviews

Content analysis of the way men and women describe their pain in the interviews, as expected, did not differ significantly. The only difference arose in the use of metaphors: 40% of the sample used metaphors; 30% of these were women and 10% men. The metaphors ranged from likening the pain to a toothache; "you know when you've got a raging toothache?, well that's what it feels like" (No.3p) to knives and pokers sticking into various parts of the body; "the pains in my feet were just like knives sticking in" (No. 4p). The metaphors were similar for both men and women, but the fact that women used them more frequently could suggest that they can describe the pain more descriptively and perhaps more easily.

So far then, there appear to be a few significant differences between men and women on the pain measurements. One significant difference found was on the faces scale where the men tended to score higher. Also, for women the faces significantly correlated with the VAS at home and hospital and the PRI (E) but for the men it only correlated with the hospital VAS suggesting that for the women, their feelings about the pain were related to how they felt about their life as a whole and that the men were giving a different picture depending on the context. In turn, this was related to the perceived affect of the pain on their ability to do certain activities such as housework as indicated by the strong relationship between the faces and NHP. But in terms of the validity of the pain measures, the strong relationship found between the evaluative dimension and the VAS when controlling for gender would support the view expressed earlier that the VAS may be measuring the evaluative dimension of the experience rather than the sensory intensity.

4. Do those living alone have more pain than those living with others?

It was expected that people living alone would say that they experience more pain than those living with others. The reasons being that people living alone are less likely to receive help and be distracted from their pain. In other words, lack of mobility and loneliness may increase the perceived pain and lead to a greater sense of "suffering" for those living alone. This would be reflected in higher scores on the measurements.

At the start of the study, looking at the difference between those living alone and those living with others was not the main intention so the number of those living alone in the study was small (n=15, 4 men and 11 women) and was more an incidental demographic feature as the majority of the female sample were elderly. The findings therefore should be treated with caution.

i) Differences in pain measurement scores between those living alone and those living with others.

Those living alone were significantly older than those living with others, t=2.83, p=.007 (see Table 7). The number of years since diagnosis of rheumatoid arthritis was also greater for those living alone (t=1.46, p=.052). In fact, this was the only difference found between the two groups in terms of differences in the measurement scores. In other words, t-tests did not show any difference between the two groups in terms of their VAS or MPQ scores.

Table 7: Comparison of Results Between Those Living Alone and Those Living With Others

	Living Alone	Living with others	T-value	Significance
Age	67.46	58.92	2.83	.007*
Duration of RA	22.80	16.32	1.46	.052*
VAS (home)	57.07	50.50	.68	.500
VAS (hospital)	58.71	45.19	-1.26	.215
PPI (now)	2.33	1.92	-1.26	.309
PPI (worst)	3.73	4.08	.90	.373
PRI(S) Total	19.12	26.27	1.68	.102
PRI(S) Sensory	11.93	12.98	.46	.649
PRI(S) Aff	5.34	6.42	.78	.439
PRI(S) Eval	2.81	2.56	.88	.383
PRI(S) Misc	4.75	5.40	.59	.561
FACES	2.75	2.37	-1.00	.322
NHP	3.16	3.66	.92	.366
NWC	7.20	9.92	1.73	.096

The measurements were then investigated to see if there was any difference in the correlations of the measurements between the two groups. As found with the total scores, no significant relationship was found between the PRI scores and the VAS (see Table 8a and Table 8b) for both groups. But when correlating the VAS taken at the hospital, differences do emerge. For those living alone, the PRI (Affective) correlated significantly with the VAS hospital (r=.570, p=.041) but this did not arise for those living with others. Again, this is surprising as those living alone did not differ in their VAS scores taken at home and those taken in the hospital (t=1.05, p=.325). The finding may be due to the small numbers in the sample.

Table 8a: Summary of Correlations Between Pain Measurements: Those Living Alone (n=15).

	VAS HOME	VAS HOSP	PRI (T)	PRI (S)	PRI (A)	PRI(E)	PRI(M)	PPI (NOW)	PPI WORST
VAS HOME	-	.563 p=.028 *	.300 p=.276	-.030 p=.914	.336 p=.260	.446 p=.196	.491 p=.149	.849 p=.000 *	.673 p=.005 *
VAS (HOSP)	-	-	.391 p=.149	.126 p=.653	.570 p=.041 *	.507 p=.134	.383 p=.274	.740 p=.002 *	.533 p=.040 *
PRI (T)	-	-	-	.852 p=.000 *	.823 p=.000 *	.524 p=.119	.793 p=.006 *	.448 p=.107	.060 p=.829
PRI (S)	-	-	-	-	.616 p=.023 *	.249 p=.486	.584 p=.076	.179 p=.539	-.223 p=.422
PRI (A)	-	-	-	-	-	.321 p=.398	.497 p=.173	.395 p=.202	.146 p=.632
PRI (E)	-	-	-	-	-	-	.785 p=.036 *	.603 p=.085	.234 p=.515
PRI (M)	-	-	-	-	-	-	-	.572 p=.107	.284 p=.425
PPI (NOW)	-	-	-	-	-	-	-	-	.721 p=.003 *
PPI worst	-	-	-	-	-	-	-	-	-

As found with the total scores, the PPI correlates significantly with the VAS. For those living alone the result was r=.849, p=.000, and for those living with others, r=.562, p=.003. Again this confirms the relationship between the VAS and the PPI. With regard to the MPQ, the PPI did not correlate significantly with any of the dimensions of the MPQ. This is different from the total finding where the PPI did correlate significantly with the evaluative dimension.

The relationship between the dimensions also appears to differ between the two groups. For those living alone, the sensory dimension correlated with the affective dimension only (r=.616, p=.023), but for those living with relatives it also correlated with the miscellaneous dimension (r=.490, p=027). The affective dimension also correlated significantly with the misc. dimension for those living with relatives (r=.486, p=.040) but not for those living alone. For those living alone though, a significant relationship exists between the evaluative dimension and the miscellaneous dimension (r=.785, p=.036) but not for those living with relatives.

Table 8b: Summary of Correlations Between Pain Measurements: Those Living With Relatives (n=25)

	VAS HOME	VAS HOSP	VAS REL	PRI (T)	PRI (S)	PRI (A)	PRI (E)	PRI (M)	PPI NOW	PPI WORST
VAS HOME	-	.774 p=.000 *	.397 p=.074	.126 p=.547	.148 p=.479	-.062 p=.791	.302 p=.181	.034 p=.886	.562 p=.003 *	.402 p=.046 *
VAS HOSP	-	-	.400 p=.072	.120 p=.567	.156 p=.455	-.261 p=.264	.177 p=.440	-.012 p=.956	.414 p=.039 *	.127 p=.542
VAS REL	-	-	-	.016 p=.955	-.072 p=.755	-.514 p=.034 *	-.096 p=.701	.027 p=.911	-.190 p=.408	-.140 p=.544
PRI (T)	-	-	-	-	.945 p=.000 *	.833 p=.000 *	.187 p=.415	.653 p=.001 *	-.021 p=.919	.006 p=.975
PRI (S)	-	-	-	-	-	.629 p=.002 *	.182 p=.429	.490 p=.027 *	-.010 p=.961	-.076 p=.717
PRI (A)	-	-	-	-	-	-	.210 p=.373	.486 p=.040 *	.284 p=.223	.362 p=.116
PRI (E)	-	-	-	-	-	-	-	-.147 p=.548	.260 p=.253	.323 p=.152
PRI (M)	-	-	-	-	-	-	-	-	-.058 p=.807	.195 p=.408
PPI NOW	-	-	-	-	-	-	-	-	-	.357 p=.079
PPI WORST	-	-	-	-	-	-	-	-	-	-

ii) The faces scale and NHP

No significant difference was found between the scores on the NHP and FACES for those living alone and those living with others. But in terms of the relationship between the pain measurements and these scales, differences did emerge. The NHP correlated significantly with the VAS at home and at the hospital for those living alone (see Table 9a) but it did not for those living with others (Table 9b). This suggests that for those living alone there is a relationship between the VAS and the difficulties their health causes but not for those living with others. In other words, the problems those living alone have are related more strongly to their pain/suffering than is the case for those living with others.

Table 9a: Summary of Correlations Between NHP and other measurements: Those Living Alone (n=15)

Measurements	Correlations	Significance
VAS (HOME)	.556	.048*
VAS (HOSP)	.680	.010*
PRI (T)	.451	.121
PRI (S)	.151	.622
PRI (A)	.440	.175
PRI (E)	.403	.321
PRI (M)	.347	.360
PPI (NOW)	.556	.060
PPI (WORST)	.207	.496
FACES	.565	.044*

Table 9b: Summary of Correlations Between NHP and other measurements: Those Living with Relatives (n=25)

Measurements	Correlations	Significance
VAS (HOME)	.117	.593
VAS (HOSP)	.224	.303
VAS (REL)	-.007	.973
PRI (T)	.232	.286
PRI (S)	.188	.389
PRI (A)	-.008	.970
PRI (E)	-.006	.979
PRI (M)	.331	.154
PPI (NOW)	-.036	.869
PPI (WORST)	-.156	.474
FACES	.585	.003*

With regard to the FACES, differences were also found (see Tables 10a and 10b). In particular, for those living alone, the FACES scale only significantly correlated with the VAS at the hospital. The same was found for those living alone, but, in addition the FACES also significantly correlated with the PPI (now), PRI (T) and the evaluative dimension of the MPQ. These results help to clarify the correlations found between the FACES and the other measurements listed in Table 2. In particular, it would appear to show that for those living alone there is a significant relationship between how happy they feel about their lives, their pain at the time of the interview and the evaluative dimension of the pain experience. This relationship does not exist for those living with others.

Table 10a: Summary of Correlations Between FACES scale and other measurements: Those Living Alone

Measurements	Correlations	Significance
VAS (HOME)	.451	.121
VAS (HOSP)	.704	.007*
PPI (NOW)	.590	.043*
PPI (WORST)	.449	.123
PRI (T)	.605	.028*
PRI (S)	.257	.396
PRI (A)	.526	.096
PRI (E)	.854	.006*
PRI (M)	.821	.006*

Table 10b: Summary of Correlations Between FACES scale and other measurements: Those Living with Relatives

Measurements	Correlations	Significance
VAS (HOME)	.371	.080
VAS (HOSP)	.430	.040*
VAS (REL)	.127	.580
PPI (NOW)	.030	.889
PPI (WORST)	.105	.633
PRI (T)	.205	.346
PRI (S)	.167	.445
PRI (A)	-.033	.891
PRI (E)	-.238	.311
PRI (M)	.346	.134

As previously noted, the NHP correlates significantly with the faces scale for the sample as a whole. This relationship was also found for those living alone (r=.565, p=.044) and for those living with relatives (r=.585, p=.003).

iii) Comparing the women who live alone with those who live with others

As the majority were women, it was felt important to see if any differences arose between the women living alone (n=11) and the women living with others (n=11). Table 11 shows that there were. Again they differed with age, which was expected, but they also differed in PPI scores and on the faces scale. To be more specific the women living alone scored higher on the PPI and higher on the faces scale. This means that women living alone were unhappier about their life and experienced more pain at the time of the interview, but they did not differ in their worst pain over the past week.

Table 11: Comparison of Results Between Women Living Alone (n=11) and Women Living with Relatives (n=11)

	ALONE	RELATIVES	T-VALUE	SIG
AGE	69.36	56.81	2.96	.008*
RA	26.09	17.45	1.48	.154
VAS (HOME)	58.72	47.90	.80	.431
VAS (HOSP)	65.45	41.50	1.85	.080
PPI (NOW)	2.72	1.54	2.39	.027*
PPI (WORST)	4.00	4.18	.39	.699
PRI (T)	21.11	23.86	.46	.648
PRI (S)	11.09	12.93	.56	.583
PRI (A)	4.98	6.94	1.08	.295
PRI (E)	2.79	2.84	.12	.905
PRI (M)	4.22	4.65	.33	.749
FACES	3.11	2.00	2.92	.009*
NHP	3.55	3.00	.99	.337

The scores were then analysed to see if there are any differences in the correlations. Tables 12a and 12b show that there are some differences. First, taking the VAS, for women living alone the only significant correlation is between the VAS and the PPI. But for the women living with relatives no significant correlation was found.

Next, the MPQ. As found with the men's scores and the total scores, for women living alone there does appear to be a strong relationship between the evaluative dimension and the PPI (r=.606, p=.111), but it was not found to be significant. This is probably due to the small sample size. In contrast, for women living with others, the relationship between the PPI and evaluative dimension is weaker (r=-.377, p=.357).

A difference also arises with the relationship between the evaluative dimension and the other dimensions. The combined scores suggested that there is no relationship between this dimension and the others, but for women living alone there does appear to be a relationship between the miscellaneous dimension and the evaluative (r=.766, p=.075), but not for women living with relatives.

As for the other dimensions, .there is a significant relationship between the sensory and affective dimensions for both groups. But the sensory dimension also correlates significantly with the miscellaneous dimension for women living with relatives only (r=.709, p=.032). This result had also been found for the combined scores.

12a) Summary of Correlations Between Measurements: Women Living Alone

	vas (h)	vas hosp	pri (t)	pri (s)	pri (a)	pri (e)	pri (m)	ppi now	ppi wors
vas (h)	-	.820* (.001)	.321 (.334)	.071 (.835)	.319 (.367)	.526 (.180)	.492 (.178)	.879* (.000)	.778* (.004)
vas hosp	-	-	.319 (.337)	.038 (.909)	.600 (.066)	.458 (.253)	.315 (.408)	.752* (.007)	.569 (.067)
pri (t)	-	-	-	.897* (.000)	.815* (.004)	.577 (.134)	.789* (.011)	.408 (.211)	.029 (.931)
pri (s)	-	-	-	-	.640* (.046)	.300 (.470)	.586 (.096)	.223 (.508)	-.126 (.710)
pri (a)	-	-	-	-	-	.276 (.548)	.457 (.253)	.351 (.319)	.083 (.818)
pri (e)	-	-	-	-	-	-	.766 (.075)	.606 (.111)	.075 (.850)
pri (m)	-	-	-	-	-	-	-	.572 (.107)	.174 (.653)
ppi now	-	-	-	-	-	-	-	-	.771* (.005)

12b: Summary of Correlations Between Pain Measurements: Women Living with Relatives

	vas (h)	vas (hosp)	vas (rel)	pri (t)	pri (s)	pri (a)	pri (e)	pri (m)	ppi now	ppi worst
vas (h)	-	.656* (.028)	.677* (.031)	.105 (.756)	.083 (.807)	.478 (.229)	.113 (.789)	.014 (.969)	.120 (.725)	.242 (.472)
vas (hosp)	-	-	.461 (.178)	-.005 (.987)	.029 (.931)	.620 (.100)	.038 (.928)	-.450 (.224)	.305 (.361)	-.207 (.540)
vas (rel)	-	-	-	.362 (.303)	.138 (.701)	-.474 (.281)	-.415 (.353)	.281 (.499)	.117 (.746)	.091 (.801)
pri (t)	-	-	-	-	.950* (.000)	.838* (.009)	-.095 (.821)	.807* (.008)	-.236 (.483)	.048 (.888)
pri (s)	-	-	-	-	-	.658* (.076)	-.026 (.949)	.709* (.032)	-.309 (.353)	-.063 (.852)
pri (a)	-	-	-	-	-	-	-.163 (.699)	.613 (.105)	-.064 (.879)	.360 (.380)
pri (e)	-	-	-	-	-	-	-	-.349 (.396)	-.377 (.357)	-.141 (.737)
pri (m)	-	-	-	-	-	-	-	-	-.115 (.767)	.506 (.163)
ppi now	-	-	-	-	-	-	-	-	-	.149 (.661)

Finally, turning to the non-pain measurements, the NHP and faces. With regard to the NHP, there are differences in the correlations between the NHP and the other measurements. For the women living with relatives, the only significant relationship is between the NHP and evaluative dimension (r=.910, p=.001, see table 13b). This same relationship does not exist for women living alone (r=.532, p=.276, see table

13a). For this group, the NHP correlates significantly with the VAS instead (r=.702, p=.034).

13a: Summary of Correlations Between NHP and other measurements: Women Living Alone (n=11)

Measurements	Correlations	Significance
VAS (HOME)	.702	.034*
VAS (HOSP)	.788	.011*
PRI (T)	.260	.499
PRI (S)	.013	.971
PRI (A)	.330	.424
PRI (E)	.532	.276
PRI (M)	.310	.454
PPI (NOW)	.500	.170
PPI (WORST)	.227	.555
FACES	.457	.213

13b: Summary of Correlations Between NHP and other measurements: Women Living with Relatives

Measurements	Correlations	Significance
VAS (HOME)	.176	.602
VAS(HOSP)	.115	.734
VAS (REL)	-.089	.805
PRI (T)	-.029	.932
PRI (S)	.021	.948
PRI (A)	-.376	.358
PRI (E)	.910	.001*
PRI (M)	-.223	.563
PPI (NOW)	-.541	.085
PPI (WORST)	.000	1.00
FACES	.365	.269

These results help to explain the differences found when controlling for the other factors above. The significant correlation between the NHP and evaluative dimension had been found for women only, but as shown above, when controlling for living circumstances as well, it is these combined factors which seems to be important. These factors also explain the significant correlation found between the VAS and NHP. This relationship only appears to arise for women living alone.

Turning to the faces scale. For women living with relatives, no significant correlation exists between the faces scale and the other measurements (see Table 14b). A similar picture had been found previously when just controlling for living circumstances, but there was one significant correlation and that was between the hospital VAS and the faces scale (r=.430, p=.040). As this was not found when controlling for gender as well, it would appear that this relationship exists only for the men.

For women living alone, similar results to those found for all those living alone were expected. For those living alone, the faces scale correlated significantly with the PRI (E), (r=.854, p=.006, see Table 14a). As expected a similar result was found for women living alone (r=.883, p=.019). The miscellaneous dimension also correlated significantly with the faces scale for those living alone only (r=.821, p=.006). Again, a similar result was found for women living alone (r=.863, p=.005).

14a: Summary of Correlations Between FACES scale and other measurements: Women Living Alone

Measurements	Correlations	Significance
VAS (HOME)	.546	.127
VAS (HOSP)	.582	.099
PPI (NOW)	.509	.161
PPI (WORST)	.153	.694
PRI (T)	.575	.104
PRI (S)	.266	.488
PRI (A)	.386	.343
PRI (E)	.883	.019*
PRI (M)	.863	.005*

The only differences appear to be that the faces scale correlated significantly with the hospital VAS and the PPI for those living alone but not for women living alone. The differences though are small and when cross-checked with the other results it would appear that, at least for the PPI, there is some degree of relationship between the PPI and the faces scale. For example, for women only, a significant relationship was found between the two (r=.462, p=.040). When compared to the results for women living alone and women living with relatives, the strongest relationship appears to arise for women living alone. The correlation coefficient for women living alone is .509, whereas for women living with relatives it is -.494.

14b: Summary of Correlations Between FACES scale and other measurements: Women Living with Relatives

Measurements	Correlations	Significance
VAS (HOME)	.536	.088
VAS (HOSP)	.140	.679
VAS (REL)	.295	.406
PPI (NOW)	-.494	.122
PPI (WORST)	.000	1.00
PRI (T)	.051	.881
PRI (S)	.186	.583
PRI (A)	-.286	.490
PRI (E)	.205	.624
PRI (M)	.094	.808

The only differences appear to be that the faces scale correlated significantly with the hospital VAS and the PPI for those living alone but not for women living alone. The differences though are small and when cross-checked with the other results it would appear that, at least for the PPI, there is some degree of relationship between the PPI and the faces scale. For example, for women only, a significant relationship was found between the two (r=.462, p=.040). When compared to the results for women living alone and women living with relatives, the strongest relationship appears to arise for women living alone. The correlation coefficient for women living alone is .509, whereas for women living with relatives it is -.494.

Finally, when correlating the faces scale and the NHP, a major difference arises. When controlling for gender and with the total scores, a significant correlation was found between the two, but for the women living alone and women living with relatives, this relationship does not arise: women with relatives, r=.365, p=.269; women living alone, r=.457, p=.215.

To summarise so far, although the results have to be interpreted with caution, it would appear that there are differences in the results between those who live alone and those who live with relatives. The differences appear to lie in the correlations between the measurements, and for the MPQ, the correlations between scoring methods. As found with the total scores and when controlling for gender, the VAS does not correlate significantly with the PRI scores, only the PPI. This adds further evidence to the hypothesis that the VAS is not measuring the sensory dimension of the experience alone but the evaluative as well.

Within the MPQ, for the total scores, the evaluative dimension was the only dimension that did not correlate significantly with the others. But when controlling for living circumstances a different picture emerged. For those living alone, the evaluative dimension correlated with the miscellaneous dimension. Also, this dimension, along with the evaluative, did not correlate significantly with the sensory or the affective. In other words, for those living alone there appears to be a different relationship between the dimensions than that found for those living with others.

The results were also compared between women living alone and women living with others and differences in the results were found there too. The most important one being that the PPI did not correlate significantly with the VAS for those women living with relatives. This finding makes interpreting the VAS even more complicated, as it goes against the previous hypothesis that the VAS is measuring the evaluative dimension of the experience. In fact, for this group of women, the VAS did not correlate significantly with the PRI scores either.

The significant correlation found between the evaluative dimension and the PPI for the total scores can be explained by the same relationship existing for women living alone. This relationship was not found for any of the other groups, including when controlling for gender.

The correlations between the different dimensions were also found to differ from the total scores. For women living alone, as expected, the results were similar to those found above. In other words, the miscellaneous dimension did not correlate significantly with the sensory and affective dimensions; only the evaluative dimension. For the women living with relatives, the results were also similar to those found for all those living with relatives and the total scores. In this instance then, it is the women living alone who appear to differ from the others. For this group, no relationship was found between the sensory aspects of the pain experience (as measured on the MPQ) and the evaluative. The only significant relationship found was between the evaluative dimension, the VAS, the PPI and the faces scale. This would seem to suggest that they are all measuring similar aspects of the experience, namely a combination of the sensory and affective/evaluative aspects. Why this should only occur for those living alone is difficult to ascertain, but this group did score higher on the PPI and faces scale than those living with others. In other words, they appear to be more troubled by their pain.

5. Can others tell how much pain someone is in?

The final question to be addressed is, can someone tell how much pain someone is in? The hypothesis is that the relatives of those in pain can tell how much pain their partner is in and mark this amount on the VAS. In other words, if the hypothesis is true, the VAS score obtained from the relative will match the VAS score of the person in pain.

Although the VAS scores between the interview raters and patients were similar, the VAS scores of those with relatives were found to be significantly different from their partners (t=-3.37, p=.003, n=22). To be more precise, 72% rated their partners' pain higher than the partner did themselves; 18% rated it lower and 9% rated it the same. The interviewers' ratings were also found to be significantly different from the relative's VAS scores (t=4.56, n=25, p=.000). In other words there was a closer correspondence between the independent raters and the patient than between the OFM and the patient. This leads to the important question of why should the researcher's ratings be similar to the patient's but not the relative's?

In the measurement chapter a study by James & Large (1992) suggested that those 'spouses' who were 'distressed' by their partner's pain tended to overestimate it, while the reverse was true of the 'low distress spouses' who were also said not to be aware of factors which mediated pain. In order to test this hypothesis as a possible explanation for the difference in results, the partners were categorised as 'emotionally supportive' or 'instrumentally supportive' by reference too the following criteria:

1. The use of 'we' or 'us' by the partner as in, "we didn't realise it was so painful".

2. Reference to talking about pain with partner, as in "I say to him (husband), 'How can it be punishment? What have I done?'"

3. Partner shows understanding, as in, "I think sometimes I couldn't go through what she does."

4. Criticism by partner, as in "I'm very quick tempered now. My wife is always telling me so."

5. Apparent acceptance of sufferer's pain, "We all take the 'mick'. I think it does upset him a bit."

6. Unwillingness of sufferer to talk to family. "I never tell him (about pain) except when I dislocated my hip."

The mean VAS score of those with emotionally supportive partners (n=12) was slightly higher than for those with partners who were characterised as being only instrumentally supportive (n=15). Fifty-two point eight compared with 50.3. This suggests that the kind of relationship that people have with their partners can also influence pain scores.

DISCUSSION

The findings show that the use of the McGill Pain Questionnaire and Visual Analogue Scale for measuring pain is problematic. A summary of the findings, how they relate to other studies and the implications of the research will comprise the following chapter.

1. The Visual Analogue Scale

The main problem found with the VAS was interpretation. Huskisson (1974,1982, 1983) who developed the VAS saw it as a measure of the overall pain intensity. In other words, the severity of the pain, but whether this is all that people include in their responses to it is far from clear. When compared to the interviewer ratings, significant agreement was found and as the interviewer ratings were based on pain descriptions covering several dimensions ie the sensory/affective and evaluative, it could be argued that the VAS was measuring more than the pain intensity.

Another measure of overall pain severity (the PPI) correlated significantly with the VAS too. This has been found in other studies (Elton et al, 1979; Davies, 1988; Taenzer, 1983) and has been used as further evidence that they are both valid measures of pain intensity. But Melzack (1975) who developed the MPQ (and PPI) found that the PPI "fluctuates considerably as a function of psychological factors at the moment: mood, anxiety level, attention and so on". This, he suggests, means that the PPI is an overall evaluation determined not only by sensory and affective dimensions of the pain, but also by patient's past experience, mood and expectation. He goes on to argue that it may even represent, in part, an implicit communication requesting help from the physician or indicating optimism that relief may occur.

With regard to the VAS, Melzack's comments would seem to suggest that it could also be affected in the same way as the PPI. In other words, the patient's mood etc could be influencing the score. More importantly, it may represent a communication between the person administering the measurement and the patient. This implies that the context in which the measurement is given will influence the outcome. An attempt to explore this issue was made in this study by the researcher taking a VAS at the hospital and one in the home. A difference was found for the men's scores only. Possible explanations for this were touched upon in the previous chapter. The first possible explanation offered was that the men were actually experiencing less pain at that time. A further theory is that although the male researcher took the scores of all the men at home and the female researcher all the women, only the female researcher administered the VAS measurements in the hospital. In other words, the scores were influenced by the gender of the researcher. This has been reported in the previous chapter in some other studies where it was argued that men 'understate' their pain to women in order to show that they can bear pain 'like a man', reinforcing stereotypes in society about how men should respond to pain. As the evidence for this is slight, further research is needed but it does illustrate the importance of social context.

Studies carried out in experimental settings have found that the affective dimensions of the pain experience (which are likely to be partly measured by the VAS) are more sensitive to contextual factors than the sensory aspects (Johnson, 1973; Price et al, 1980). As previously mentioned in the Introduction, a study by Ignelzi (1980) found that ratings of pain intensity varied depending on which medical professional was administering the measurement (lower scores when the test was administered by a psychologist or psychiatrist). This implied that the person was trying to communicate a message about their pain, perhaps exaggerating their pain to the person who they perceived was most likely to help them obtain pain relief.

This has led, as discussed in the measurement chapter, to the development of visual analogue scales which aim to measure separately the sensory and affective dimensions of the experience (Price et al, 1983; 1987). This is important for treatment as physicians are more able to tell which aspect of the experience has changed and prescribe appropriate treatment accordingly. But these measurements have mainly been tested on people in experimental settings which is problematic in itself. As Price et al commented (1983), the context of an experimental setting is different from that of the everyday setting in which people live. It would also seem impossible to control for factors like mood and attention in a normal setting. More importantly, if the score also represents, in part, a communication, then interpreting the score on a sensory and an affective VAS becomes problematic as patients could manipulate both according to what they are wanting to say about their pain. Finally, as the gate control theory suggests, the meaning of the context can also influence the perception of the sensation. It is a common experience that people "feel better" when they are at the doctors.

Another way of assessing the operational validity of the VAS was to see how it related to the measures of depression (the FACES scale) and daily living (Nottingham Health Profile). As discussed in the methodology chapter, these aspects are supposed to relate strongly to pain severity. It was found that, for the total scores, the FACES but not the NHP correlated significantly with the VAS. This finding is interesting as it was expected that functional ability and relationships, which was what the NHP was measuring, would be strongly affected by the severity of the pain a person was experiencing as several studies have reported that depression is an important predictor of disability in chronic pain patients (Haley, 1985; Dworkin et al, 1986; Doan and Wadden, 1989). But the fact that the VAS correlated with a measure of depression (the FACES) has been found in other studies (Romano and Turner, 1985), although they did use different measures of depression from the FACES scale. The relationship between depression and pain has received much attention, particularly whether it is that depressed people are more likely to experience chronic pain or that chronic pain leads to depression. The consensus appears to be that the latter relationship occurs.

But the important question is whether it is pain intensity (sensory) per se which makes people unhappy/depressed or whether it is other factors such as the restrictions which pain causes. Analysis of the interviews, which will be discussed in more detail later, showed that it is the effect pain has on the person's life which causes the unhappiness and not the intensity of the pain sensation itself, although it did play a part. As the VAS is measuring the overall intensity of the experience, the emotional and sensory, this could be the reason why the FACES and VAS correlated significantly. In other words, it is these two aspects together which comprise the pain experience and have important repercussions for the person in pain.

A similar view has been put forward by Turk, Kerns and their colleagues (Kerns & Turk, 1984; Rudy et al, 1988) who have emphasised the importance of cognitive appraisal as a mediator of the chronic pain-depression relationship to explain the variation of observed emotional distress in patients. To be more specific, they proposed a cognitive-behavioural mediation model whereby "patients' perceptions of the impact of pain on their lives, declines in activities associated with the resultant loss of social rewards and declines in perceptions of self-control and personal mastery influence the subsequent development of depression in chronic pain patients" (). According to this model, pain alone is not a sufficient condition for the development of depression; specific cognitive appraisal variables related to perceived pain impact and the ability to control one's own life are necessary to mediate this relationship.

A study by Turk et al (1992) into age differences in chronic pain and depression, suggests that the relationship between pain and depression may also be influenced by the social environment in which the person is living. In their study, the younger patients were more likely to be living with others; this was also the case in this study. According to Wallston et al, (1983),

> "the availability of social support, the process by which interpersonal relationships promote psychological well-being and protect people from health declines particularly during stressful life circumstances, has been found to enhance recovery, increase adherence to treatment recommendations and promote psychosocial adjustment across a variety of medical conditions." (Wallston et al, 1983: 236)

But despite the fact that the elderly in this study and the study by Turk et al, (1995) were more likely to live alone, in Turk's study they were less emotionally distressed than the younger group. This differs from the results found in this study that those living alone were more depressed than those not living with others.

The fact that the VAS did not correlate with the NHP requires careful analysis. It was found that, when controlling for living circumstances, ie whether the person lived alone or not, for those living alone, the VAS did correlate significantly with the NHP. It could be argued that for those living alone, there was a stronger relationship between the intensity of the overall pain experience and difficulties of everyday living than existed for those living with others. Those living with others had more readily available help than those living alone and were also able to get out and about more with help (social activities were reported as being affected the most by those living alone). In this respect, the sensory intensity (which stops people doing things) had more of an impact for those living alone than it did for those living with others. In other words, for those living with others, it was the evaluative aspects of the experience, ie the fact that they had to rely on others etc which was more annoying than the pain intensity, whereas for those living alone it was the sensory aspects and the limitations that it brought about which they found annoying/frustrating. The nature of the pain experience as described by those interviewed will be discussed in more detail later in the chapter.

Interestingly, it was also found that the NHP correlated significantly with the FACES regardless of gender or living circumstances. This shows quite clearly how a person's perception of their health and hence the effect of pain on their daily lives relates strongly to their happiness. The relationship between the FACES and VAS and in some cases the NHP provides further evidence that the VAS is not just measuring the sensory aspects but a combination of the sensory and emotional. In addition, measurements may not just be reflecting the intensity of the pain but the effect the person perceives it is having on their lives and how they feel about this.

Finally, another important issue in the validity of the VAS was the important finding that the other family members tended to score the person's pain significantly *higher* than the person did themselves. This differs from a study by Kerns & Turk (1984) who found that wives' ratings of the severity of their husbands' pain were significantly correlated. They did use different measurements ie the PPI, but this does correlate with the VAS so a similar finding would have been expected. One possible explanation could be that in Kerns' & Turk's study they were asking people to rate their present pain, not worst pain. Memory may have played a part here as the VAS asks people to rate their worst pain during the past week.

In addition, as previously mentioned, it was found that the independent ratings were significantly similar to those of the person in pain. The question then was, how did the independent raters manage to rate the person's pain "more accurately" than their own family?

As discussed in the Methodology chapter, the research interview is not a neutral situation. It emerges out of the social interaction between researcher and interviewee "where both sides construct themselves in the eyes of the other as competent actor in their social world" (Gerhardt, 1991: 425). In other words, in the narrative interview, people are (re)presenting themselves as "normal", or as acting in the "morally correct" way to certain situations (namely their illness/pain).

> "Adjustment to illness .. involves people in making sense of their situation, in giving meaning to painful and sometimes frightening experiences, and in legitimising their ways of coping in the eyes of other people. The signification and justification of these experiences is carried on through the communications which people make to others about what they are doing in order to deal with their illness situation." (Radley, 1989: 234)

In the interviews, people were not just recounting their experiences in an objective way, they were '(re)constructing' them for the researcher in reference to moral concerns. In relation to the pain measurements and in particular the ratings made by the researchers, one explanation for the similarity between the researchers ratings and the VAS scores of the patients is that both the interview and the measurement score were representing the response to pain in relation to the above. In other words, they represented how the person conceptualised their pain and their relationship to society.

This can also help to explain why the other family members (OFM's) VAS scores did not match those of the patients. The interviews with the relatives revealed differences in the kind of support they gave. In the same way that the patient's actions (and scores) should be viewed as representing a particular stance towards their pain and illness, so too should the OFM's. Differences or similarities between scores, therefore, indicate a similar or different view regarding the response to pain.

A way of conceptualising the above can be found in a study by Radley (1989). He has argued that the different ways people adjust to illness should be analysed through the concept of 'styles of adjustment'. The term adjustment does not relate to a functional-adaptive process ie that the body is set within a fixed social context and attempts made to assess which individuals are better adapted. Instead it is argued that different people do not meet the same problems when ill because their social and bodily circumstances are not identical. Attention is therefore drawn to the means or basis of coping with illness. The resolution of social and bodily constraints by the chronically ill, therefore, are located in the practices and in the discourse of the people concerned" (Radley & Green, 1987).

Radley (1989) analysed the 'styles of adjustment' to heart disease by patients and by husbands and wives respectively. By categorising couples on measures relating to changes in their work and domestic status, the pattern of their conjugal role practices and their degree of social contacts, Radley (1989) found it possible to indicate how particular representations of illness expressed by the patients were consistent with forms of domestic life which husbands and wives negotiated. In other words, the degree to which husbands and wives did or could negotiate how they would cope with the period of the men's surgical treatment. Two 'ideal' styles of adjustment were conceptualised. The first being that of 'opposing' the illness. Limitations to negotiation were set out by men who were in a marked traditional marriage relationship with their wives, the latter restricted to responsibility for the home. In these examples, the husband's role as wage-earner was often coupled with assertions of his ability to work and his need to exercise this capacity. Illness was a weakener of valued roles and identities.

In contrast to this style of adaptation were the men who did not oppose illness, but sought, through a variety of 'accommodations' to work around it in order to achieve more limited but still valuable ends. These always involved their wives who were active in monitoring their husband's activities and also legitimised their husband's illness through the acceptance of his occupying an altered role either at home or at work.

According to Radley (1989), one 'constraint' to which people are subject is the flexibility of their role-relationship which lies in the degree of role-discretion available to different people in different social contexts (Bernstein 1971). Where members of a family are subject to regulation in terms of their respective positions, then the actions of each member are subject to clear cut definitions of relative status. This is a situation, according to Berstein where the range of alternatives is limited and doubts or possibilities are less likely to be verbally elaborated. Illness in this context is likely to be seen as a disrupter of social life or an external threat beyond personal control. For people in this situation, illness is countered with the same object which it disrupts, positional power. Illness in Radley's study was often minimised through attempts to return to work or through physical activity around the home. This can be compared to the families for whom there was greater discretion in the roles which they play. This includes couples who have moved away from the traditional marriage roles and where discussion of the possibility for change is permitted.

Radley's concept of 'style of adjustment' and the two 'ideal' types of 'opposition' and 'accommodation' offer a possible explanation for the differences in measurement scores. Analysis of the interviews where a wife scored significantly higher than her husband; and where a wife scored the same show that there does appear to be a relationship between 'style of adjustment' and pain score.

1. First, a couple where the wife scored significantly higher than her husband. The wife scored 100 on the VAS, the husband 51. Analysis of the relationship between the couple revealed a similarity with couples who 'opposed' illness in Radley's study. The husband was awaiting a hip operation. The operation had been postponed several times which caused much frustration, particularly on the part of the wife.

> "He's really getting to me, I could scream sometimes at him.
> ... I still think if they took him in now, he'd certainly be a lot
> better, you know, because he's got another couple of months
> and it's getting worse and worse and when you have to take
> tablets off someone so that he don't take too many, you know,
> I think they should take him in." (wife, no.18: 41-56)

The blame for his "unbearable" pain was also related, not just to the illness but to the health service for allowing him to "suffer" for so long:

> ".. but I still think it's bad to leave him like this. I suppose if you had the money you could have it done yourself, but if you haven't then it's tough." (162-168)

This is an illustration of one of the social constraints felt by the wife on adapting to her husband's illness. In addition, talk about her husband's physical pain was often related in terms of the limitations it had on their social activities.

> "He said it's like as if something is sticking here and as he sits down it bangs into something and the pain's unbearable. We used to go out a lot, but we can't even go out now." (213-218)

The pain also resulted in a change in work around the house which the wife found difficult to adjust to.

> "He don't do nothing. I do all the housework, but he just can't now. Sometimes he might sit at the sink and do some potatoes and that but nothing else and just moaning all the time, you know, you're trying to do all the work and he's moaning." (245-252)

Finally, as with the men in Radley's study, to the wife, the operation signalled the return to 'normal', everyday activities.

> "We used to go for walks and that but now he can't do nothing like that and I think, you know, if he could just get his leg done, or his hip, if he could just get that done now, we've got all summer to build him up so we can go away on holiday." (393-399)

Turning to the husband, he does report problems in terms of having to leave work, but this was only after working for several years with the arthritis. His work colleagues used to 'cover-up' for him.

> "I was working like and I had a couple of good mates in there when I was a bit bad like, my mates would cover up the job."
> (husband, no.18: 144-147)

His comments represent to the interviewer someone who did not let the arthritis prevent him from working and hence from the husband's view, took the 'morally correct' stance towards his illness. Differences arise between his wife's comments and his over the affect of the arthritis on his life. He reports problems in walking far and some activities around the house, but for him, these changes were something he had to accept and so did his wife:

> "I know I've got it, there's not a lot you can do about it." (493)

And further on in relation to his wife:

> "You can't say to her you feel sorry for her like, I do now and again like, but the way I see it, it's for better, for worse, you've got me now, you're going to stick with it. She's good like that."
> (no. 18: 903-908)

For this couple, the above quote illustrates a strict following of a traditional role relationship. The wife did have a job in the past but gave it up to look after her husband and her job appeared to take second place to his. For the husband, the illness was something which he felt he was powerless to do anything about as it was "in the body". This illustrates another important point that acceptance does not necessarily mean 'accommodation' to the illness. The important question then is, if the couple both share a similar adjustment style, that of 'opposing' the pain/illness, why were their scores not similar? As Radley also points out, the two styles of adaptation are 'ideals' and people do not fit into them perfectly. This can be extended to argue that the 'style of adjustment' illustrated by this couple is experienced differently by each of them. The wife, in particular, seemed more emotionally distressed by her husband's pain and their situation than he was. The difference in scores between the couple, therefore, may have been due, in part, to their differing interpretations of the appropriate way to adjust to the pain/illness within the social context in which they were situated. In other words, both of them wanted to return to what they perceived to be a "normal" way of life but experienced the constraints differently.

2) Turning to a couple where the scores were similar (the wife scored 72 and so did the husband). Analysis of the interviews showed a marked difference between the above couple in terms of 'style of adjustment' and a similarity to couples who 'accommodated' the illness in Radley's study. The first important difference was the way in which the wife played an important part in helping her husband to make sense of any pain he had, particularly in the early stages of the illness, before diagnosis.

> "Well, he came home from work and he said, "my foot hurts", and "my neck aches" and I said, "don't worry, you probably done something silly"." (No. 7: 11-15)

This 'sharing' was also exhibited in the way the wife often used "we" to talk about the pain, "we didn't realise it was so painful" (389). But the main important difference was the wife's (and daughter) attempts to help her husband feel "normal" by buying him tools so that he could continue with the DIY around the house:

> "Anything that we (wife and daughter) feel can be useful so that he can carry on as normal." (507)

There were also several illustrations of ways in which they had 'accommodated' to the pain/illness and subsequent difficulties he experienced doing his 'traditional' jobs around the house as follows:

> Researcher: "So in what ways has it changed his life?"
>
> Wife: "Dramatically for Fred because he was a DIY person and dramatically for me because he used to decorate, repair things, plumb in the washing machine and I do it all because he tells me what to do and then my hands are his." (101-107)

This change had been "upsetting" for her husband and again, illustrates the point that adjusting to illness is not mechanical. Prior to the illness, there had been a traditional demarcation of roles, (although the wife did go out to work) which the wife mentioned herself but attempts had been made, as above, to adapt activities so that life can continue almost as it was before and helps to sustain a positive self-identity for the husband.

> "It (her support) helps him as a person in that he's not much different as a persón than to what he was because we won't make a big thing of it, you know, because after all, it isn't his fault is it?" (359-365)

In addition, whereas the previous wife found it difficult to do everything for her husband, the wife in this relationship, interpreted her role of carer in terms of her Christian faith and that she knew he would do the same for her.

A further aspect of the couples who 'accommodated' to the illness could be found in their attitude towards social activities. As found in Radley's study, this couple shared all social activities, something which they had done previously before the illness. With regard to the pain, another important difference can be found in the way the wives respond to their husband's when they are in pain. The wife in the 'opposing' relationship reported that her husband 'moaned' all the time which she could not bear and had to leave the room. She also mentioned that he only did this when she or her family were around but not otherwise. For the wife above, she was able to tell her husband was in pain without him always saying and she never questioned when he did say he was in pain. This can be related to her insistence on treating her husband as "normal" , in that legitimating her husband's pain is part of her understanding of sustaining a positive self-image for her husband. But this wife also experienced other constraints which limited their ability to adjust to the pain/illness as they wanted to. These were mainly financial. She had wanted to try other treatments such as acupuncture but could not afford them.

To summarise so far, there do appear to be differences in the 'styles of adjustment' between couples who score the VAS the same and those who score it higher. The couple who seemed to have an 'accommodating' style to the illness in terms of negotiating ways in which to continue activities or including others which were important to the husband in terms of helping him feel "useful" around the house and hence "normal", scored the VAS the same. Whereas the couples who appeared to be 'opposing' the pain and illness scored the VAS differently from their partners.

As with Radley's study, the couples did not fit neatly into either category. In some instances, some couples did appear to be trying to accommodate to the illness but conflict had arisen over how this was to be achieved. Also, as with the couple with widely differing scores, where there were differences in terms of the constraints felt by the husbands and wives, the scores also differed. Further, the degree to which the scores differ, therefore, may be in part representative of the degree to which couples have negotiated a way to adjust to the illness.

One of the most interesting findings was that those living alone tended to score higher on some of the measurements suggesting that for this group the pain experience differed from those living with others. One possible explanation discussed earlier on in this chapter was that the majority of those living alone were older than those living together and that pain impacts differently on patients' lives depending upon the age group (Turk et al, 1995). The significant relationship found between the faces scale and pain measurement (PPI) for those living alone suggested that pain severity and depression were linked. But the study by Turk et al (1995) suggests that this relationship is mediated by other factors, namely perceived 'Life control' and 'Interference'. As Turk et al also found in their study, the pain experienced by those living alone was more chronic (ie they had experienced RA for a longer duration) and the older patients, therefore, may tend to perceive their pain as more of a permanent disability in comparison to the younger group. An increase in pain for the elderly group, therefore, may more likely result in an increase in depressed affect.

According to Turk et al (1995), an alternative explanation for the differences in the pain-depression relationship between the two groups may be understood in terms of their social environment. The availability of social support, it is argued, is important for promoting psychological well-being and has been found to enhance recovery (Wallston et al, 1983). But as Turk et al (1995) conclude, living with others may not be universally beneficial and social support must be evaluated within each individual context. There may be instances where social support has a negative effect (Revenson et al, 1991, Turk et al, 1992).

While the above studies are interesting they offer a narrow definition of social support and social context. The social 'environment' is viewed as an external force or pressure on the person's ability to manage their illness. It has been suggested in the previous chapter that a wider definition of social context be used. One in which "social constraints are embodied in everyday conduct and bodily changes are made sensible through meanings engendered within discourse" (Radley, 1989, 230). Herzlich (1973) has argued that, as illness progresses, it ceases to be a quality of the external world (the locus of disease) and becomes an aspect of people's conduct through their attempts to combat or to adjust to its demands. From this perspective then, physical and social constraints are not oppositions, because the individual's relationship to society is realised within bodily conduct, while disturbances of the body are defined and limited by social interpretations. In addition, it can be argued that different people do not meet the same problems when ill for the simple reason that their social and bodily circumstances are not identical.

Analysis of the interviews revealed the following differences between those living alone and those living with others:

1) The majority of those living alone were older than those living with others. This is important as the limitations brought about by the illness were interpreted by the older ones in the sample, in terms of an inevitable part of "growing older". This did not necessarily mean they found it easier to accept the limitations, but were more accepting that there was nothing else that could be done to reduce the effects of the illness.

2) Those living alone had to rely on different sources of support than those living others. This included help from social services and other family members and friends. There were various differences in the kind of 'instrumental' problems people living alone experienced ie some reported minor difficulties eg reduced mobility while at the extreme end one woman was unable to get a drink without help from others. Having to rely on others and the kind of support offered for those living alone differed from those living with others. It was mentioned in previous chapters that 'dependency' was interpreted by many people in British society as something to be avoided and the ways in which people resisted it were discussed. For many of those living alone having to rely on others was critical if they were to survive. In order to avoid being seen as 'dependent' on others, assistance was rationalised in ways which reduced the threat to a 'virtuous' self.

> "I never ask them to do anything, they do things for me, they do it because they want to. I never say I want this done or that done because I don't think it's fair to demand other people do things for you, although all me life I've had to do it for them because I was that much older." (Mrs R; 859)

3) This leads to a further important difference found in the NHP scores. The major problem experienced by those living alone was social relationships. For the majority of those living alone, mobility was restricted by the chronicity of their illness and access to others who could take them out. Some were fortunate in that they had

relatives who would take them out, but for many of those who were once married, the death of their husbands combined with increasing disability reduced their social contacts. Some had developed ways of adapting to this. One woman reported that she had got quite used to her own company and sometimes preferred it, while others longed to get out.

> "I sit in here day after day in the same position. The only time I know it is raining is if somebody walks past with an umbrella up, but I mean it's day after day in the same position." (Mrs F: 436)

4) Those women who were widowed reported missing their husbands greatly. The husband used to help them around the house, with mobility and was also company, ie someone to talk to.

> "I get very lonely. See, if you live with someone and you can have a chat, I mean, then you're left on your own and you think, how am I going to manage to do things? (Mrs F: 644-651)

The majority of those who were widowed also came from traditional marital backgrounds where the wife was expected to stay at home and the husband worked. This highlights the important point that many of these women living alone had previously managed their illness within the context of a marital/family relationship(s). It could be argued that these women have experienced a shift in the social context which leads to changes in the 'style of adjustment' to the illness. The nature of this shift and the ways in which the current 'styles of adjustment' differ from previous styles is therefore important.

One of the changes related to the response to pain and its effect on activities. As the following woman described, now she no longer has a family to raise, she could pace herself:

> "You can't let the pain get the better of you, as much as sometimes you feel like screaming, but I think if you take your life at a steady pace to your ability, not to anybody else's, you get through your day much easier." (Mrs A: 727)

> "... because when you're younger and you've got children you feel as though you've got to make the effort more but as my children

> grew up and I had more operations, I knew that I'd got to slow right down and that is it." (Mrs A: 788)

This illustrates the point that although her activities have changed and she has to do them slower, her attitude to the pain has not. In particular, her view that pain is something you "fight". Part of this response of "fighting/denying" the pain was the notion that she felt she had not changed as a person due to the illness:

> "I don't really miss out on a lot. I go on holidays and that... I mean, if we were booked for a holiday tomorrow and I didn't feel well, I wouldn't tell you. I'd still go because I would fight against it." (Mrs C: 615-324)

As Radley (1989) pointed out, denial of pain is part of wanting to continue as if "normal", but while the above suggests that this woman is 'denying' her pain, she has also 'accommodated' to it by pacing herself and having assistance around the house.

A similar view and 'style of adjustment' was shared by another woman who was widowed.

> "You have to learn to live with it, I mean, you can't say I want it to go and it's gone. You just have to take each day as it comes." (Mrs C: 1377)

This woman had also "slowed down" and was also limited in her mobility but she described herself as "quite happy in my own way" (1336). She listened to the radio, read books and attended a club for the elderly.

A further aspect to this 'style of adjustment' related to their answers to the question, "Has the pain/illness changed you as a person?". For these two people, the changes were viewed in a positive light:

> "I suppose I think about people more than I used to, I'm not quite so selfish in me ways. I mean, before my husband and I, we had no children, we used to go out and enjoy ourselves and that. We used to help people if we saw them in trouble, don't get me wrong, many a time we stopped and helped somebody on the road. I think it's made me, .. we used to see people in

> the street in wheelchairs, but we used to walk past them and took no notice, know what I mean? like everybody else, but I think that now, I take more notice of people." (Mrs C: 1268-1283)

This contrasted to the women who were finding it difficult to adjust to their pain. As well as reporting major problems in functional matters they also reported constraints on the self. One woman described how she felt "useless" at not being able to do the housework or carry her grandchildren. There do appear to be differences within those people living alone as well as between those living alone and those not.

At this stage it is important to point out the differences between the women who were widowed and those who had never married. There were two instances of this and both women had spent most of their lives caring for their own sick mothers. One of the mothers had arthritis and her mother's response or adjustment to the illness had influenced her own.

> "My mother said to me, once you learn to accept it, you're find it easier and that is really quite true because once I thought right okay, I've got it, that's it." (Mrs S: 243)

This woman's style of adjustment, therefore, was shaped by her relationship with her mother. It provided a context in which to make sense of what was happening to her and was demonstrated in her response to the pain.

> "I detach my mind from them (feet) and try not to think about it. It's like, I can, some mornings I get up and I do feel really achy and I think to myself, I could really stay at home today, but I don't because I think once you let it get hold of you it will get worse." (Mrs S: 830-837)

To clarify, what is being argued is that for those living alone, the ability to continue as if "normal" and to sustain a positive sense of self, takes on a different form (or 'style') than for those living with others. For those who were once married, they had to adapt to managing the illness/pain within different relationships and with different constraints. These constraints were partly physical ie due to the increasing chronicity of their condition but also social. Those who had relied on their husbands assistance now had to rely on others. These relationships had a different 'meaning' from that of marriage. Many were worried about "bothering" other family members and neighbours too much (one woman described herself as "Mrs Nuisance"). Assistance from the spouse had enabled these woman to continue engaging in a social world which placed value on independence and to sustain a relatively "normal" life. Once this had gone, they had to engage in other activities or adapt others in order to construct a "normal" life without their spouses. Some of the women living alone had managed to do this by 'accommodating' not only to the pain but to the changes brought about by the death of their spouse, while others were finding it more difficult.

This can be partly explained by the different type of relationships which people living alone are involved in compared to those living with others. This is not to suggest that for those living with others, they were finding it easier to adjust than those living alone. Some of them were just as lonely and socially isolated as those living alone. In several respects, the fact that many of those living alone received assistance from social services for cleaning and shopping was perceived as not only functional assistance but as a way of avoiding the threat of being seen to be 'dependent' on others as state help in this form was often perceived differently from help from family or friends (Williams, 1993). Those women living alone who saw it their "right" to receive help from social services were those who were more likely to have 'accommodated' to the pain.

To summarise, there appear to be important differences between those living alone and those living with others in terms of 'styles of adjustment' to pain and illness. This also suggests that differences should occur between men living alone and women living alone and between men who have never married and those who are widowed. Age was also found to be an important factor in terms of response to pain in that the older members of the sample tended to view the lack of mobility caused by the pain as a part of growing older. Attempts to change this situation, for example by surgery were seen as futile. Finally, the above arguments suggest that more research is needed into this area, in particular, analysis of the way the response to pain, or 'style of adjustment', responds to changes not only in circumstances (such as the death of a spouse) but also to wider societal changes. These include the change in traditional marital roles to ones which are more 'equal' in terms of women going out to work.

Having discussed the operational problems with the VAS, there was also evidence of some of the technical/design problems discussed in the measurement chapter which may have influenced the results. One problem which researchers are concerned about and which could affect pain measurement is the recall of pain sensations. Gaston-

Johansson (1983) found that patients reported their usual pain to be twice as intense as their present pain. Burckhardt (1984) noted that patients are apt to acknowledge only mild or no pain during the interview but when asked to recall their usual or worst pain, they scored their pain intensity higher. A similar result was found in this study in that the PPI scores were significantly lower than the VAS scores taken at home and in the hospital. This could be interpreted in several ways. First, it could mean that at the time of the interview, people were in less pain than their worst pain over the past week. Second, as the studies above suggest, people found it difficult to recall their worst pain over the past week and hence overestimated how much pain they were in. Third, the context of the interview situation may have influenced the perception of the pain ie by distracting people from it. Finally, the time of day when the measurement was taken is important as worst pain usually arises for people with RA in the morning/evening and after overexertion.

Concerns have also been voiced over the words used at the ends of the VAS. A study by Gaston-Johannson (1981) into the intensity of the words pain, ache and hurt found that cross-culturally pain was seen as being the most intense, followed by ache, then hurt. This was also the case for health professionals. But in the interviews in this study, although ache was viewed as less intense than pain, it was worse in the sense that it was the most difficult to relieve.

> "It's aches and pains you know. Sometimes you get the ache, which is like a dead ache and there is no way you can relieve it. The pain is more like a sharp, shooting pain, but the ache I think is probably worse than the pain normally." (No. 4p: 577-580)

This has important implications for the VAS, particularly if it is used for those with rheumatoid arthritis. If the word pain is used at either end then the person may just rate their pain and not the ache. This could give a misleading picture in terms of what treatment to give as in the case above it is the ache which needs relief more than the pain. It also shows that it is not necessarily the intensity of the pain/ache which is important but whether it can be relieved or not. Having another VAS which measures the emotional intensity separately could clarify this issue as it would probably show that emotionally the ache is more intense than the pain.

Having discussed the main problem areas as regards the VAS, we now turn to the MPQ.

2. The McGill Pain Questionnaire

As with the VAS, the problems with the MPQ can be divided into two areas: those relating to technical/design issues and those relating to operational issues.

a) Operational Problems

First, the operational problems. People did choose similar words from the MPQ as they used in the interview. The most frequently chosen word from the MPQ and used in the interview was "ache". This accords with other studies of people with rheumatoid arthritis (Davies, 1988; Burckhardt, 1984; Dusbisson & Melzack, 1976) and adds further evidence that "ache" is a central feature of the pain experience.

But despite people choosing similar words, discrepancies occurred between the MPQ scores and the interviewer ratings. For example, not all of those who were rated in the high pain group scored highly on the MPQ and vice versa. The reason for this appears to centre on the *weighting* of the words used in the MPQ. As discussed in the measurement chapter, there is concern over whether the sensory dimension of the MPQ should be scaled according to intensity (Reading et al, 1982). In addition, large differences have been reported amongst subjects over how the adjectives within a group describe the intensity of pain (Reading et al, 1982). In a study of the affective domain of pain (Pallin & Morley, 1993), significant differences were found between different chronic pain groups in their weighting of the dimensions. This study found a similar problem as those who used the word ache had varying VAS scores. This may be because the VAS is a measure of overall pain intensity, incorporating sensory and affective aspects, but the MPQ does scale the sensory words according to intensity so some degree of correlation would have been expected. The VAS scores also varied for those who chose the evaluative word, annoying, which was the most frequently chosen word from this dimension. Also, analysis of the different meanings people gave to the same words shows that they need to be interpreted in their social context. In other words, someone may find their pain a little bit annoying because it does not limit them too much, while another person may describe their pain as very annoying because they feel very limited. It was not the pain sensation per se which was annoying but the effect it was having on what they could or could not do.

The language people use to communicate their distress has been shown to vary across social class (Bernstein, 1964, 1974). Bernstein's argument was that speech forms were generated in social relations and exercised a constraining effect on social behaviour and the experience of the speakers. Two basis categories of sociolinguistic code were proposed, namely restricted and elaborated. Bernstein identified the propensity for the first code to be used mainly by the working class and the first and second by the middle class. The codes, it is argued, reflect differences in subjective experience, the concept of self and the articulation and elaboration of 'inner states' between the two groups. According to Bernstein, for the working class, distress will typically be experienced and communicated in a relatively proximal, localised immediate way, that is through the medium of the body. For the middle class, it is suggested that distress is more likely to be experienced in individuated, personalised ways, with more emphasis on the psyche as a site of experience.

This links into the studies by Fabrega (1976) discussed in the Introduction, where it was argued that the different cultural ways of describing pain could also shape the experience. Blair (1993) suggests that differences in the experience and communication of distress may also vary according to gender. In other words, the cultural/social context in which pain emerges, it is being argued, could lead to differences in the way it is experienced and communicated. This has implications for the translation of the MPQ into different languages. This has already been achieved to a certain extent with some agreement across cultural groups over the weighting of the words. In particular, Gaston-Johannson asked people from three different cultural groups to rank the words, pain, ache and hurt according to intensity. She found significant agreement across all three groups in the ranking of the words. But again, as found above, the emotional intensity of these words may not necessarily be the same across the groups. Also, many of these translations have been carried out in countries with a language structure similar to English. In other words, the MPQ has not been translated into Bengali where pain descriptions also rely on changes in sound/pitch to emphasise intensity rather than the use of different words and vary according to who is being spoken to. Constructing an MPQ for this cultural group may, therefore, prove problematic and difficult to achieve.

As well as problems associated with the social context of pain language, there are also other problems at the time of administering the measurement which could have influenced the results such as mood and attention. As discussed in the measurement chapter, the degree of affective distress that the person is experiencing has also been shown to influence the choice of words. This point was also explored in this study. Whereas these studies found that people who were affectively distressed chose more affective and sensory words and words of a higher intensity, this did not arise in this study. Where differences were found it was in the VAS and PPI scores. In particular, those who chose an unhappy face scored higher on the VAS and PPI than those who chose a happier face. The difference in PPI scores is interesting as it includes evaluative words. The fact that the more depressed people chose the higher intensity words would seem to suggest that the PPI is a measure of suffering (or affective distress) and the same could be said for the VAS. These scores, therefore, were reflecting the combined sensory and emotional intensity of the experience. Further research in this area is needed as only a small proportion of this sample actually chose an unhappy face (n=9, 20%).

This finding raises the question as to why the other MPQ scores did not detect differences between those who were depressed and those who were not. Again, the problem could lie in the problems discussed above in relation to the use of pain language. In other words, the choice of words could be influenced by other factors not directly related to the pain experience such as education, attention etc.

The social relationship between the person administering the instrument and the person in pain could also influence the scores. As discussed earlier, Melzack (1975) reported that the word chosen from the present pain intensity scale may not only be influenced by mood and attention but may represent a communication between the person doing the measurement and the patient. In other words, the choice of words could be influenced by the social context. The cross-cultural differences in pain description discussed in the Introduction illustrate this clearly, in particular instances where language was formalised to a doctor but informal to others eg family.

This could also arise in English. For example, Cornwell's (1984) study of public and private ways of talking about health and illness shows how people describe their experiences differently. Public usually includes how they think they should behave towards their illness and private includes how they actually behaved and experienced it.
People, therefore, may choose words from the MPQ which portray the public image of how you should cope with pain. For example, on the PPI, someone may find the experience unbearable but see this in a negative light as they want to portray an image of someone who can stand pain and thereby choose a different, less intense word.

This leads on to the next point, ie is the MPQ measuring the three dimensions of the pain experience proposed by Melzack & Wall? As discussed in the measurement chapter that there have been numerous studies investigating the three-factor structure of the MPQ. Most of the studies support it and in this study the majority of the sample chose at least one word from each dimension indicating that these aspects of the experience featured strongly. In a few cases, some of those interviewed used words from each dimension in the interview, but did not do so on the MPQ. Relying on the MPQ in these instances, therefore, would have given a different picture of the experience than described in the interview. The possible reasons for this will be discussed in the technical section of the MPQ.

There is also concern over the relationship between the different dimensions. As found in other studies of the MPQ (see measurement chapter) significant correlations were also found between some of the different dimensions of the MPQ suggesting that the 'dimensions' may not in fact be all that discrete; the evaluative dimension did not correlate significantly with any of the other dimensions. It has been suggested, however, that the fact that there is a correlation between the other dimensions does not mean the MPQ lacks discriminant validity but that the dimensions of the experience should correlate as they are related (Gracely, 1992). This does not necessarily mean that the more intense the sensation, (ie the higher the sensory dimension), the higher the affective-evaluative dimensions. In most cases the sensory and affective dimensions seemed to be similar in scores, ie a high sensory score usually went with a high affective score, but it was the evaluative dimension where the scores contrasted most. In other words, a high sensory score did not always go with a high evaluative score. One reason for this could be the weighting of the words, but there are other possible reasons. One is that people respond differently to similar pain intensities. For example, one man in the study scored quite high on the sensory dimension but low on the evaluative. In the interview he described how he had pain but it didn't bother him as much as it used to. This was because he was now retired and did not have the pressure of work which was difficult when he had pain. In contrast, one woman chose a low intensity sensory word but quite a high evaluative word. In the interview, she said the pain was mild but made her feel miserable as she had problems doing things.

The adequacy of the three-factor structure of the MPQ was also explored by comparing it to the faces scale and NHP. The PPI and the miscellaneous dimension of the MPQ were the only scores to correlate significantly with the faces scale. This is interesting as the faces is purported to be a measure of depression (how the person feels about their life as a whole). As the faces did not correlate with the sensory dimension or affective dimensions individually, it could be interpreted that the overall intensity of the experience is related to how the person feels about the pain in the context of their lives; not just the sensation itself. If VASs of the sensory and emotional aspects of the experience were used and correlated with the faces, it would clarify this issue and determine whether it was the construction of the MPQ which led to the poor correlation between the dimensions and the faces or whether the VAS is measuring a combination of the two aspects. Price & Harkins (1987) have suggested that there may be aspects of the affective dimension of pain which originate from general thoughts and feelings about the person's situation which are not directly related to the sensory intensity. In this study the evaluative dimension did not correlate with the other dimensions and this may be the reason. In other words, it is measuring the meaning the pain has in the context of the person's life rather than something which is thought of as the physical representation of the pain, the pain intensity.

Studies into the effect of the 'placebo response', Wall (1995) argues, reinforce the theory of different dimensions of the pain experience and their measurement. Gracely et al (1978) and Gracely (1979) examined the placebo response to see if all the dimensions of pain were equally involved. They used volunteer experimental subjects who received gradually random shocks to the teeth or skin. The subjects were asked to rate separately the intensity of the pain and the unpleasantness of the pain. The subjects were then given a saline injection with the assurance that they were being given a powerful analgesic. The results found that the intensity of the pain was completely unaffected but that at low-shock levels the unpleasantness was markedly reduced but at higher intensities was unaffected. Gracely et al (1978) then went on to show that diazepam, a tranquilliser, could produce exactly the same effect. However, in 1979, Gracely investigated the effect of fentanyl, a narcotic, on the same types of pain and found a different result. It reduced the intensity but not the unpleasantness.

Beecher (1955) and Lasagna et al (1954) found placebos to work on severe pain and not just mild pain as Gracely found. Patients with migraine or postoperative pain or cancer report pain relief of both aspects. Wall (1995) concludes that the placebo effect can change the intensity and unpleasantness dimensions separately or together depending on the circumstances of suggestion, expectation and instruction.

There are various explanations for the placebo effect on pain. By the far the most common is that the placebo effect depends on the expectation of the subject. In a trial of two drugs versus placebos on 100 patients, Nash & Zimring (1969) tested specifically for the role of expectation. The two drugs had no effect which would differentiate them from the placebo, but there was a strong correlation between measured expectation and the placebo effect.

Although there is support for the three-factor structure, and in this study, people did use words from each of the dimensions, there is still doubt over what the MPQ is actually measuring. Due to the influence of affective distress on the way the MPQ words are selected, it has been suggested in the measurement chapter that the MPQ is measuring the suffering the person is experiencing, rather than the pain. Even the choice of words from the sensory dimension have been shown to be influenced by how depressed the person is and it is therefore not a pure or uncontaminated measure of sensory intensity. Although evidence for this was not found in this study it is an important point. In particular, it has also been shown that people who are depressed also score higher on the VAS than those who are not (see study by Peet et al in the measurement chapter). As discussed earlier, a similar result was found in this study in that those who chose an unhappy face also had higher VAS scores. It could be argued then that the VAS is also influenced in the same way as the MPQ. In other words, those who are depressed have perceptual and cognitive problems in using visual analogue scales. But, it could also be argued that it is not necessarily that depressed people have difficulty in using the VAS but that the VAS is measuring the suffering that the person is experiencing. This suffering is a combination of the sensory and emotional aspects of the experience ie the meaning of the pain, and they are linked in such a way that for people in chronic pain they become indistinguishable. Also, as the gate control theory of pain argues, emotional feelings can affect a person's sensory perception. This is not something that can be controlled but is an important element of the nature of the chronic pain experience. It was also interesting to find that those who tended to score higher on the faces, VAS and PPI were living alone. This is important because if the pain measures are taken to be measures of suffering then it would appear that those living alone are suffering more than those living with others. The reason why this should be will be explored further on in the chapter during the discussion of the nature of the chronic pain experience of those interviewed in this study. Now we turn to the technical/design concerns of the MPQ.

b) Technical/Design Problems

As well as problems associated with operationalising Melzack's theory of pain, there were also other problems in the design and use of the MPQ not directly related to the pain experience. One problem with using pain language is education. Gaston-Johansson (1984) found that nurses chose more words from the MPQ than the patients did. She partly explains this by the nurses being better educated and therefore being able to understand more of the words. This issue was difficult to ascertain in this study as the majority of the sample were not well educated and could be described in general terms as working class. But it is an issue which should be explored further.

There is also the important point, mentioned in the measurement chapter, that the MPQ is weighted more towards the sensory aspects of the experience. In particular there is only one subgroup (list of words) for the evaluative dimension. The words in this category may not describe their experience adequately, even though this dimension does feature in it. For example, the words annoying and miserable are grouped together and so could not both be chosen. It was found in this study that some people used both of these words in the interview to describe their experience. Pain was annoying because it made doing things difficult and in turn this made them feel miserable. But this was not always the case. Some found it annoying but they did not feel miserable. It would seem that some sort of "happiness" scale, like the faces is needed or the expansion of the evaluative category.

Summary of discussion of pain measurements

A discussion of the main problems with the MPQ and VAS shows that when interpreting the scores, caution should be taken. In particular it would appear that the scores represent a mixture of the pain intensity and pain evaluation; that they are a representation of suffering rather than physical pain. The theory that there are different dimensions to the pain experience would appear to be validated by the interviews in the this study. The problem appears to lie in operationalising the theory. In particular, the weighting of the words on the MPQ was found to be problematic in that it neglected the social context. In addition, although the MPQ (and more recently the VAS) attempt to overcome the influence of social context, there are problems as discussed above and as the following quotes from the people interviewed in this study illustrate. More importantly, it would appear that 'social context' is an important element of the pain experience which cannot be separated as a variable from the pain experience.

The Nature of the Chronic Pain Experience

The argument so far is that pain is an interpretation shaped by the social context in which it takes place. The nature of the chronic pain experience as described by those in this study does have similarities to other sociological studies of chronic illness as discussed in the Introduction. But there are certain concepts which have particular relevance for the study of pain and need to be explored further.

One important concept is that of 'normalisation' (Wiener, 1974). This refers to people in pain carrying on as if they did not have it, in other words doing what they normally do despite the pain.

> "The thing about arthritis is that the pain is always there, so if it hurts while you're sitting doing nothing, then it's still going to hurt when you do it, so I'd rather do it." (Woman, no.33: 160-165)

> "I don't really make it control my life. I just carry on as normal. All right I've got it, but I don't let it get me down, unless I'm feeling low with it, then I will rest, but I do just keep going generally, I just don't give into it." (Woman, no. 25: 223-229)

But the concept of 'normalisation' is more than a strategy for keeping going, ie to get things done, it is also a way of sustaining a positive self-identity. Charmaz (1983), conceptualises the experience of chronic illness as leading to a form of suffering beyond that of the physical, namely a "loss of self". Charmaz argues that chronic illness leads to "crumbling away" of former self-images without the development or sustainment of new ones. One way of sustaining a positive self-image is through 'normalisation'. In other words by covering-up the pain and continuing with activities which demonstrate the kind of person they want to be ie independent, not a moaner, a positive sense of self can be maintained. But as Wiener noted in the Introduction, there is a tension between normalising the pain and the desire to have pain legitimised. In other words people may want to be "normal" but there also comes a point when the pain becomes so bad that they need help (ie more medication) and want people to acknowledge their pain.

Examples of this can be found in the interviews. One woman told how her doctor had shown a visiting doctor her high ESR (which is used to show how active the arthritis is and is used as evidence that a person is in a lot of pain, although there is no correlation between the two):

> "Dr ... said I can stand a lot more pain than other people. ... when I go and see Dr .... sometimes and there's another doctor there, and the ESR's up to 100 and the doctor says, "oh gosh, 100, you must be able to stand more pain than

> anybody else." The trouble is, you can stand a lot but there does get to a time when you think enough's enough sort of thing." (woman, no. 23:103-111)

This woman was also reluctant to tell the doctor how she really felt, "I've never been one to moan about it". This may be due to the image of a "good patient" which the doctor had of her combined with the ESR as "objective" proof of the amount of pain she's in:

> "I say to him I am still in a lot of pain and he says to me I don't doubt it, I know, but unless the ESR is very high, but it's not, it has been up to 120, it's only 96, so if it goes up to 120 he might do something about it." (597-603)

This illustrates the point that it is how you want to be perceived by others which can influence the decision whether to disclose or cover-up pain. One man described how he covered-up his pain to keep his independence. In other words he thought that if he continually moaned about his pain, his wife would do everything for him.

A further aspect of sustaining a positive self-image is to see the construction of self as the "pursuit of moral virtue" (Williams, 1984, see Introduction). In other words, "normalisation", and the strategies used, should also be seen as the enactment of a virtuous self. Values in western societies such as independence influence people's perceptions not only about the appropriate way to respond to pain but what it means to be a valued member of society, ie a "good person". The crucial point is that people have self-images of how they would like to be seen and are continually involved in the construction of the self through their actions. In addition, virtue not only refers to being a "good person" but being true to yourself, being the kind of person you want to be. Pain and illness can threaten a person's ability to do this and lead to a "loss of self" as the following extracts from the interviews illustrate.

For many women, the important concern was housework and cleanliness. When pain became too intense, they often found it difficult to do their housework to the standard they wanted and this often caused frustration and distress:

> "When I have a bad day, I get very depressed because I can't do nothing, because I want to do things. I have always enjoyed doing a bit of housework. I get a lot of satisfaction doing a room

> out and it's surprising how it hurts when you can't do things how you want to do them." (Woman, no. 21: 208-212)

For this woman, her inability to clean the house to her own standards threatened her sense of self. For the majority of the men, the main concern was working. When the illness meant they had to leave work, this was a major threat to their self-identity. One man in particular described how he tried to commit suicide due to his inability to provide for his family. As his wife said, pride in being seen to be providing for your family and not being a burden on others was important to him.

> "I was about 29 at the time, "I can't take this pain, people will be better off without me," you know. Everybody was looking after me, doing their best, I was just a bloody nuisance. That's how I felt." (no.42: 1138-1144)

It was not just the pain per se which made him want to do this, but the effect of the pain on his life and his sense of self. In addition, this highlights the important point that experiences may differ between men and women, as what counts as virtuous varies in our society according to gender (see Bendelow, 1994).

But the ability to sustain a positive self-image can fluctuate as much as the pain of RA itself. One woman describes how she used to find it difficult to cope with her pain but now she feels "normal".

> "I used to go through a stage where I wasn't getting enough rest, I wasn't able to sleep when I went to bed. I wasn't interested in eating. I lost a lot of weight and felt life was just unbearable. But I seemed to have turned that corner now and I think probably over the last, oh good couple of years, I've been sleeping well, eating, exercising and it's just a lot better." (Woman, no.25: 276-286)

Further on she describes in what way she feels "normal":

> "I just carry on as normal. There's nothing that I've stopped doing that I used to do, so I'm still basically the same person." (Woman, no. 25: 748-750)

For this woman, the fact that she could still continue with the activities that she felt were important and had always done in the past meant that, for her, she felt "normal" and a positive self-image was sustained. She still experienced pain, but carried on despite it:

> "There may be a day that I've got to give it up (horseriding), but at the moment I still enjoy it and I'm prepared to take the pain with it. It is hard work, but I think it is doing me good because it gives me that challenge that I've got to get up in the morning, so it gets me going." (912-928)

But there were others who were resigned to the fact that their lives would get worse and that there was no hope of continuing in the activities that had been important to them:

> "... I know I won't get any better. I've made my mind up to it that it will get worse rather than better really, so while I'm able to move, I move. I can't move around and do things like other people and I know it's going to be different or if there is medication found that could more or less kill off all the pain , but other than that, I've just made my mind up to it and that's it." (Man, no. 5: 912-925)

While others had found new interests which helped them to be more positive about themselves and the future. One man in particular looked after Bantum (chickens) which he visited everyday to feed and often just to watch them. This, he said, took his mind off the pain and gave him an interest in life.

Finally, as illustrated earlier, other people can have an important influence on the individual's ability to sustain a positive self-image. The 'style of adjustment' showed the various ways in which people with pain try to reconcile bodily and social constraints. This resulted in different interpretations of self-identity and ways in which identity can be maintained through activities in everyday life. The majority of the couples in this study were from a working-class background and identity was maintained through physical activity in the form of DIY, housework or paid manual work. Different styles of adjustment to arthritis may be found in couples from a non-manual background, where, it is hypothesised according to Berstein (1972), marital roles can be discussed and negotiated in more flexible ways.

Other people who have an important role in people's efforts to sustain a positive self-identity include the medical professionals as well as family and friends. For example, one of the women interviewed described a recent incident where she was suddenly immobilised by pain and was bedridden for four days. She was visited by two locum doctors who gave her painkilling injections. Also, because this incident had been the worst she had experienced she decided to move her consultant's appointment forward. When the time came to go, she had improved, but decided to go anyway because she thought it would be rude to cancel. The consultant checked her knees and showed her her ESR (which was low) and implied that she had wasted his time. In addition, he did take any interest in what had occurred a few days earlier. She was very upset about this experience as she had liked the consultant before but now she felt he doubted her word:

> "I think because of that time, I felt that, you know, I don't know what I thought, it's like a feeling of, "I don't think you believe what I'm saying to you", like. (No. 21: 862-865)

She also doubted the use of the ESR as it did not relate to her own experience:

> "... they take your blood and they look for the thickening or crystals and it tells them how active it is, so I feel like saying, well, if you're testing my blood, how am I getting some worst days than I've ever had, without you knowing about it, looking at my blood?, because it seems as if whatever amount doesn't count. I feel like I was making it up or something." (879-889)

For this woman then, being believed by the consultant, in other words, having the pain legitimated was very important. People in pain are very vulnerable in this sense as, unlike the more objective signs of disease such as inflamed joints, there is no way of telling how much pain a person is in. Even though there is no correlation between inflammation and pain reports, doctors still continue to use it even though it can conflict with patient's own experiences.

To summarise so far, what is being argued is that the interpretation of pain and its meaning does not take place in a social vacuum - it is a social construction. In other words, the social context in which the sensation arises will influence how it is experienced. A major part of the social context is the construction of self identity. The response to pain, therefore, or the meaning given to it, is influenced by the self that the person is wanting to construct. Self-identity is social in that it is constructed through interaction with others as discussed above. Medical professionals and OFM's, therefore, are important in the construction of a positive self-image and hence in the shaping of the pain experience itself. Measurement scores, therefore, represent not just a representation of the physical sensation but the meaning of the pain.

In theoretical terms there are a further two important concepts which can provide further understanding of how people make sense of their pain. These are 'narrative' and 'lifeworld'. They have been touched upon briefly in the Introduction but require further discussion.

The concept of the "lifeworld" originated from the philosopher Husserl (1952) who defined it as the world of our common, immediate experiences. Schutz (1974) developed Husserl's concept and defined it as "that province of reality which the wide-awake and normal adult simply takes for granted in the attitude of common sense" (Schutz, 1974:3). In the lifeworld everything is experienced unquestionably and appears unproblematic until further notice. More importantly this reality is not private, it is intersubjective. In other words it is shared by others and created through social interaction, transforming natural things into social objects. Further, understanding of the world is based on a stock of previous experience, personal experiences as well as experiences transmitted from other people. All of these experiences form a unifying stock of knowledge which serve as reference points for acting in the world. The nature of the everyday reality that comprises the lifeworld therefore is the arena in which the experience of pain is interpreted.

The nature of the common-sense reality as opposed to that of science is important for a study of pain as it highlights important differences between the two in terms of how pain is interpreted. For example, many of those interviewed spoke of the weather influencing their pain. This has not been scientifically proven but people still see it as important. Schutz would argue that this is due to the way in which knowledge is acquired in the lifeworld as compared to the way science views reality and hence acquires knowledge. The "background stock of knowledge in the lifeworld is not the result of rational cognitive events in the theoretical attitude, it results from sedimentation of experiences in the lifeworld" (Schutz, 1974:14). In other words, the stock of knowledge or common-sense understandings which form the background for understanding the everyday world is constructed differently than that of scientific knowledge. According to Schutz, reality in the everyday is preselected and preinterpreted into commonsense constructs and these determine behaviour and help people come to terms with their natural and socio-cultural environment.

A key important feature of the lifeworld is the "pragmatic motive". In other words, the stock of knowledge serves a person for the solution to practical problems. People are interested in being able to orient themselves in their actions in routine ways eg if things are so and so, then I will act so and so. Because of the successful enactment of these actions, a person does not need to go to new solutions of problems, but act as they have already acted in similar circumstances. Examples of the "pragmatic motive" can be found in the interviews, particularly in relation to the choice of treatments to relieve the pain. Those who had found medicine to work, continued to use it, whereas those who found no relief sought other methods. Many for example had tried alternative or complimentary medicine such as acupuncture, the wearing of copper bangles, prayer etc.

The "pragmatic motive" can be seen in the narratives people construct. For example, linkages made between the weather and pain are constructed in the form of a narrative. Some of these narratives show evidence of personal experience and medical understanding intermingling. As Hillier argues (in Scambler,1987), these lay theories are not totally irrational, they just represent linkages based on common sense notions which are influenced by many sources. For example, a person may have heard from others that the weather can affect arthritis pain or they may notice that at particular times when their pain is bad the weather is always damp. If this happens on a regular basis it becomes reliable knowledge and forms part of the background understanding that a person has about their pain. According to Schutz, people only know what they need to know in order to master the situation. People know there are different and more precise explanations but they do not want to know because they are sufficiently familiar for their own purposes eg they do not want to know the scientific details about their RA, they just want to know enough in order for them to live with it ie will it ever go away? Will it get worse/better? Will I be able to continue working?

This highlights the important point that the interpretation of pain is context-bound; it will depend on the background stock of knowledge of the person which is built up over time through interaction with others and is also partly personal to them ie they may have experienced pain before and this will influence how they view future pain. This contrasts to the medical understanding of pain which does not link the experience to the person's social context.

The effect of pain on the self has been discussed earlier and it is important to note that it is in the lifeworld that the self is constructed. In constructing the self, narrative is also very important, as, according to MacIntyre (1981) it is through narrative that we construct the self. It is not only in making sense of their experiences that people use narrative but that they also live out narratives:

> "It is because we all live out narratives in our lives and because we understand our own lives in terms of the narratives that we live out that the form of narrative is appropriate for understanding the actions of others." (MacIntyre, 1981:197)

An important part of lived narratives, according to MacIntyre, is that they have a teleological character. In other words, the present is informed by some image of the future, a variety of goals or ends towards which people are moving or failing to move. In other words, people have their own personal narratives built up over time and each with its own particular meaning or telos. Williams (1984), previously mentioned in the Introduction, has shown how the telos has a moral character. In other words, the enactment of a personal narrative should be seen as the "pursuit of virtue".

Having outlined the concepts of lifeworld and narrative and their importance in understanding the interpretation of pain, the concepts are also important for understanding how the everyday world can be "disrupted" by the onset of pain (Good, 1991). As discussed in the Introduction, Good suggests that pain can threaten the everyday experience of the lifeworld leading to its "dissolution" and in turn threaten the self. The effect of pain on the lifeworld as outlined by Good can be seen in the interviews to a certain extent, especially at the early stages of the illness. Schutz refers to these occasions where "objects" do not fit into previous experience and cause the taken-for-granted nature of reality to "explode". This was illustrated in the interviews where many people were shocked by the diagnosis of rheumatoid arthritis. Such a diagnosis brings knowledge to the forefront which was previously taken-for-granted or only existed in the background. These include a more conscious awareness of the body and the limitations it can have on activity.

For the majority of those interviewed, pain and the physical changes brought about by the illness became part of the background stock of knowledge and more importantly part of the self.

> "I know I'm handicapped in that my hands look different, but I don't

> feel any different to you or anyone, it's only when I see myself in a shop window that I realise I do, but it doesn't feel any different to me inside, and so, because the pain is always there in the background, I can't visualise what it would be like not to have it there." (No.33: 467-472)

In turn, as discussed by Good, the experience of pain and illness changes the previously taken-for-granted nature of reality and the way it is experienced, as the woman above describes when talking about the future.

> "Now and again, and I think it is due to the fact that I'm getting older, I think about things I'd like to do and I think I ought to get on and do things while I can, because I know that in 10-15 years I might not be as mobile as I am which is probably something that most people don't think about, where it does colour, it must colour the way you're thinking." (No.33: 497-508)

For people who do not have a chronic illness, they do not think about the future in the same way. In many respects, for people like the woman above, the future dominates their thoughts more than it would have done otherwise. As Schutz has pointed out, the future, and in particular the understanding that the world will be familiar and that I will be able to continue doing what I have always done is a major part of the everyday lifeworld, but this changes with the onset of chronic illness. People with chronic illness are more uncertain about the future, and although it worried people to differing degrees in the interviews, it was a constant feature of their background knowledge and influenced their actions in the present. A few described how they tried to do too much at the beginning of their illness because they were afraid they would not be able to do them in the future.

The idea that the pain forms part of the background stock of knowledge and even becomes taken-for-granted is important for understanding the narratives that people construct about their pain. For example, one woman described how the pain was always there but it was only when it became "bad" that she really noticed it. By "bad" she meant that the pain became "overwhelming". Consequently it prevented her from doing anything; took up all her concentration; and made her withdraw from contact with others. This was highlighted by Good where he argued that pain becomes the centre of the lifeworld and consciousness and hence distorts the experience of everyday reality. A similar experience was described by others in the interviews. For one man in particular, the pain made him "fly across the room" in a rage which he was unable to make sense of and sometimes was not even aware of. Schutz offers possible explanations for this by his theory that there are different realities ie dreaming, fantasy etc with their own meaning-context. Perhaps the onset of "bad" pain leads to a shift in the reality of the everyday world to a different reality with its own structures and forms of experience. In other words, it is not just that pain leads to an unmaking of the world as Good would argue but that people move into a different reality, one where the body and pain dominate.

More importantly, from the viewpoint of doctors trying to interpret how much pain someone is in, the point that "bad" pain is pain which dominates a person's life ie by restricting their activities or shifting their focus from other areas of life towards the pain, would seem important, particularly as pain can become "taken-for-granted" by those who have lived with it for long periods of time. In addition, whether pain becomes taken-for-granted may depend on what is happening in other areas of an individual's life. For example, pain that limits a person's ability to work will be more central to their world than when they do not have to work ie when they retire. An example of this was mentioned earlier, where a man said he was not "bothered" by his pain anymore as he did not have to work, but it did matter when he was younger and had to work to support his family. For this person, the pain in the later years had become "taken-for-granted" and unproblematic. Again, the "pragmatic motive" would seem relevant to understanding this change of view. Good's (1991) argument, therefore, that a phenomenological approach to pain is required is important. The way that pain can transform the experience of the everyday lifeworld and in particular the way that pain can shift from being "taken-for-granted" to "overwhelming" and hence leading to the "unmaking" of the everyday world or to a shift into a different reality are important for an understanding of the pain experience and in particular the interpretation of pain measurement scores.

There are other theories which are useful in understanding pain as a phenomenological experience. Denzin (1987), who was mentioned briefly in the Introduction, argues that pain should be viewed as an emotional experience. To elaborate, in order for the person to act on his/her body and give it meaning, it must become part of his/her consciousness. This is achieved through intentional focusing on the body. When this occurs, all of the body and all of the person, including thoughts and feelings become part of a single experience. With regard to pain, Denzin suggests that pain involves the joining of two structures of experience; consciousness and the lived (psychic) body. The consciousness that experiences and becomes aware of illness or pain within its psychic body directs itself towards it in a feeling, emotional manner. In other words, the person adopts an attitude towards the pain that is felt eg enduring it, hating it etc. To summarize in Denzin's words:

> "With pain, the lived body becomes the object and subject of the person's and others' consciousness. Initially pain is experienced as part of the lived body and is located in the situated practices of the person at the time that it appears. This pain is at first private, unnamed and known only to the person. When it is reflected on it becomes an emotional object that combines physical feelings of pain with emotional definitions. As a part of lived experience, pain or illness exists alongside the person's consciousness and his psychic body. It is localised in the body and lived as a particular conscious fact. At this level there is no distance between the feeling of the pain and the consciousness of the pain. They are united." (Denzin, 1984: 118)

Denzin's theory provides a further dimension to the argument that the interpretation of pain is a social construct. More importantly, it illustrates how the social dimensions, the feelings towards the pain, join together with the physical sensations. In terms of measuring pain, therefore, this suggests that people's scores are not just direct representations of the physical feeling but the physical combined with social definitions.

To summarize, what is being argued is that pain should be understood as an experience which is interpreted in the lifeworld in the form of narrative. This lifeworld consists of knowledge about pain or narratives from several different sources, including medicine. In turn, narratives of pain differ from those of medicine and science in that they are context-dependent. This is because the nature of the pain experience is such that the physical cannot be separated from the emotional/social.

The above suggests a phenomenological approach to the study of pain but there are other levels at which pain should be studied. The relationship between pain and medicine has been discussed in the Introduction, where it was suggested that medicine has "rationalised/"medicalised" a "natural" physical and emotional experience into a sensation. Medicine's role in rationalising pain could be seen as part of the wider change in society towards modernity. According to Bauman (1992), modernity has resulted in the denial of "subjectivity" (Bauman, 1992):

> "As nature became progressively 'de-animated', humans grew

> increasingly 'naturalized' so that their 'subjectivity', the primal giveness of their existence could be denied and they themselves could be made hospitable for instrumental meanings." (Bauman, x: 1992)

In terms of pain, therefore, the "subjective" elements are seen as separate from the actual physical sensation and often viewed as secondary responses to the sensation, "contaminating" the true measure of pain. The search for a "gold standard" of pain measurement, as discussed in the measurement chapter, is due to this concern with identifying and controlling these aspects so that the "real" pain can be measured.

It is in the origins of modernity which the reason for technicising pain can be found. According to Bauman (1992), modern society emerged out of the discovery that human order is vulnerable and devoid of reliable foundations. This discovery was "shocking" and led to the effort to make order solid and reliably founded. The idea of order and the practice of ordering emerged together, for in order for order to exist something needs to be done. Medicine's attempt to measure pain and hence to control it can be seen as part of this attempt to bring order to the world. As has been mentioned by Bauman (1992) the result has been the 'devaluing' and 'demonizing' of the 'raw' human condition and the "disenchantment of the world". The subject, who acts on the world is viewed as separate from the world, the object. This can be seen in the modern concept of pain as an object, part of the natural world and hence separate from the person experiencing it.

The rise of the process of rationalisation has also been explained as the result of the outgrowth of a particular religious orientation to the world of Luther and Calvin, and of aesthetic Protestantism in general (Weber, 1958; Habermas, 1972; Tenbuck, 1980). The unique feature of asethetic Protestantism, it is argued, is that it transformed worldly action and behaviour leading to "the methodical conduct of life". As the following quote from Weber illustrates:

> "Only the vocational ethic of ascetic Protestantism produced a principled, systematic and unbroken unit of an inner-worldly vocational ethic with the assurance of religious salvation... This inner-worldly asceticism has a number of characteristics and consequences not found in any other religion. It demanded of the believer not celibacy, as in the case of the monk, but the elimination of all erotic pleasure or desire; not poverty, but the elimination of all idle enjoyment of unearned wealth and income, and the avoidance of all feudalistic, life-loving ostentation of wealth; not

> the ascetic death-in-life of the cloister, but an alert, rationally controlled conduct of life and the avoidance of all surrender to the beauty of the world, to art, or to one's moods and emotions. The clear and uniform goal of this asceticism was the disciplining and methodological organization of conduct. Its typical representation was the 'man of conduct'; and its specific result was the rational, functional organization of social relations" (Weber, 1958:556)

More importantly, Weber argues that the process of rationality leads to a differentiation of cultural orders and spheres of value. In other words, as pre-modern traditional societies of Europe grow larger and more complex there is an increasing 'specialisation' and differentiation of those spheres of activity which Weber identifies as political activity, art, religion, intellectual development economic development and even the pursuit of erotic pleasure. In the course of this differentiation, the spheres become autonomous, which means that each is regulated by norms which are increasingly incompatible with those of the others. Habermas has taken from Weber and developed a similar argument, as outlined in the Introduction, the three basic orientations to the world: technical; hermeneutic and moral.

Habermas' further argument was that rationalisation has led to a particular form of "system" rationalisation (the system being the social and economic structures) which interpenetrates with the lifeworld. As mentioned in the Introduction, the lifeworld is the vast stock of taken-for-granted definitions and understanding of the world that give coherence and direction to our everyday actions and interpretations. With regard to pain, it could be argued that pain is an experience which people struggle to make sense of and express through narrative construction. The medical strive towards the gold standard of measurement, therefore, is an example of the "colonization" of the lifeworld by the system. In other words, the technicisation and definition of pain as an object with no meaning beyond that of a physiological sensation; and hence something that can be quantitatively measured.

There is a further dimension to the relationship between medicine, society and the pain experience. It could be argued that pain in modern society is seen as a threat to rationality and the social management of modernity (Giddens,1991: 161-162). Along with other phenomena such as death, madness, criminality, sexuality and nature, pain, it could be argued, has become institutionally repressed, not psychologically repressed, and removed from the major arenas of modern life. Pain is perceived as threatening to modernity in that it affects a person's ability to make rational decisions.

More importantly, as Lutz (1986) argues, emotion (and it could be argued that pain is in part an emotional experience) is viewed as 'natural' and hence part of the natural world which, as Bauman says above, represents chaos and therefore needs to be controlled. Interestingly, with regard to Britain, Payer (1988) argues that "the high status of pain relief may not reflect the British fear of pain but rather that they fear the loss of control that may come with pain" (115: 1988). Pain, therefore, is seen as a state of being out of control and more importantly as a threat to social order.

The role of medicine as a form of social control has been theorised by Foucault (1976,1979) and provides an interesting dimension to the above argument. Foucault, like Weber, was also interested in the rationality of western society. He also argued that western society has become increasingly regulated and dominated by standards of reason through the application of science to everyday life. The 'ethic of world mastery' elevated the mind over the life of the senses which were rooted in bodily functions. The ethic, therefore, sought to subordinate feeling to reason, body to mind. The reason for the increasing uniformity of society, suggests Foucault, is that we cannot and will not tolerate ideas and lifestyles which diverge too far from the "normal" (as primarily defined by medicine). Foucault was also concerned with how human feeling and emotion are subordinated to normalisation through medicine which establishes acceptable criteria of 'normal emotion'.

The suggestion that medicine "normalises" pain is important. There have been many psychology studies reporting "normal" and "abnormal" pain behaviour and the application of these terms can be seen in medical practice. The 'normal' way to respond to pain differs culturally and is therefore socially controlled. Evidence of the role of medicine in reinforcing and constructing cultural norms about pain expression was seen earlier where a patient was praised for being able to bear her pain well.

Finally, medicine also has an important role in deciding whether pain is "real" or not. The application of these terms and the role of medicine in the legitimisation of pain does not exist in a social vacuum. For example, the impact of pain on work and in particular the growing concern over loss of productivity is a major concern in America (Wall & Jones, 1991). Medicine therefore has a powerful role to play in deciding who is to receive benefit and who is "malingering". The study of pain, therefore, not only requires analysis from the micro level ie from the viewpoint of the person in pain, but also requires an understanding of pain at the macro level ie the institutional control of pain.

CONCLUSION

The aim of the research was to assess the validity of two commonly used pain measurements, the MPQ and VAS. In order to do this, the results of the measurements were compared with each other ie did they produce similar results and also compared to in-depth interviews which were independently rated by two people (0.7 correlation between raters). The conclusion of the research is that the pain measures are both methodologically and theoretically problematic.

Methodological Problems

Turning to the methodological problems, for the VAS in particular, there were several problems encountered in the use of the VAS. One problem which related to rheumatoid arthritis was that the pain not only fluctuated during the day, but the nature of the pain also changed. In the morning there was usually stiffness which was not always described as 'painful' but nevertheless restricted their movements. A distinction was also made between 'ache' and 'pain' during the interviews where 'pain' was more intense but 'ache' was more difficult to alleviate. This leads to questions over which words should be used at either end of the VAS. Alternatively, a different VAS could be used for stiffness, pain and ache. In addition, a VAS would be needed for different times of the day and in reference to certain activities. For example, certain movements brought on pain whereas the ache tended to arise at any time. The pain and ache also affected different joints so a VAS would be needed for different parts of the body as well.

Turning to the MPQ, the main problem with the MPQ arose over the weighting of the words. The most frequently chosen words from the different categories were correlated against the VAS scores. It was found that the VAS scores varied considerably for these words indicating that the words had a different meaning for each individual. It would have been expected that a person who chose a low intensity word from the MPQ would have a low VAS score or that the total MPQ scores for all three dimensions would correlate with the VAS scores. As this was not found to be the case it raises questions over the validity of the weightings. This was further examined by analysis of the interviews where it was found, as discussed earlier, that "ache" can vary in intensity. Evaluative words chosen such as "annoying" also varied in their weighting given in the interviews. One person would describe the pain as "very annoying" while another would describe it as "a little bit annoying".

The other pain measurement on the MPQ, the Present Pain Intensity (PPI) was also assessed for validity. This measurement consists of evaluative words and was found to correlate significantly with the VAS suggesting that they are both measuring a similar construct, namely pain intensity. As discussed in the measurement chapter, Melzack and Wall who constructed the MPQ and other researchers have found that the PPI is influenced by factors such as mood, attention, expectation and may even represent a communication between the person in pain and the person administering the measurement. If this is the case, then the same could be said not only for the VAS but also for other pain measurements. Pain researchers are now concerned with trying to control these factors. This may be possible to a certain extent with experimental pain but with chronic pain it is virtually impossible. As it was shown through analysis of the interviews, these "factors" are an inherent part of the pain experience and the question is not can the chronic pain experience be measured but whether it should be measured. This will be discussed further on.

In order to further analyse the construct validity of the pain measurements, the scores were compared to the semi-structured interviews. The methodological standpoint of this study was that the interviews were taken to be the more 'valid' account of the pain experience. This was based on the argument that the interviews allowed for the description of pain in the individual's own words. The ability of the interview situation also has some limitations however. As discussed in the previous chapter, the accounts that people give of their pain in the interviews are representations of how they want to be seen to be responding to their pain and not necessarily how they do really feel or respond to it. But this is a problem inherent in all research and attempts were made to make the interviews more valid by doing the interviews in the person's own home and also by interviewing their partner or person they lived with if there was one. Interviewing the person in their own home enabled us to see how the person lived, how they moved about when they made the tea and the various devices they had to help them around the house. The OFMs were also interviewed to cross-reference instances where the person described problems with mobility, dressing and changes in personality. They also provided useful information on who the person talked to about their pain and whether they were likely to tell their doctor about the pain or not. But again, the OFMs were also involved in the representation of their relative as someone who was responding in a particular way towards the pain. In some instances the OFM supported a similar viewpoint to that of the person in pain ie by providing instances of their 'willpower' or praising their stoicism. In contrast, several partners disapproved of the way their partner responded to the pain. In addition to providing information about observable actions the OFMs also provided information to help to explain why their VAS scores differed from those of their partner. It was suggested that where the scores differed, these couples also differed over how they perceived a person should be responding to their pain and illness. Whereas where the scores were similar (only 2 instances) the couples tended to agree on their interpretation of the pain and illness and how to respond to it.

In order to compare the interviews with the measurements, a system of quantifying the interviews was used. The interviews were divided into three categories; high pain, medium pain and low pain and it could be argued that this conflicts with the above argument about the importance of not forcing an individual's account of their pain into categories. But the method used (see methods chapter) did not just take words in isolation but interpreted the meaning behind the words by referring to their context. For example, it was noted that pain can be "very annoying" in terms of restricting mobility for one individual but for another this may be only a minor annoyance. In other words, more information was provided by the interviews as to the meaning of the pain.

By categorising the interviews in this way, they could be compared to the measurement data from the MPQ and VAS. It was found that the VAS scores of the person in pain correlated significantly with the researchers categories. As with the correlation between the VAS and PPI, this finding did not necessarily mean that the pain measurements were valid measures of the intensity of pain. What it does show is that the pain scores that people construct represent a variety of aspects of their pain; for some the intensity may play a central part but for others it may represent the effect the pain is having on their quality of life. To reiterate, it was noted that psychological factors can influence the perception of pain and measurement scores, therefore, represent a combination of the sensory and emotional/evaluative elements of the pain experience. In addition, as the interviews were categorised by evaluative descriptions of pain ie how they felt about it or how it made them feel, this provides evidence for the argument that the VAS is a measurement of the overall evaluation of the pain and not simply a straightforward measure of the pain sensation.

The validity of the pain measurements was further assessed by comparing them with non-pain measures, the FACES scale and the NHP. The nature of the relationship between the measurements was used to analyse the construct validity of the pain measures. The findings were that the VAS correlated significantly with the FACES but not the NHP. In other words, evaluation of pain related to happiness with life but not reported problems. This was further confirmed by the finding that the FACES and

NHP correlated. In other words, a relationship between happiness with life and reported difficulties.

These findings were further analysed by relating them to living circumstances where it was found that those living alone scored higher on the FACES and PPI. In other words they reported greater constant pain and unhappiness with their lives. The VAS also correlated with the NHP for this group. This can be partly explained by the difference in NHP scores for this group. In other words, those living alone reported greater difficulty in maintaining social contacts and a social life. The correlation between the VAS and NHP and FACES for this group needed further analysis. The interviews were analysed to see whether it was the pain intensity which led to social life problems and whether pain intensity was making people unhappy. For those living alone, it was found that pain did restrict their activities and in particular their ability to socialise but it was not necessarily the intensity of the pain itself which made them unhappy but the fact that it did restrict them. But the fact that those living alone had higher PPI and VAS scores suggested that they did not necessarily have more physical pain. If, as it has been argued the pain measurements represent an overall evaluation of the pain in the context of an individual's life, then the pain scores are reflecting this unhappiness. The correlation between the FACES, NHP and pain measurements would seem to support this argument. Also, analysis of the interviews showed how when a person says their pain is "unbearable" they are also referring to their current situation as being "unbearable". As Denzin (1987) argues, the physical sensation and the emotional evaluation become one.

Theoretical Problems

From a theoretical point of view, the measurement of chronic pain is problematic for several reasons. The first and main problem is the narrow definition of 'chronic pain' that is used. Certain important concepts were discussed in the course of this study in order to try and understand and theorize the nature of the chronic pain experience from the point of view of the person in pain.

a) Context

One of the important concepts was that of 'context' and its role in the pain experience. As previously mentioned, 'context' is often used by pain researchers to refer to individual 'factors' such as attention and expectation. In the previous chapter, the interviews were analysed to show how the concept of 'context' in relation to pain should be broadened. It is not only that the immediate context can influence the perception and interpretation of pain but the wider social context can as well.

b) 'Lifeworld' and 'Narrative'

In order to conceptualize the context of the pain experience two further concepts were drawn upon, the concepts of 'lifeworld' and 'narrative'. It was shown how people make sense of their pain through the construction of a 'narrative'. There are different discourses in society about the appropriate way to respond to pain and which people draw upon. The dominant one in western society being that of medicine where pain is defined as a realist phenomenon which can be alleviated by medicine and is treatable by the medical profession. Medicine is perceived as being able to interpret the bodily signs that a person is experiencing and defines what is 'real' pain and the cause. There are many other discourses which people can draw on. As Kotarba (1983) described there are subcultures who construct narratives about the meaning of pain and how to respond to it. Where a subculture is not available people draw on other meaning systems such as religion. Discourses about pain are intertwined with other discourses in society not only about how to respond to pain but how a person should act with regard to other aspects of life. In other words, there are moral discourses which people draw upon and which shape their actions towards the pain. A society which places value on independence will lead to people trying to maintain their independence despite the physical pain through the strategies of 'normalisation' for example. These lay discourses are used to construct narrative. As Williams and McIntyre have argued people are actively living out and constantly constructing a self narrative. It is through the construction of a narrative that self-identity is formed, a narrative linking past selves to present and future selves.

c) 'Self-identity' and the chronic pain experience

The strategies that people engage in, in particular those in this study, should be understood as the ongoing construction of self. In addition, this self has a moral aspect in that the values of society influence the perception the individual has of themselves as a person. The ability of the individual to sustain a positive or morally acceptable self-identity will depend on how their actions are interpreted by others and how that person perceives their actions are being interpreted. Other people are therefore important in the construction of a positive self. Self-identity and the construction of self, therefore, is an integral part of the way people make sense of and communicate the experience of chronic pain. This is an important element which is often overlooked by those constructing pain measurements. But if we are to gain a better understanding of the experience the current concept of 'chronic pain' needs to be widened much further. More importantly, it appears that the chronic pain experience encapsulates the very essence of what it is to be 'human'; the way we make sense of the world around us and our place in that world.

It is through the narrative, therefore, that people acquire knowledge about the world, their place in it and the way they communicate their understanding of the world. The concept of the 'lifeworld' was used to describe the everyday reality in which people live as compared to the world constructed by the rationality of science. The features of the 'lifeworld' included a background stock of knowledge which people draw on and a perception of the world/reality as pre-given or taken-for-granted (see Schutz, 1972). It was argued that the onset of pain can lead to a change in the lifeworld where areas of life that were previously taken-for-granted now shift to the fore and need re-construction in order to make sense of them. It could be argued that this happens with the onset of pain where the physical body becomes the centre of attention and attempts to interpret its cause and what to do about it are paramount. There may be things happening which can influence when and how the pain comes to the foreground of experience such as attention and expectation as Melzack has mentioned but there may also be other factors such as the sense of self, particularly in relation to chronic pain which has to be managed in a variety of social contexts.

It was noted in the interviews how the evaluation of pain was relative to how the individual interpreted its meaning in the context of their lives. If the person needed to work for example, and the pain prevented them from physically doing so then the pain was viewed as 'unbearable' but when work became less important due to retirement the pain became less important. It did not intrude on the individual's life as much. In other words the meaning of the pain changed and the rating given to it would change. In turn it was often reported by those interviewed that having experienced pain for many years, it became part of their background knowledge of the world, it was normalised and taken-for-granted in many cases. It was only when the pain became 'overwhelming' that it was considered to be pain at all. The instances of how pain can shift from the background to the foreground and how an individual experiences this shift requires further research. With relation to the pain measurements it raises further doubt about their validity in terms of what aspect of the pain experience the measurement is measuring.

d) 'Representations' of the chronic pain experience and the role of 'social context'

Evidence in this study for the different ways in which people make sense of their pain and 're-present' it to others was as follows. First, the hospital VAS scores were significantly lower than the VAS scores obtained at home for men only. This difference suggests that the men were representing a different picture of their pain experience depending upon the context. One difference between the two contexts was that of the gender of the researcher and the meaning of the context ie hospital versus home. As the researcher in the hospital was female and the researcher in the home predominantly male, the meaning of the interaction, it could be argued, shaped the representation. In other words, social/cultural meanings about how men and women should respond to pain were shaping the representation. As it was mentioned earlier the representation of pain is influenced by how the person perceives they are being judged by others. This will lead to a presentation of themselves as responding in the morally appropriate way to their pain. This example illustrated the important influence of the role of the person to whom the pain is being communicated to and how an understanding of the meaning of the interaction to the person in pain is an important part in understanding the chronic pain experience.

The role of 'social context' not only includes the immediate context in which the communication is taking place but also the actual context in which the person in pain is living and the way this can shape the pain experience. As noted in the analysis, a further difference was found in the measurement scores between women living alone and women living with others. To reiterate, those living alone scored higher than those living alone on the VAS, FACES, NHP and PPI. Possible explanations for this were discussed. One explanation was that the social context of those living alone led to different constructions of pain. This leads to the important question of the role of others in the construction of pain. Interviews with the women living alone suggested that other people were important in the construction of their experience of pain. Those that were widowed described how they missed chatting to their husbands; had limited social activities; and missed the assistance their husbands used to give around the home, helping them cook and dress etc. The loss of husbands led to a loss of social contacts in many cases, particularly friends which were considered just as important as maintaining contacts with the family. There has been much research into the role of social support in the quality of life of people with chronic illness. The main consensus is that social contact rather than attachment is more important (Fitzpatrick et al, 1988). An example of this was one woman who spoke of wanting a penpal to write to even though she saw her daughter everyday. But the kind of social support varied from individual to individual. One widow preferred her own company and was reluctant to attend social clubs. Another woman, who had never married, was able to continue working and differed from those that were widowed in that her pain scores were not higher than for those living with others. This highlights the important point that not all the people living alone reported high pain scores and do differ in their experiences.

The role of social support is further complicated by the finding that OFMs scored significantly higher on the VAS than the person in pain. Analysis of the interviews of those where the VAS scores were the same; where the OFM scored the VAS lower and where the OFM scored the VAS higher suggested that the scores could be partly explained by the different 'styles of adjustment' the couples had adopted. Those who had 'accommodated' to the pain and illness had similar views about the appropriate way to respond to pain and illness and about their relationship to each other. While those who had not 'accommodated' had restricted understandings about their relationship as husband and wife and differed over their interpretations of the way to respond to pain and illness. Radley's (1989) concept of 'styles of adjustment' does go some way to explain the difference in scores but it requires further development. In particular, an awareness that the construction of a 'style of adjustment' emerges over time and is contingent upon the social context.

Evaluating the concepts

The concept of 'lifeworld' provided a useful tool in trying to make sense of the reality of chronic pain but it requires further development. Schutz (1972) suggested that there are different 'realities', for example, dreaming. This research argues that another 'reality' should be added, that of the 'pain(ed) world'. The onset of pain leads to a different 'reality' unlike any other. It is constantly in the background, threatening to 'engulf' the person without warning. The features of the 'pain(ed) world' need exploring. A long-term study could assist in identifying the transition from the previous 'lifeworld' to the 'pain(ed) world'. It could also help to understand how/why for some individuals pain is constantly at the centre of their world and how for others it can be pushed aside. In other words, the 'pain(ed) world' is not static, it is constantly changing.

Conclusion - *Can* we measure chronic pain?

The aim of this study was to assess the validity of two chronic pain measurements. The findings would suggest that both methodologically and theoretically the measurements are not a valid measure of the chronic pain experience. The main problems, therefore were not purely methodological ie that the concept was inadequately operationalised but that the concept of 'chronic pain' itself was too limited.

The role of the social in the experience of chronic pain raises important questions about how it should be conceptualised. In other words, does pain exist independent of the society in which it arises? Or to put it another way, is chronic pain purely a social construction? Cross cultural studies discussed in the Introduction suggest that there is a universally understood phenomenon of pain but that the way it is interpreted or made sense of is largely dependent on the culture/society in which it arises. This leads to differences not only in the language used to describe pain but in the actual experience. As discussed in the Introduction, for the Japanese, pain is more of an emotional experience whereas in western societies attention is placed on the physical aspects. To a certain extent then, the pain *experience* is socially constructed. In addition, as mentioned earlier, the pain experience intertwines with other dimensions of experience such as self-identity. In terms of understanding the pain experience, therefore, attention needs to be placed on the wider social/cultural meanings about pain and identity and the role they play in the experience of pain.

So what are the implications of the findings of this study for the use of pain measurements in medical practice? It has been argued throughout this study that the current definition of chronic pain on which they are based is far too narrow and should include other elements, especially the role of self-identity. Bearing these points in mind, the important question then is can a chronic pain measurement ever be developed which can capture all the important elements of the experience. This question can be answered on two levels. The first is that of a technical level. In other words is it methodologically possible to measure the experience? It was found in this study and reported in many others that there are many aspects of the chronic pain experience which cannot always be controlled for, such as memory, attention and mood. More importantly the influence of the nature of relationship between the person in pain and the person doing the measurement can also lead to different scores being presented.

It could be argued from this study that as the researchers were closest to the person in pain in terms of rating their pain, then there were certain aspects of the nature of the relationship which permitted a more 'valid' measure of the pain. It is still not clear whether it was the nature of the relationship or the surroundings in which the measurement took place which led to this result. To reiterate, for the men, the VAS did differ between the hospital and the home and the researcher was different (ie female). Further research is required into this area before definite conclusions can be made.

A major part of the measurement of pain is quantification. This was found to be problematic in terms of the MPQ as the words used were taken out of their social context and were open to a range of meanings being attributed to them. More importantly, the meaning of the words varied from person to person depending on how they not only interpreted the words, but also how they interpreted the pain in the context of their lives. The same can be said for the VAS. Not only were there problems in interpetating the scale and the words used at either end, but there were also problems in interpreting the score. It was found that the VAS appeared to be measuring the overall evaluation of the pain experience. Again this evaluation is complex and individual. It is shaped not only by the immediate context but also by the wider social context and, to stress again, the meaning of the pain to that person. It would appear to be impossible to control for all these 'factors', in particular the social context.

This leads onto the theoretical problems with the measurement of pain. The concepts of 'lifeworld' and 'narrative' were used to show the complex nature of the chronic pain experience. Although different elements can be identified, it is very difficult to control them individually, particularly out of experimental settings. More importantly, as Denzin (1987) argued the physical and emotional become one. It is impossible to experience the physical without making an evaluation. How this evaluation arises and why it should vary from person to person and change over time was partly explored through the use of 'lifeworld' and 'narrative' where it was argued that the evaluation or meaning of pain is shaped by the 'lifeworld' in which that person lives. This is a very important part of the chronic pain experience as found through the interviews with people in pain and requires more detailed study. It also adds further evidence to the argument that the chronic pain experience cannot be quantified entirely. Certain aspects can be quantified. As illustrated by the ratings made by the interviewers, people do quantify their pain to a certain extent, ie from a little to a lot, but the meaning of the pain in that persons life cannot be quantified so easily. But it is this part of the pain experience which is most important to the person in pain. They are not only concerned with *how* much pain they have but how it affects their lives. Instead of searching for a gold standard measure of chronic pain, more research is needed into the effect of living with constant pain and in turn how the social context can shape the meaning of the pain. In other words, the pain experience is not only shaped by the social context (ie the meanings that people draw on to make sense of their experience) but can in turn change the way they interpret their world. Perhaps leading to the 'pain(ed)' world discussed earlier.

Implications of the study for future pain research and measurement

The main argument of the thesis, therefore, is not only that chronic pain cannot be measured but that it *should* not be measured. By quantifying the experience vital elements are lost which need to be taken into account if people in chronic pain are to be helped. It has been suggested that a measure of the change in quality of life brought about by different treatments would be more beneficial to people in pain rather than just a change in the pain itself. There have been many measures of the quality of life incorporating various aspects from physical to spiritual and emotional but it could be argued that these measurements are still problematic in the same way that the pain measurements are.

One of the reasons is that, as Frank (1992) argues, research into pain involves social scientists making claims about pain and the response to suffering.

> "social science is a moral discourse, presenting claims about the nature of suffering and the proper response to suffering"
> (Frank, 1992: 467)

There are problems, therefore, with viewing the ill person from the objectivist stance implicit in pain and quality of life measurements. With these, experience is categorised as data which is used to assess the form of intervention. The reasons for this were discussed in the previous chapter. According to Habermas (1972), a functionally driven subsystem such as medicine driven by a limited form of rationality requires that ill persons become patients and patients must accept and adjust to their illness. Much psychological pain research has focused on 'normal/abnormal' responses to pain and the differences between those who have learned to 'cope' with their pain and those who have not. In a similar argument to this study, Frank (1992) points to several aspects of experience which have been lost by the 'quantification' of illness.

The first is that individual lives are 'embodied' and categorisation does not capture the quality of this. Current treatments, particularly for those with terminal illness as Frank focused on his study, are concerned with people getting over feelings, not having them. With regard to chronic non-terminal pain as in the case of rheumatoid arthritis, the long-term duration of the pain may be normalised by some but it does not necessarily lessen the impact. Several of those interviewed were told by their doctors after the initial diagnosis that rheumatoid arthritis was something that they had to "learn to get on with". How they were to do this was not suggested by the doctor other than having to "accept" that there was no cure and to follow the prescribed treatment. In turn, several of those interviewed commented that they had "accepted" the illness in terms of the fact that they were not going to get better but this occurred over time and varied from individual to individual according to their circumstances. In addition, acceptance did not necessarily make living with the illness any easier. People had feelings about their pain and illness, feelings of frustration and anger at not being able to maintain what they perceived to be a 'normal' life. This is often neglected in medical care or viewed as something which people should get over by restricting their activities and resigning themselves to their fate.

A further important aspect of acknowledging lives as 'embodied' is capturing the experience of what it is like to be constantly monitoring the body for signs of pain and how pain can lead to a greater awareness of how action can be restricted by the body. For those not in pain, the body becomes 'taken-for-granted' but with pain the body is pushed to the foreground. How the 'body in pain' comes to the foreground and what it is like for the person is lost with quantitative measurement but is important for understanding the pain experience. As it was noted earlier, there were several accounts in the interviews about the way pain can become 'taken-for-granted' and a part of everyday reality but that it can also become 'overwhelming' and 'unbearable'. How pain shifts in this way cannot be captured by quantitative measurement nor can it be understood purely by studying the transmission of nerve impulses. As noted in the earlier chapters, the correspondence between physical 'signs' of pain and an individuals account of pain is often very poor.

The features of the 'pain(ed)' world need to be explored further and are revealed in the narratives people use not only to describe their experiences but also to make sense of them. In other words, the onset of pain leads to a reconstruction of narrative in an attempt to make sense of the change in the perception of reality and the everyday world. The 'world' is not only experienced differently but also the self. The person's view of the world is never the same and is often experienced as what might have happened otherwise. Aggregation as in a VAS measurement loses the contingency of what happens to the 'lifeworld' with the onset and persistence of pain.

A further important point is that a person's life consists of interrelated parts that are abstracted from each other by medical treatment. In other words, the unit of study is the pain but as this study has shown there is also the family, employment and friendship networks of which the ill person is a part to consider. The parts which are affected by the pain will vary over time and changes in one part will lead to shifts in another.

Finally, 'suffering' is lost in much pain research. Researchers have noted that there are emotional/affective aspects of the pain experience but the nature of the suffering is not mentioned. Instead, the suffering is something which the person does alone while medicine deals with the 'physical pain'. Social support and in particular the role of others in the experience of 'suffering' is also important. If as Frank is arguing we need to witness the suffering rather than try to categorise it then perhaps it is social relationships which allow 'witnessing' which are most beneficial for people in pain. Several of those interviewed described who they felt understood their pain and who did not. In the majority of cases it was people who had experienced chronic pain who were perceived as being the only ones who would really know what the experience was like. After this came the doctors, some husbands/wives and even the researcher. Doctors and the researcher were viewed as being able to understand due to their 'knowledge' about the condition. Talking to the doctor and researcher also had a different meaning from talking to friends or family and it could be useful. Many of those interviewed spoke of not wanting to talk to friends about their pain/illness as they feared it would lead to them being judged as 'moaners' and hence lead to a loss of friendship, whereas for the doctor and researcher this was not the case. A similar view was expressed with regard to OFMs. As Bury (1985) has commented about spouse relationships and the expression of pain. How much pain is expressed in the home is a negotiation and that while an intimate relationship between partners is helpful in maintaining the self-esteem of people with rheumatoid arthritis, even in intimate relationships only as much pain and suffering will be expressed as is consistent with the maintaining of self-respect. This partly explains why emotional attachment in social relationships is not so important for those with chronic illness. Emotional attachment may mean the person is less likely to want to talk about their pain/illness through fear of threatening the nature of that attachment.

This leads to the question of how are we as researchers to encounter the person in pain? Frank (1992) argues that the ill person should be engaged from a reflexive stance rather than an objectivist one that includes knowing what is not shared as well as what is lived in common. The response to suffering is not to compensate for devastating changes but to show people the possibilities of restructuring their lives. In other words, to witness people's suffering in order to widen understanding about a shared human condition which cannot be denied. The measurement of pain fragments the experience to an extent that important elements are lost. The current drive towards a 'gold standard' of pain measurement, therefore, is not only methodologically problematic in that it disregards several important aspects of the pain experience, it is also morally inappropriate in that it serves the interests of the medical system rather than those of the person in pain. What is needed instead is a human dimension to pain research.

Criticism of the medical treatment of people with chronic illness is not new nor is the call for a more humanistic social science. It is not being suggested here that there is no place for the medical treatment of pain. Many people do find relief from pain by using medication and research is still needed into the cause of chronic diseases such as rheumatoid arthritis. What is being argued is that in addition to this research and while there is no cure for rheumatoid arthritis, the suffering of those with chronic pain needs to understood in order to help them live with it better. This will involve witnessing their narratives as with the interviews, but rather than viewing the situation as interviewer and interviewee, the person in pain should be acknowledged as another human being. This will involve an awareness of pain as a common human condition and understanding gained through comparing the differences and similarities in experience between the person who is in pain and the person who is not.

In terms of 'treatment' the answers are not simple. How to foster a relationship in which the person can express their suffering is not easy or straightforward. There is the problem that not everyone may be willing or want to talk about how they feel. A few of the interviews illustrated how in some cases people have not always thought about the way the pain makes them 'feel' and in some instances they do not want to think about the pain as a way of coping with it. As Radley and Bernstein have pointed out in the reference in the previous chapter, there are differences in the way people conceptualise and express their suffering. The majority of those interviewed were from 'working class' backgrounds and tended to talk about their pain and suffering in physical terms ie by reference to what they could or could not do, or where the pain was in their body. This contrasted with the very few people from 'middle class' backgrounds who described their pain and suffering in terms of emotions ie feeling depressed.

One possible way is to allow people to talk about the pain in their own words and to help them engage in 'cognitive restructuring' (Newman & Revenson, 1993). This involves rethinking the meaning and impact of the pain and arthritis. But as argued throughout this study, the onset of pain and illness always involves the evaluation of the meaning of the pain experience and the transformation of self-narratives. More importantly narrative is restructured through social relationships and the meaning of the pain and illness negotiated through these relationships. Mathieson & Stam (1995) have conceptualised the process of evaluation as 'identity work' and emphasise the importance of understanding the identity issues faced by individuals over the course of their illness. In other words, rethinking the meaning and impact of pain involves a rethinking of self-identity. Mathieson & Stam (1995) and Williams (1993) have noted the important role of others in the way individuals make sense of the meaning of pain and self-identity. In the interviews as part of this study, people were often asked to think about areas which they had not previously thought about such as self-identity (do you think you have changed as a person since the arthritis?) and in reflecting on these questions they were involved in the restructuring of self narratives to incorporate the meaning of the pain/illness. Through listening to individual's narratives about their pain, other people, for example the doctor, can gain understanding of the meaning of the pain in that person's life, not only in terms of mobility but also in terms of the way they perceive themselves. In other words, the impact on self-identity. The interviews in this study showed that for a few, the experience of pain had not resulted in a change in self-identity and in several instances had resulted in positive changes. But for many others, the experience of pain had had a detrimental effect on their sense of self. It is here then perhaps where assistance is needed - the development of ways in which a positive sense of self can be restored. Deciding on the form of assistance cannot be achieved solely through questionnaires as the experience is personal to every individual in the same way that the life biography or narrative is unique to every individual. It will also change over the life course as different concerns come to the fore and the meaning of the pain/illness changes.

The study of the validity of pain measurements, therefore, has raised many questions concerning the nature of the chronic pain experience, how to gain knowledge and understanding of it and also how we are to help those who have to live with it. The answers are not simple nor easy, but it is hoped that through this study attention will be moved away from the search for a 'gold standard' of pain measurement and directed instead towards a greater understanding of the suffering of those who have to endure pain and the development of a form of care which goes beyond tending purely to physical needs.

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APPENDIX

Appendix 1.1

The Visual Analogue Scale

(not to scale)

MCGILL PAIN QUESTIONNAIRE

Patient's name ______________________________ Age ________

Ethnic Group ____________________________

Marital Status:

	Unmarried		Number of children
	Married		Number of children at home
	Divorced/separated		Ages of children at home
	Widow/widower		Number of others at home

Diagnosis : ________________________________

____

____

Analgesic: 1. Type ______________________

2. Dosage ______________________

3. Time of last dosage __________________

****

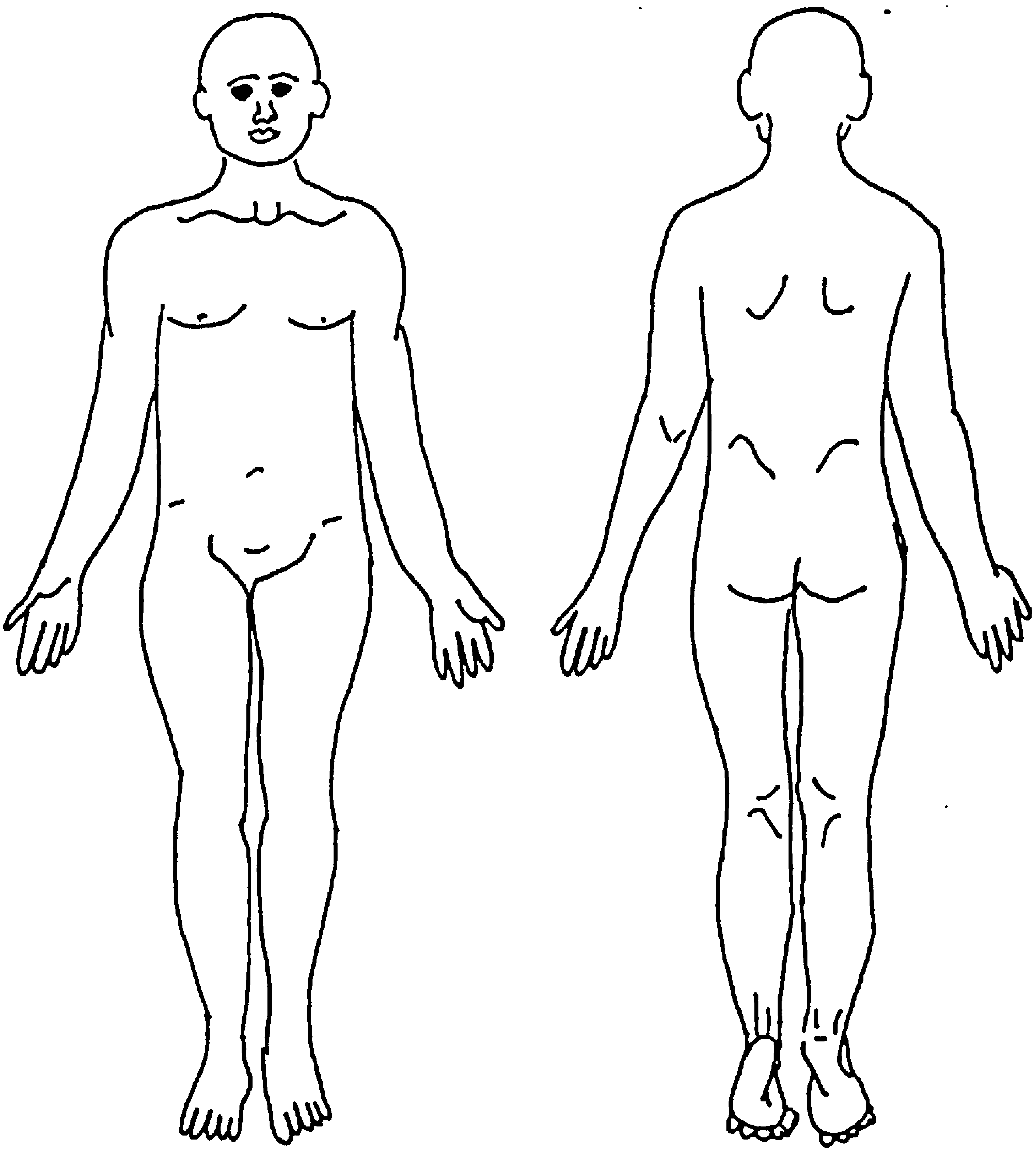
This questionnaire has been designed to tell us more about your pain. Four major questions we ask are:

1. Where is your pain?
2. What does it feel like?
3. How does it change with time?
4. How strong is it?

It is important that you tell us how your pain has felt during the past week. Please follow the instructions at the beginning of each part.

PART 1 **Where is your Pain?**

Please mark on the drawings below, the areas where you have felt the worst pain during the past week. Put E if external, or I if internal, near the areas which you mark. Put EI if both external and internal.



Part 2. What Did Your Pain Feel Like During the Past Week?

Some of the words below describe your worst pain during the past week. Circle ONLY those words that best describe it. Leave out any category that is not available. Use only a single word in each appropriate category - the one that applies best.

1

Flickering
Quivering
Pulsing
Throbbing
Beating
Pounding

2

Jumping
Flashing
Shooting

3

Pricking
Boring
Drilling
Stabbing
Lancinating

4

Sharp
Cutting
Lacerating

5

Pinching
Pressing
Gnawing
Cramping
Crushing

6

Tugging
Pulling
Wrenching

7

Hot
Burning
Scalding
Searing

8

Tingling
Itchy
Smarting
Stinging

9

Dull
Sore
Hurting
Aching
Heavy

10

Tender
Taut
Rasping
Splitting

11

Tiring
Exhausting

12

Sickening
Suffocating

13

Fearful
Frightful
Terrifying

14

Punishing
Gruelling
Cruel
Vicious
Killing

15

Wretched
Blinding

16

Annoying
Troublesome
Miserable
Intense
Unbearable

17

Spreading
Radiating
Penetrating
Piercing

18

Tight
Numb
Drawing
Squeezing
Tearing

19

Cool
Cold
Freezing

20

Nagging
Nauseating
Agonizing
Dreadful
Torturing

Part 3. How Does Your Pain Change With Time?

1. Which word or words would you use to describe the pattern of your pain?

1	2	3
Continuous	Rhythmic	Brief
Steady	Periodic	Momentary
Constant	Intermittent	Transient

2. What kind of things relieve your pain?

3. What kind of things increase your pain?

Part 4. How Strong is Your Pain?

People agree that the following 5 words represent pain of increasing intensity. They are:

1	2	3	4	5
Mild	Discomforting	Distressing	Horrible	Excruciating

To answer each question below, write the number of the most appropriate word in the space beside the question.

1. Which word describes your pain right now? __________
2. Which word describes it at its worst? __________
3. Which word describes it when it is least? __________
4. Which word describes the worst toothache you ever had? __________
5. Which word describes the worst headache you ever had? __________
6. Which word describes the worst stomach-ache you ever had? __________

Appendix 1.3

The Nottingham Health Profile

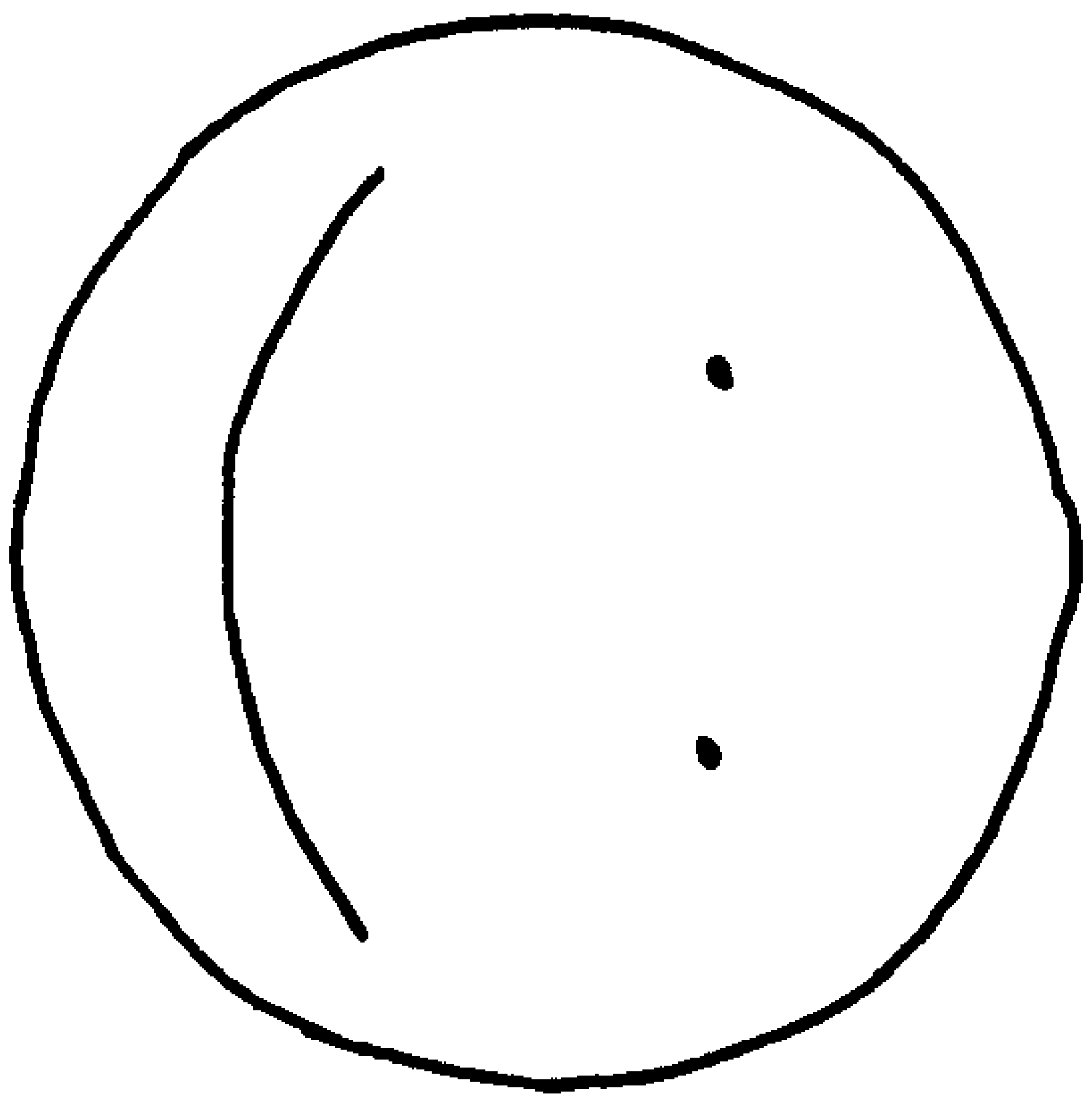
Please answer the following questions by placing a tick in the relevant box.

Is your present state of health causing problems with your ...

	YES	NO
Job of work (that is paid employment)	☐	☐
Looking after the home (examples: cleaning & cooking, repairs, odd jobs around the house)	☐	☐
Social life (examples: going out, seeing friends, going to the pub etc)	☐	☐
Home life (that is, relationships with other people in the home)	☐	☐
Sex life	☐	☐
Interests and hobbies (examples: sports, arts and crafts, DIY)	☐	☐
Holidays (examples: summer or winter holidays weekends away)	☐	☐

Appendix 1.4

Here are some faces expressing various feelings. Which face comes closest to expressing how you feel about your life as a whole?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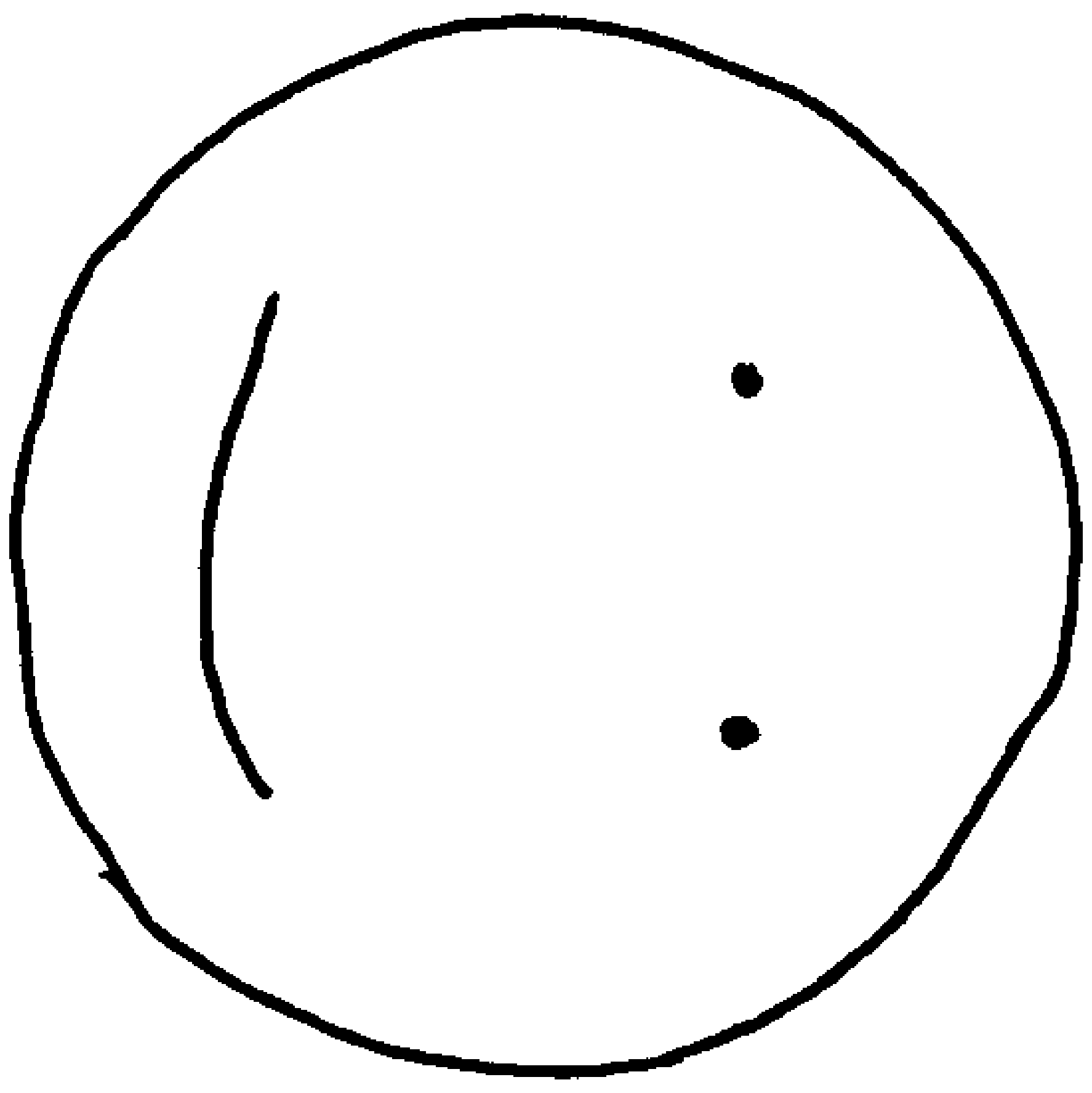
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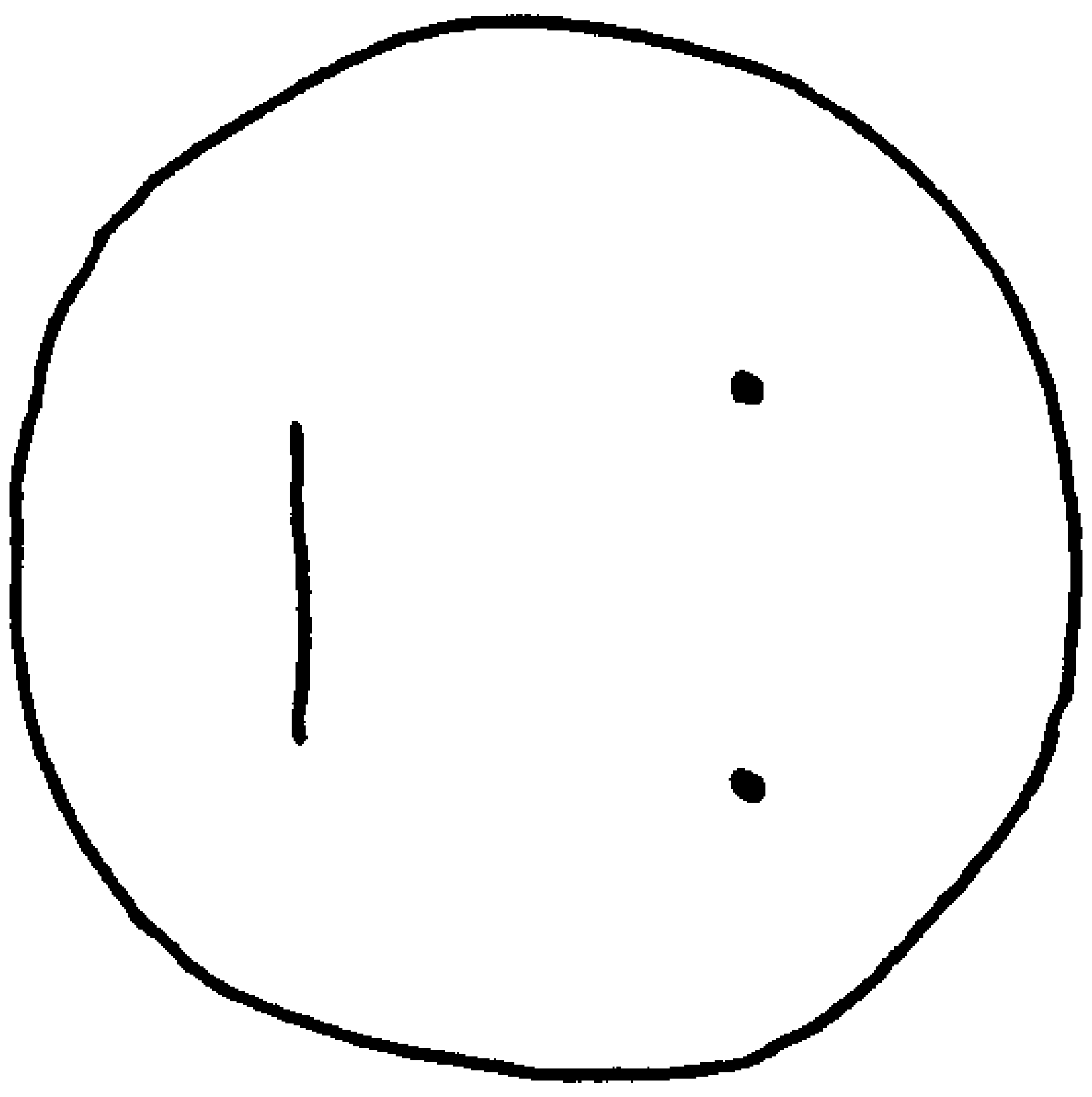
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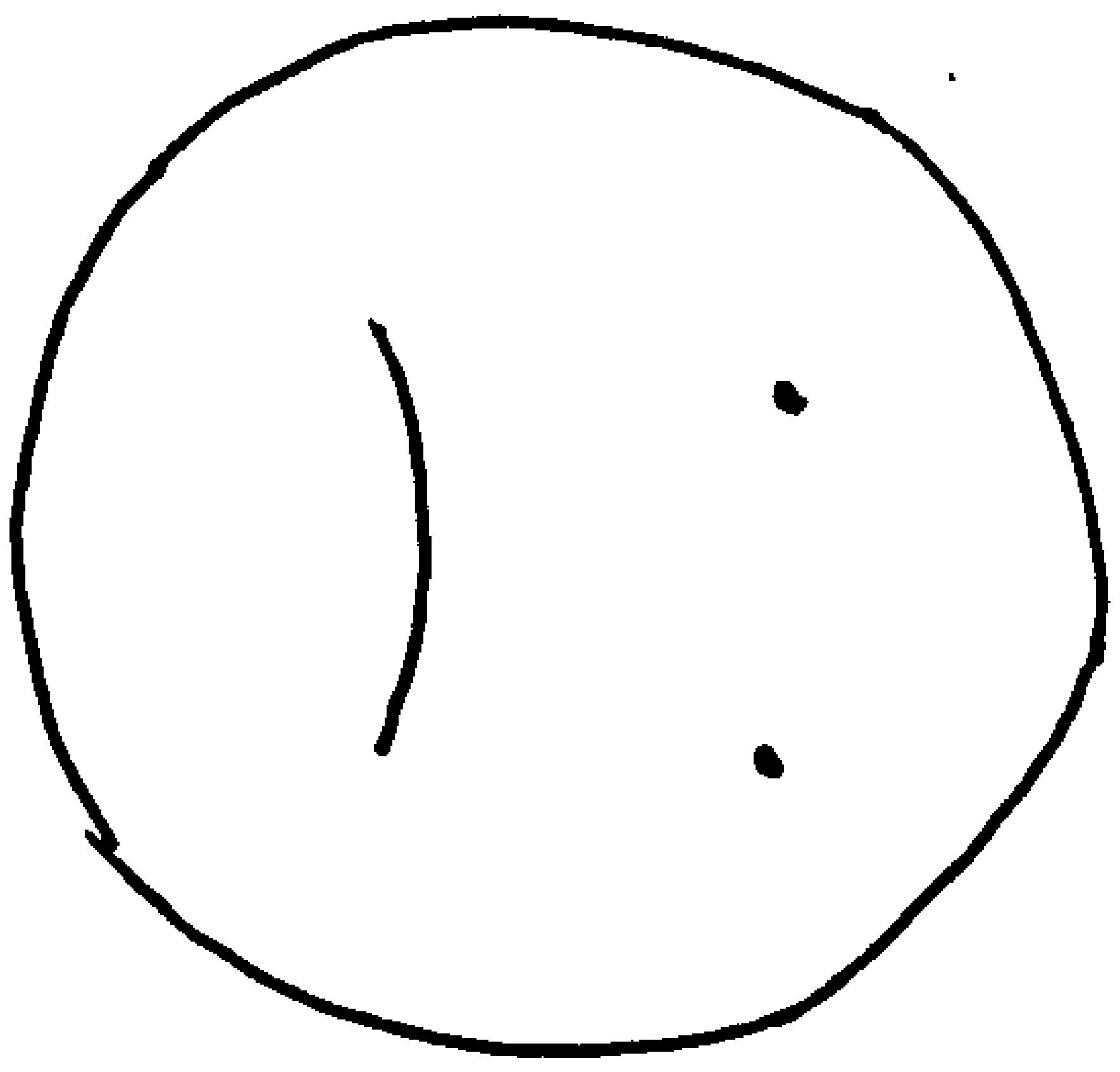
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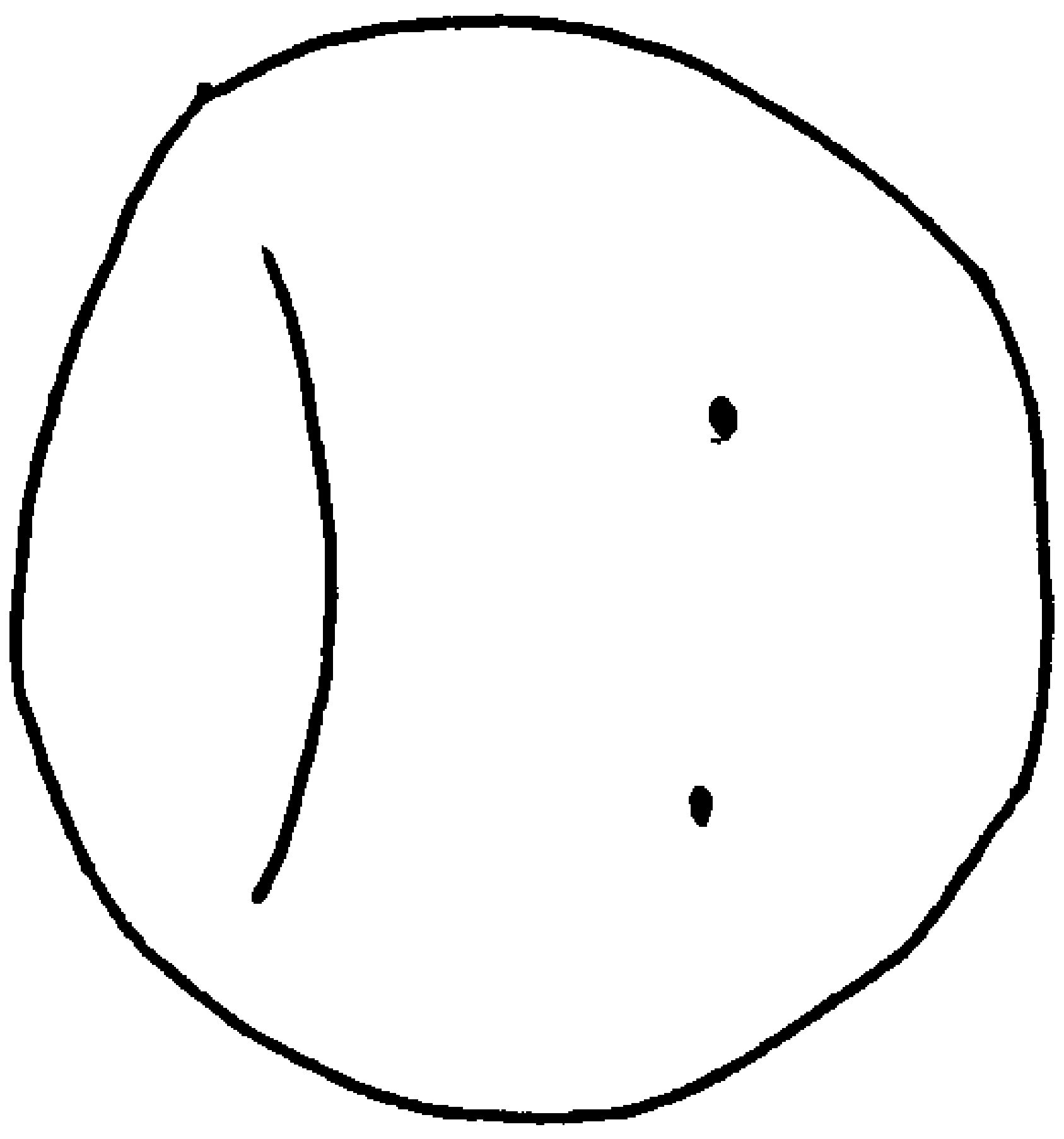
5

Appendix 2.0 List of Questions Used in Semi-Structured Interviews

a) Introduction

We are not doctors, we are social researchers and we are trying to find out more about what it is like to live with arthritis. Doctors look at your joints and ask you a few questions but we want you to tell us as much as you can about what it is like to have arthritis, how it affects your life and how you manage it.

Do you mind if we tape-record to save us writing?

b) Living with Arthritis

(1) How long have you had arthritis?

(2) When did it start?

(3) How did you feel when you were told the diagnosis?

(4) Has having arthritis affected your life in any way?
What has changed?
Have you stopped doing anything that you used to do (work, housework, sports etc)
Has it restricted your social life?

(5) What would you say were the worst aspects of having arthritis?

c) Description of Pain

(1) How would you describe the pain you have had over the past week?

(2) Where is the pain at the moment?
Where has it been during the past week?

(3) How long does the pain usually last?

(4) Is the pain worse at particular times of the day?

(5) What seems to make the pain worse?

(6) What improves the pain (hot, cold, exercise, etc)?

(7) Why do you think you get the pain?
Is it a warning to stop?

(8) How do you feel when you have the pain?

(9) What are the worst aspects of the pain?

d) Treatment

(1) What medication do you take?

(2) Does the medication relieve your pain?

(3) How do you feel about taking the medication?
Are there any side effects?

(4) Do you follow the doctor's orders about taking the medication?
Do you sometimes take more?
Do you ever try taking less?

(5) Do you take any medication which is not prescribed?

(6) Do you take any special foods for your arthritis?
Anything like cod-liver oil? Any tonics?

(7) Have you ever tried any alternative treatments?
Acupuncture? Homeopathy?

e) Coping with the Pain

(1) How do you cope with the pain?
Do you try to relax, exercise, pray, talk, distract yourself?

(2) Do you think this helps?

(3) How often do you have to do this?

(4) Is there anything else which could be done to relieve the pain of rheumatoid arthritis?

f) Relationships with Others

(1) Do you know anyone else who has arthritis?

(2) Do you talk to them about your pain?

(3) Do you think it is helpful to talk to someone about your pain?
(why/why not?)

(4) Who do you talk to most about it?

(5) Why do you talk to that person?

(6) How often do you talk to them about your pain?

(7) Do you experience any difficulty in talking to people about your pain?

(8) Do you think people can tell when you are in pain?

(9) How do you think they know?

(10) Do you think your family/friends understand your pain?

(11) Would you say they are supportive?
How are they supportive?

(12) Do you think that only people who have experienced pain can really understand it?

(13) Has having arthritis and the pain affected your relationships (with husband/wife/children etc)?

(14) Has it brought you closer together?

(g) <u>Relationship with Medical Staff</u>

(1) Do you tell the doctor about your pain?

(2) Do you think he/she understands?

(3) What does the doctor do if you say the pain is worse?

(h) <u>Pain and Identity</u>

(1) Do you think that having rheumatoid arthritis has changed you in any way? In what ways?

(2) How do you feel about the kind of person you have become?

(3) What affect has the pain had on your life?

(4) What changes have you made to your life since having the pain?

(5) What do you do about planning future holidays etc?

(6) Do you plan ahead at all?

(7) Why do you think people get RA?

(8) Why do you think you got it?

(9) Is there anything else we should have asked you about?

Questions for Other Family Member

a) Introduction

We are not doctors, we are social researchers and we are trying to find out more about what it is like to live with arthritis. We would like you to tell us as much as you can about what it is like for someone to have arthritis, how it affects their life and how it affects your life. Here is a written explanation of what we doing and if you agree to be interviewed we would ask you to sign the form to say that you consent.

Do you mind if we tape-record the interview?

b) Living with Arthritis

(1) How long has your husband/wife had arthritis?

(2) When did it start?

(3) How did your .... feel when told that he/she had arthritis?

(4) Has the fact of having arthritis changed your wife's/husband's life at all?
(given up work/hobbies/social life/housework etc)

(5) What would you say are the worst aspects of having arthritis?

c) Description of the Pain

(1) Are you able to tell when your wife/husband is in pain?
How do you know?
Can you tell when he/she is in great pain?
What about pain at night time?

(2) How much pain has she/he had over this last week?

(3) Where has the pain been in the last week?

(4) How long does it usually last?

(5) Is it worse at particular times of the day?

(6) Why do you think he/she gets the pain?

(7) What are the worst aspects of the pain?

(8) Do you do anything when he/she is in pain?

(9) Can you tell when the pain is very bad? How?

(10) Do you talk about the pain?

(11) Has the pain affected your relationship with each other?
(stopped you doing anything together?)

(12) Does he/she tell the doctor about the pain?

(13) What does the doctor say?

d) <u>Treatment</u>

(1) What medication does he/she take?

(2) Does that help to relieve the pain?

(3) Does the medication have any side-effects?

(4) Does he/she do exactly what the doctor has said?

(5) Does he/she sometimes reduce the amount of medication?

(6) Does he/she take more sometimes?

(7) Does he/she take any medication not prescribed by the doctor?

(8) Any diet supplements, like cod-liver oil?

(9) Has he/she tried any alternative treatments?
(acupuncture/homepathy etc)

e) Coping with the Pain

(1) How does he/she cope with the pain?

(2) Does that help?

(3) Is there anything else that you think could be doen to relieve the pain of RA?

(f) Relationships with Others

(1) Do you know anyone else with RA?

(2) How does their pain compare to your .....?

(3) Do you think it is helpful to talk to someone about the pains you/he/she have?

(4) Who does he/she talk to most about it?

(5) Does she/he find it difficult to talk about his/her pain?

(6) Do you think other people know when he/she is in pain?

(7) How do you think they know?

(8) Do you think the family/friends understand what it is like to have the pain of RA?

(9) Are family/friends supportive?

(10) How do they support them?

(11) Do you think you have to experience pain to understand it?

(12) Would you say that your wife's/husband's RA has brought closer together?

g) Relationships with Medical Staff

(1) Do you think the doctor understands his/her pain?

(2) What does doctor do if he/she says the pain is worse?

h) Pain and Identity

(1) Do you think that having RA has changed your wife/husband in any way? How?

(2) How do you feel about that?

(3) What changes have you made to your life since your wife/husband has had RA?

(4) How about the future, do you make any plans for the future? (where you might live, how you might manage a holiday)

(5) Do you plan ahead at all?

(6) Why do you think people get RA? (what causes it)

(7) Is there anything else you could tell us about living with RA that we have not asked you about?

Thank you for your help.