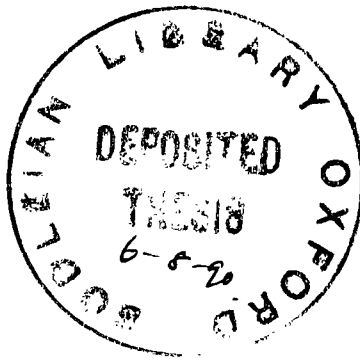


**SOCIAL AND PSYCHOLOGICAL FACTORS AFFECTING THE IMPACT OF
PAINFUL CHRONIC ILLNESS UPON MENTAL HEALTH**

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*A thesis submitted in Michaelmas Term, 1989, to the
Faculty of Psychological Studies in the University of Oxford,
for the degree of Doctor of Philosophy.*



10 November 1989

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This thesis is dedicated to my parents.

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ABSTRACT

This thesis is a report of a study on patients suffering one of two painful chronic illnesses (rheumatoid arthritis (RA) or migraine), and attempts to discover possible determinants of psychological reactions to long term painful illness.

One hundred and sixty chronically ill individuals were interviewed, (80 migraine and 80 RA sufferers). In keeping with other evidence, the extent of psychological disturbance was found to be higher for chronically ill individuals than for general population samples. There were no zero order correlations between reported pain and psychological distress. Age and length of suffering have often been cited as possible factors influencing mood state, but no evidence was found for this in the data gained in this survey.

The results provide no evidence for the use of coping strategies as a method of adapting to the demands of the painful chronic illnesses studied here. Beliefs in control over illness have been posited as possible factors that may influence psychological state, and were measured in this research using a health locus of control scale. However locus of control scores were not found to be associated with mood state, although, in keeping with other research, scores were found to be associated with age and social class, with both lower social class and older sufferers scoring higher on externality than those from higher social classes, or whom were younger.

The strongest association was found between aspects of subjective health status and mood state. The major finding of this study is that patients assessment of their own health state, in both illnesses, is the major factor associated with psychological state.

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LONG ABSTRACT

This thesis is a report of a study on patients suffering one of two painful chronic illnesses (either rheumatoid arthritis or migraine), and attempts to uncover possible major determinants of psychological reactions to long term painful illness. It has been suggested that the experience of long term pain is a major influence upon mood state. However, not all sufferers become psychologically disturbed. The research reported here attempts to determine the major factors that are associated with psychological disturbance. It has been suggested that the origins of depressed mood in chronic illness can be uncovered only if the relative contribution of social, psychological and disease state variables are considered, and that most studies address only a limited number of such variables. This thesis examines the possible part played by a number of social, psychological, and medical variables in relation to mood state in chronic painful illness.

It has been suggested that a major aspect of chronic illness that is causal of psychological distress is pain. The choice of the two illnesses studied here is to determine whether psychological state in an illness characterised by pain alone (migraine) is affected by similar factors that may be influential of psychological state in an illness of which pain is just one manifestation of the disease process (rheumatoid arthritis (RA)).

One hundred and sixty chronically ill individuals were interviewed. Eighty of the subjects were migraine sufferers attending an out-patient neurology clinic, and 80 were suffering RA, of which half of the sample were in-patients on a rheumatology ward, and half were presenting at an out-patients RA clinic. Information was gained on demographic variables, reported pain, coping strategies, locus of

control and health status. A postal survey was undertaken on a sample of individuals not suffering chronic illness (n=160) to compare results gained from the migraine and RA samples.

In keeping with other evidence, the extent of psychological disturbance was found to be higher for chronically ill individuals than for general population samples, and from the sample of non-chronically ill individuals surveyed for this research. However, not all sufferers were found to be psychologically disturbed, and the part played by pain coping behaviours, locus of control, health status, as well as demographic and medical variables in relation to mental health was explored.

There were no zero order correlations between reported pain and psychological distress, despite the fact that pain was measured on a number of different indices. Age and length of suffering have often been cited as possible factors influencing mood state. However, there is no evidence for this in the data gained in this survey.

The study provides no evidence for the association of psychological state with coping strategies. It has attempted to address the issue of coping with chronic pain on two distinct groups of chronic pain sufferers. The items used are similar to those suggested by Brown and Nicassio (1987) (re: the Vanderbilt Pain Management Inventory), although the questionnaire deliberately did not include items which were regarded for the purposes of this study as outcome measures (i.e. statements of negative affect). The results reported in this study do not provide evidence for the use of coping strategies as a method of adapting to the demands of the painful chronic illnesses studied here. Coping behaviours are not found to be associated with psychological state or the extent of pain reported. The evidence presented here

suggests that a number of coping strategies are adopted, but that these are not associated with psychological well being.

Locus of control has been posited as a possible factor that may influence psychological state, and was measured in this research using a locus of control scale designed to assess individuals beliefs in control over their health. However locus of control scores were not found to be associated with mood state, although in keeping with other research, scores were found to be associated with age and social class, with both lower social class and older sufferers scoring higher on externality than those in higher social classes, or whome were younger.

It is argued that it is neither the intensity of pain experienced, nor the length of suffering the painful illness that is the major determinant of adverse emotional reactions. The strongest association was found between aspects of subjective health status and mood state. The impact an illness upon daily life seems the most salient dimension for psychological reactions to chronic illness. It is suggested that pain is important insofar as it affects the daily lives of sufferers. The major finding of this study is that patients assessment of their own health state, in both illnesses, is the major factor associated with psychological state.

It is suggested here that the perceived impact of an illness upon daily life is a major determinant of psychological distress. For both the migraine sample and the sample of rheumatoid arthritics, aspects of perceived health status provided the strongest associations with mood state. However, from this study the direction of causality cannot be determined. It is possible that psychological distress causes patients to over-report the impact of illness upon

their lives, or that the impact of illness influences mood state. Longitudinal data is required to provide an answer to this question. The research reported here addresses itself to the issue of the relative extent to which social and psychological factors are associated with psychological reactions to painful chronic illness, and has found subjective assessments of health status an important factor. The results indicate that a fruitful area for further research is to explore the issue of subjective health status in relation to mood state, whereas the part played by other social and psychological factors seems limited.

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CHAPTER 1

OVERVIEW OF THE RESEARCH

1.1. GENERAL INTRODUCTION

Social and psychological factors are increasingly seen as influential upon reactions to chronic illness, and can have important implications for health care of the long term sick. Reactions to illness are in part influenced by the beliefs, expectations and attitudes of sufferers, as well as by social and economic factors. One of the most critical aspects of illness that can influence behaviour and mental state is pain. Pain, it has been stated, is one of nature's earliest signs of morbidity (see Adams and Martin, 1984). It is the symptom that is most likely to lead individuals to seek medical treatment, (Safer, et al, 1979). Research has indicated that pain is both one of the most feared elements of sickness (Melzack, 1973), and also one of its most psychologically distressing manifestations (Bond, 1979; Fordyce, 1976). The frequent association of pain and depression has been noted by a number of authors (see Merskey and Spear, 1967; Frank, et al, 1988). This research addresses itself to the question as to the impact of painful long term illness upon mental

state, and the factors that may affect the extent of this impact.

Psychological disturbance and depression are much more widespread amongst the chronically ill than in the population at large (Bond, 1979). However not all people suffering painful chronic illnesses are psychologically disturbed. The study reported here is an examination of the ways in which patients with long term pain attempt to cope with the pain of their illnesses, as well as an analysis of social, psychological, and demographic variables that may influence adjustment as measured in terms of psychological disturbance.

This research analyses the relationship between chronic pain, health status, coping behaviour and health beliefs upon psychological disturbance, as measured on an established psychiatric screening device; the General Health Questionnaire (Goldberg, et al 1972). It is the contention of this thesis that the presence of a specific painful chronic illness does not necessarily cause an individual to develop psychological distress, because the impact of illness and chronic pain is affected by numerous factors. An attempt is made here to discover which factor, or complex of factors may lead, in the short term at least, to successful psychological adjustment.

1.2. PSYCHOLOGICAL DISTURBANCE AND PAINFUL CHRONIC ILLNESS

There is extensive evidence that depression is common amongst individuals suffering from chronic illnesses, (see, for example, Rimon, 1974; Zaphiropoulos and Burry, 1974; Blumer and Heilbronn, 1982; Swanson et al, 1986). However, the reasons for different degrees of psychological disturbance in samples of the chronically ill have yet to be discovered.

Studies in chronic illness have been largely unsuccessful in pinpointing factors that associate highly with psychological disturbance¹. However, a commonly mooted source of psychological distress is the extent and nature of the pain a person suffers with the illness, (see Bond, 1979, Fordyce, 1976). It is generally agreed that chronic pain is associated with mental health problems and that patients suffering chronic pain exhibit more helplessness

1. It was suggested by Pincus, et al (1986), that one potential explanation for the manifestation of depression in chronically ill individuals suffering RA was that of disease specific statements in the instruments being adopted to measure depression, and, specifically claimed this was the case, in RA at least, for the Minnesota Multiphasic Personality Inventory. In other words, the 'presence' of depression in this illness was no more than measurement error. Disease specific statements in the questionnaire accounted for the tendency for depression to be *apparent* in the sample. Whilst such a view is a salutary reminder of the pitfalls of adopting standardised measures in research on chronically ill samples, other researchers have consistently found elevated depression scores in samples of the chronically ill, *even after attempts have been made to remove illness specific statements* (e.g. Zaphiropoulos and Burry, 1974, excluded disease specific items from the Beck Depression Inventory in their study upon RA sufferers).

and depression than individuals in the general population (Sternbach et al, 1973; Sternbach, 1974).

This study addresses the impact of pain upon psychological disturbance in two illnesses, one of which is characterised by chronic pain alone (migraine), and one which also affects overall health state (rheumatoid arthritis (RA)). A number of authors have noted a relationship between pain and depression, although the exact causal mechanisms are the subject of controversy, (Romano and Turner, 1985). This thesis adopts the view taken by authors such as Melzack (Melzack, 1973; Melzack and Wall, 1982; 1988) that pain is one of the most distressing aspects of illness for sufferers, and causal of psychological disturbance. Melzack and Wall cite evidence that pain is causal of depression, rather than the result of neurotic symptoms, as suggested by writers such as Pilowsky et al (1977), from studies where the relief of pain has brought with it relief from psychological disturbance, (Melzack and Wall, 1988). There are certainly a number of studies that claim higher levels of pain are associated with psychological disturbance amongst the two illnesses studied here. For example, McKenna and Wright (1985) found that 66% of patients with RA ranked pain as the most important symptom of the disease, whilst Frank et al (1988) noted a relationship between the presence or history of depression and higher levels of pain amongst RA

sufferers. Cox and Thomas (1981) note that clinical experience indicates that patients presenting with chronic headaches frequently become depressed because of the refractory head pain. Likewise, Ziegler et al (1978) found that levels of depression were significantly greater among subjects in a non-clinical population reporting a history of severe or disabling headache than those denying such a headache history. However, it is suggested here that it is not pain per se that causes depressed state, but the impact of the pain upon individuals lifestyles, and that numerous social and psychological variables can influence this effect.

This study investigates a number of social and psychological factors that may act so as to lessen the impact of the painful chronic illness upon mental health, and undertakes a comparison of their relative contributions in explaining the variance in mental health both within and between these illnesses. It has been argued elsewhere (in relation to RA) that many studies have failed to analyse the relative contribution of psychological, social and disease state factors upon depressed mood, (Newman, et al, 1987; 1989). This is true of research upon chronic illnesses in general (i.e. not just RA), and hence the decision was taken for this research to cover as wide a range of factors as possible in order to discover their relative effects. The remaining sections of this chapter provide a brief

outline of research undertaken on the social and psychological factors to be explored in this thesis.

1.3. COPING AND ADJUSTMENT

1.3.1. Introduction

The impact of an event is substantially influenced by how a person perceives it and reacts to it. The perception of an event is thus a major determinant of later action. It has been argued that primary appraisals seek to determine whether events are positive (benign-positive), neutral (irrelevant) or negative (stressful) in their perceived and potential implications for the self. Such primary assessments may be conscious and deliberate, unconscious or on the fringes of consciousness, (Cohen and Lazarus, 1979). Positive events and neutral events are those that are not perceived as potentially harmful or threatening, and are assessed either for benefits to the self, or simply ignored, respectively. Events that are judged to be negative in their implications, however, will further be judged in terms of harm and loss already done, the future threat associated with the event, and the potential challenge of the event. Secondary appraisals are then made of the available coping resources and options available to the individual, and these are assessed to see if they are sufficient to overcome, or in some other way deal with, the threat, (Lazarus and Folkman, 1984).

Stress manifests itself after secondary appraisal of an event. Potentially stressful events are referred to as 'stressors'. Evidence that events are not stressful per se, but that evaluation of the event leads to stress has been provided in experimental studies (Schachter and Singer, 1962; Speisman, et al, 1964). However, it would be untrue to assume that assessment of stress is so subjective that there are no generally agreed stressful situations. It is generally agreed that the death of a spouse, or involvement in a car accident, or pain through illness is stressful. Stress experienced from any of these situations, or a whole host of others, varies from one individual to another. This is partly due to the assessment made of the situation in terms of possible threat and harm, as well as due to the coping strategies adopted, and the success in utilization.

Major chronic illnesses can make considerable demands upon the individual. Sufferers may experience varying levels of pain, discomfort, anxiety, uncertainty, disability and social isolation. However, despite the impact of chronic illness upon everyday life many patients adapt to the demands made of them in their long term sick role. It has often been claimed in the psychological literature that in order to understand how some individuals successfully adjust to the demands of their illness, whereas others are unsuccessful, involves the investigation of the process of coping, (see Lazarus

and Folkman, 1984). Coping is a term that has been subject to a variety of interpretations, although perhaps the most famous treatment of this issue is that undertaken by Lazarus and his colleagues. For Lazarus and his colleagues the central theme in their definition is that of 'effort'. That is, coping is seen as '...efforts, both action orientated and intrapsychic to manage, (that is master, tolerate, reduce, minimise) environmental and internal demands, and conflicts among them, which tax or exceed a person's resources' (Lazarus and Launier, 1978). Coping is seen as the process of managing demands, be they external to the individual, or internal, that are perceived and appraised by the individual as taxing or exceeding the available resources of that person, (Lazarus and Folkman, 1984). Thus, coping is seen as an active and dynamic process in which the individual is engaged. As Ray, Lindop and Gibson (1982) remark, coping is '... action directed at the resolution or mitigation of a problematic situation.' Coping is not simply seen as an outcome of efforts manifested to deal with a situation, but is the very process of dealing with the demands.

1.3.2. Coping with Chronic Pain

Research has indicated that individuals use a variety of strategies for coping with chronic pain, (see, for example, Tan, 1982). However, systematic studies upon coping with chronic pain are relatively rare. Brown and

Nicassio, (1987), documented and identified the use of distinct active and passive focussed behaviours in a group of Rheumatoid Arthritis sufferers. Those who engaged in active coping were found to report lower levels of depression, helplessness, pain and functional impairment as opposed to passive copers. However, the implications of this study could, it is suggested here, be interpreted by a pattern in which individuals with RA who are functionally less impaired, and suffering less pain, are simply less ill, and hence able to adopt active strategies whereas those with RA further advanced cannot do so². After all, the universe of coping strategies available to an individual crippled with arthritis is obviously less than that of someone with arthritis affecting only the distal joints of the hand. The former cannot engage in as many active coping strategies as the latter (e.g. 'staying busy or active', or 'engaging in physical exercise' would be more difficult for an individual with extensive functional limitations caused by deformation of the joints). Hence, the extent to which pain-coping strategies are determined by the nature and severity of disease rather than the severity of pain remains something of an unanswered question. Further, the question as to whether pain-coping strategies are unique

2. Indeed, the authors themselves remark, '...Passive Coping was related to greater functional impairment as measured by the Mobility, Physical Activity, Activities of Daily Living and Social Role scales of the A(rthritis) I(m pact) M(easurement) S(cale)...The Passive Coping scale was more strongly related to pain and functional impairment measures than the Active Coping scale.' (Brown and Nicassio, 1987, p59, text in parentheses added).

to particular illnesses is not addressed in the research upon coping with chronic pain. Most studies investigate single illnesses, (eg back pain, or myofacial pain), (Rosenstiel and Keefe, 1983; Keefe and Dolan, 1986; Turner and Clancy, 1986). A few coping studies address comparative issues (Felton et al, 1984; Viney and Westbrook, 1981), although they have not specifically examined pain from a comparative perspective. These issues will be addressed in the research presented here.

1.4. FATALISM AND CONTROL

1.4.1. Introduction

Perceptions of control over one's life may be dramatically altered by long term painful illness. It has been found that individuals suffering chronic illnesses, of which the course is unpredictable and difficult to influence, tend to perceive less control over their lives than do individuals who suffer illnesses the course of which is predictable and responsive to treatment, (Felton, Revenson and Hinrichsen, 1984). Indeed, it has been consistently reported that those who measure high on externality have worse states of mental health (see, for example, Affleck et al, 1987; Reid and Zeigler, 1980, 1981). It has been argued that becoming more external in one's beliefs is a likely outcome of a chronic disease or disability, which can in turn affect individuals' perceptions of their overall health, as well as affect energy levels. Further, such externality can lead to an

excessive reliance upon others (Barton, Baltes and Orzech, 1980). Typically, locus of control has been measured on a continuum from internal to external, and this dyadic notion lies behind the formulation of Rotter's (1966) now famous locus of control questionnaire. However, it has been argued that such a notion is oversimplistic, and that locus of control should be regarded as a multidimensional construct, (Levenson, 1973). Wallston, Wallston and DeVellis, (1978), developed the Multidimensional Health Locus of Control Scale (MHLC) to enable measurement of externality, internality and also belief in powerful others, in populations of sick individuals. From a summary of research done using the MHLC Wallston and Wallston (1981) suggest that the most internal groups are those selected because they had adopted preventive health behaviours (eg smoking reduction, birth control users etc), whilst the most external groups tended to be patients with chronic disease and/or persons of lower socio-economic status. Wheaton, . (1980), has also suggested that social status can influence ability to cope with illness, in that personality traits such as fatalism are associated more with working class than middle class individuals.

1.4.2. Mental Health and Perceptions of Control

Wheaton (1983) has argued that dispositional characteristics of fatalism and inflexibility can have a

strong moderating effect on the impact of stress and, whilst there are variations for types of stress and the symptoms of the illness experienced, can be maladaptive dispositions for successful coping. An internal locus of control may be a useful adjunct to adaptation to illness. Externals, and those who depend heavily upon 'powerful others', may thus manifest higher levels of psychological disturbance than internals. The research undertaken for this thesis will investigate the relationship between locus of control and mental health.

1.5. HEALTH STATUS

It is suggested here that an often overlooked area of potential importance for mental health is that of health status (i.e. the general health of an individual). There is certainly considerable support for the hypothesis that chronic illness is associated with a higher incidence of depression than in the general population (Bond, 1979). This thesis addresses the question as to what features of chronic illness can lead to depression. So far variables such as the nature of the illness, and the pain associated with it have been mooted as possible sources of psychological disturbance, though variables such as coping behaviour (Aldwin and Revenson, 1987; Felton, Revenson and Hinrichsen, 1984), and personal control (Anderson, et al, 1985) have been suggested as possible mediating factors of the impact of chronic illness on mental health. In recent years a number of instruments

have emerged which are concerned to assess the different dimensions of health status and quality of life, (McDowell and Newell, 1987; Walker and Rosser, 1988). They may be illness specific or generic. Typically, they assess the impact of chronic illness on dimensions such as, for example, pain, mobility, social isolation, emotional well being. The main purpose of such instruments has been to provide quantitative expression of health state for use in clinical trials, evaluation studies or cost utility analyses. However, it is argued here that measures of health status, because they provide information regarding the impact of illness on different aspects of daily life, may also be used to explore how perceived illness state is related to psychological well being. One study which has done this (Newman, et al, 1989) uses the physical scale of the Functional Limitations Profile (FLP) to assess physical disability in a sample of outpatient rheumatoid arthritis patients. Newman et al report that their findings suggest that 'comprehensive behavioural measures of disability are powerful predictors of depressed mood'. The FLP score was found to be a major variable in explaining depressed mood. Thus, depression was found to be associated with a number of factors of which disability was the most significant (Newman et al, 1987, 1989). Indeed it is suggested here that the results of studies on coping such

as that by Brown and Nicassio (1987) support this view³. They found that passive copers were more psychologically distressed by their illness than active copers, and more severely disabled by their illness. It could be argued that health state influences the repertoire of available responses to illness, and this plays a causal role in the onset of depression. The most important determinant in this chain is initial health state. However, in keeping with the work of Lazarus and his colleagues (see Chapter 1.4.) it is suggested that individual *perceptions* of disability is an even more salient feature for the understanding of reactions to illness. Perceived health state refers to the extent to which individuals regard themselves as affected by their state of ill health. Measures of health status are, however, variously interpreted. Sometimes they are regarded as a generic measure of health state and at other times they are regarded as perceptual and subjective assessments of health status. There has certainly been a growth in interest in the assessment of health state from the point of view of the patient, (Hunt et al, 1986; McDowell and Newell, 1987; Walker and Rosser, 1988). This thesis will

3. A fuller exposition of the work by Brown and Nicassio (1987) is given in Chapter 1.3.

explore the link between psychological disturbance and health status.

The two illnesses chosen for this study pose very different clinical and social problems. Indeed Rheumatoid Arthritis is a chronic illness that has substantial implications for daily living, and it is an illness which is recipient of substantial resources within medicine. Migraine, on the other hand, is an illness that is regarded medically as a minor complaint. The choice of two such distinct illness groups permits the hypothesis to be tested that the extent to which an illness is associated with mental health is in large part determined by the *perceived* extent of ill health.

CHAPTER 2

OUTLINE OF HYPOTHESES TO BE TESTED AND ILLNESSES UNDER STUDY

2.1. HYPOTHESES

2.1.1. The General Aims of the Empirical Research; An Overview

This thesis is concerned with social and psychological factors that may influence the success an individual may have in adapting to chronic painful illness. By success it is meant that a person does not show signs of psychological disturbance. There are numerous social and psychological factors that can influence adjustment, and that the relative importance of these factors has not often been closely studied, (Newman, et al, 1987, 1989). This thesis undertakes an analysis of the part played by a number of social and psychological variables in chronic illness and attempts to discover their relative importance for mental health.

Broadly, this thesis explores two issues:

It will explore the extent to which pain is associated with mental health in two distinct illnesses. In order to test this hypothesis two illnesses are studied and compared:

rheumatoid arthritis (RA) and migraine. Migraine is characterised by painful attacks whilst RA is characterised by pain and functional disability. If depression were more prevalent in the two illness groups than in general population samples, and pain was significantly associated with depression it would be reasonable to make the claim that pain is the most important aspect of illness in determining depressed mood¹.

The second major issue explored in this work is the part played by various social and psychological factors in adjusting to illness. The relative contribution to mental health of these factors has rarely been studied, and this is what this thesis aims to do. The remaining part of this section will outline the social and psychological factors under study.

2.1.2. Demographic Variables

Demographic variables are often cited as influential factors upon depressed state. Age, sex, and social class factors are often invoked as partial explanations for depression. For

1. It is worth pointing out that whilst migraine is regarded for the purpose of this work as a pain only illness, it is an illness in which there is evidence for an underlying organic dysfunction. Pain from migraine is therefore reflective of an underlying pathological disorder, and is not simply a reflection of psychological state. Thus, claims such as those made by Magni and Merskey (1987) that chronic pain patients presenting without lesions are more likely to suffer psychological disturbance, than those pain patients presenting with lesions, are addressing pain illnesses in which no organic lesion whatsoever is present or assumed. In their study they found that 97% of the non organic pain sufferers scored as psychologically ill whilst only 39% of the organic pain sufferers did so. This supports earlier findings by Chaturvedi et al (1984).

example, Spicer, Hare and Slater (1973) found that many depression is more common amongst the elderly, whilst Gove and Tudor (1973) identified ways in which the nature of a woman's social role increases risk of psychiatric illness, and Brown and Harris (1978) identified links between social class, and psychiatric symptoms.

Whilst the research undertaken for this thesis is not primarily concerned with the part played by demographic variables upon mental health, information was obtained on age, length of illness, social class etc. These can be important background variables, and it was assumed that they may account for some of the variance in mental health. For example, Chaturvedi (1987) found in a sample of depressed and non depressed chronic pain patients that age and employment were associated with frequency of depression. That is, those patients who were both old and unemployed scored more frequently as depressed than did younger patients. However, Kramlinger, et al (1983) and Dworkin, et al (1986) in studies of pain patients found depressed and non-depressed chronic pain patients to be similar in relation to demographic variables. However, as sex is often cited as an important variable in depression it was decided to interview only women for this research, and in doing so attempt to account for variance in mental health within a single sex sample. Further, the two illnesses studied here are more prevalent among women than men.

2.1.3. Pain Coping Behaviour

Much research undertaken on the impact of chronic illness upon mental health is concerned with the use of coping strategies. Coping strategies are often posited as a potential explanatory group of variables that can provide an explanation as to why certain individuals suffer depressed mood under certain stressful circumstances whilst others do not. Thus, accounts are sought of the coping strategies adopted by individuals in order to cope with the demands of their illness. However, relatively little attention has been paid to the impact of chronic pain upon mental health in the coping literature, although much research has suggested that pain is a major precipitating factor in depression (Bond, 1979; Fordyce, 1976). Indeed, it is the contention of this thesis that much research into coping with chronic illness tends to ignore the specific demands of illnesses, and that many of the coping strategies cited as adopted by individuals are often reflective of the type of illness an individual is suffering, or the extent of the illness. Demands of illnesses and extents of illnesses differ dramatically and certain coping strategies are more suitable to certain situations than others. However, coping research undertaken on samples with a mixture of illnesses give little consideration to the differing demands these illnesses may make upon individuals. In one such study Viney and Westbrook (1982) interviewed 89 chronically ill subjects about the coping strategies they adopted at stressful times in their lives. However, the characterisation of the group

was varied, with patients suffering a wide range of illnesses ranging from circulatory problems to genito-urinary illness. In all, there were eight groups of illnesses mentioned by the authors, with no admission of the possible differences the illnesses may have in terms of demands upon an individual. However, in research where a single illness is studied there does not exist the possibility of exploring whether certain coping strategies are utilised across illnesses. For example, studies on low back pain patients such as that by Rosenstiel and Keefe (1983) alone do not permit comparison of strategies with other groups (e.g. Rosenstiel and Keefe, 1983).

In the research undertaken here two groups of chronically ill individuals were studied. One group consisted of individuals who suffered an illness characterised mainly by pain (migraine) whilst the other group consisted of patients suffering an illness characterised by functional impairment and pain (rheumatoid arthritis). The demands of RA are very different from those of migraine. However, both illnesses are prone to periods of inactivity interspersed with very painful flare-ups. The two illnesses were deliberately chosen to enable a comparison of coping strategies. If, as researchers suggest, pain is one of the most feared and potentially depressing aspects of illness (see Chapter 1) then it is an interesting empirical question as to whether cross illness coping strategies do exist that enable individuals to cope with the pain of their illness, and hence not suffer psychological distress.

2.1.4. Helplessness and control

A major potential determinant of the use of coping strategies in illness is the belief that people can actively influence their health. It is possible that sickness may influence individuals belief of their personal power over health (Wallston and Wallston, 1981). However, it has been argued that individuals adapt to the demands of their illness if they believe that they are in a position to control the demands it places on them, (Janis and Rodin, 1979). The two illnesses chosen for study in this research are both unpredictable in the long term, and also on a day to day basis. Patients cannot be sure of the long term course of their illness, or whether, on any given day, they will suffer a flare up or migraine attack. It is possible that the unpredictable nature of these ailments will influence people's beliefs in control over their illness, and be a major cause of depressed state. Further, other variables, such as class, can influence people's beliefs that they can influence the course of their illness, (Wheaton, 1980). This thesis will examine the relationship between beliefs of power and efficacy over illness, and their association with mood state, class and health status.

2.1.5. Health Status

As has been noted above, there is considerable variation in the demands illnesses make upon sufferers, and the available coping strategies are themselves determined by the illness.

For example, an RA sufferer with severe joint destruction who is unable to walk, does not have the option of going for walks in order to reduce feelings of stiffness. Hence this particular strategy is unavailable, and it would be obviously useless for a clinician to suggest such an individual should adopt such a strategy. Thus, the range of available coping strategies for any individual is determined in large part by health status. As has been argued, there are a number of different ways of measuring health status. Conventionally, the medical profession has relied upon either global clinical assessments of severity of illness (e.g. the assessment of severity of rheumatoid arthritis on the four point Steinbrocker, (Steinbrocker et al, 1949)), or more specific clinical measures (such as grip strength in RA), or radiological and laboratory measures. More recently alternative measures have become available that attempt to measure subjective assessments of health state. Subjective aspects of health status are not commonly made by clinicians or in research on adaptation to illness. Subjective assessments refer to an individuals' own judgement of their health. It is suggested here that a useful adjunct to studies on psychological adjustment is assessment of health status. How ill individual's feel themselves to be can have a major impact on their action (afterall, it is frequently the case that it is perception of ill health that leads an individual to seek medical attention in the first place). In this research assessments of health were taken not only from clinicians on the patients, but also from the patients themselves. It is therefore possible to see whether

perceptions of health status are associated with mental health.

2.2. THE ILLNESSES UNDER STUDY

2.2.1. Introduction

This study is comparative. Two groups of long term pain patients were analysed. The illnesses under study are Rheumatoid Arthritis (RA) and migraine. The RA group is comprised of two sub-groups, of which one is made up from in-patients, and the others were selected from an out-patients department. No respondent questioned as an RA in-patient was questioned in the out-patients department or vice versa.

2.2.2. Rheumatoid Arthritis (RA)

Arthritis is one of the major causes of pain (Melzack and Wall, 1982). In Britain alone 20 million people experience some form of rheumatic disorder each year. Approximately eight million people consult GPs every year concerning rheumatic disorders, which accounts for nearly 18% of all consultations in general practice, (Macleod, 1985), and it has been estimated some 44 million working days a year are lost due to these illnesses, (Scott, 1980). Five million people suffer Osteoarthritis (OA), which is often regarded as an old persons' disorder, (Mandell, 1983), caused by joints becoming worn, whilst *Rheumatoid Arthritis* (RA) is a disease present in about half a million adults, and a further 12,000 children suffer chronic juvenile arthritis (Still's Disease). Rheumatoid Arthritis is present throughout the world in all climates and in all ethnic groups. The overall

prevalence in the developed countries is about 3%, with a female to male ratio of approximately 3:1, (see Macleod, 1985) with onset typically in the third and fourth decades of an individual's development.

RA and OA are often regarded as similar. This is inaccurate. OA is essentially the degeneration of the bone of the joints due to use over time. RA is a degenerative tissue disease the aetiology of which is uncertain and a source of considerable debate in medical research, (Grennan and Jayson, 1984). Genetic and microbiological (i.e. viral infective agents) factors have been implicated in the causation of the disease, but there is no conclusive evidence for them. Nevertheless, it is currently believed that the disease is a result of altered immune reactivity, and persistent antigen stimulation, in persons genetically predisposed, (see Macleod, 1985).

The disease attacks connective tissue *throughout* the body, but joints are typically the most effected sites, especially the hands, feet, and the other large synovial joints (hips, knees, and elbows). RA can affect every one of the 187 joints in the human body. The extra-articular manifestations can be important in so far as they determine the disease's

morbidity and mortality. There is, typically, a family history of the disease, (Rubenstein and Wayne, 1985).

At onset, the earliest signs are swelling, stiffness, and pain upon movement. As the disease progresses spontaneous pain at rest and early morning stiffness are characteristic. Typically, the small joints of the toes and of the fingers are affected with swelling occurring at the distal, rather than at the interphalangeal joints. As the disease progresses, with or without intervening remissions, it typically affects the wrists, elbows, shoulders, and the subtalar and midtarsal joints of the feet. Ulnar deviation develops in the fingers. In some patients the onset of RA is palindromic in which the disease is typified by recurrent and painful attacks of short duration (1-7 days) about 2-3 weeks apart. A third of such cases develop into more typical polyarthritis (i.e. arthritis affecting several joints). In approximately 10% of cases RA starts as acute polyarthritis, with severe systemic symptoms including weight loss, fever, fatigue and malaise.

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In the long term, pain, muscle spasm, and progressive joint destruction result in limited locomotion. The involved joints become swollen, and it is possible for fixed deformities to occur as the disease progresses. Destruction of articular cartilage in the joint spaces can cause bone deformities to develop. Likewise swelling of tissue can

deform bone. Muscle wasting, most typically in the small muscles of the hand, occurs, although it can occur at any affected joint. Inflammation of soft tissue around joints causes swelling, tenosynovitis (i.e. inflammation of the thin synovial lining of a tendon sheath), and even tendon rupture. Localised subcutaneous nodules, caused by debris from swollen joints draining away from the affected site, are present in 25% of patients and indicate severe destructive disease. Ocular disturbances can also develop, with the most common being episcleritis, which is a painless swelling of tissue around the eye, to more painful swellings such as kerataconjunctivitis sicca, present in 10% of RA sufferers.

Clinical assessment seeks to determine the number of joints affected, and the extent of pain and stiffness experienced by the sufferer. Radiological evidence is provided by X-rays which provide evidence of the extent of joint destruction. Laboratory measurement is made by blood tests. An elevated ESR (Erythrocyte Sedimentation Rate) indicates the activity of the disease. Tissue destruction, and swelling, cause an increase in the ESR. The disease can also affect the haemoglobin count of the blood. Rheumatoid factor is also present in 50-70% of persons with RA, and is caused by

protein globulins (called immunoglobins) reacting with other immunoglobins.

Numerous treatments exist for RA. In chronic diseases where no cure is yet available all sorts of remedies are forwarded. Some are more believable than others, and the following list gives an indication of the variety of treatment methods that have been suggested from various quarters: acupuncture, apple-diet, bee venom, copper bracelets, chemotherapy, extraction of teeth, fasting, gin, hypnotism, mud baths, rhubarb diet, standing inside the body of a whale, to name a few, have all been seriously forwarded (Scott, 1980). Evidence for the success of RA treatments of these sorts is, at best, conflicting. Within the medical profession, physical treatment, drugs and surgery are the methods adopted.

Physical treatment attempts to retain the maintenance of function and the prevention of deformity. Bed rest for a period of three or four weeks can reduce swelling and tenderness providing good posture is maintained. More active exercises are also important to prevent deformities developing, and prevent muscle wastage, (Scott, 1980).

Drugs are used to control the *symptoms* of RA but cannot, unfortunately, cure the disease. Response to drugs is wide and unspecific, with many RA preparations being potentially

toxic. The most common preparations are the NSAIDs (the Non-steroidal anti-inflammatory drugs). This is a large group of drugs, which combine pain relief (analgesia) with suppression of inflammation. NSAIDs are relatively non-toxic, and widely prescribed. The most common NSAID is aspirin, but others are ibuprofen, fenbufen, fenoprofen, indomethacin, and naproxen. The drugs are non-specific, so that responses to them vary, with some providing relief for one person and yet not for another.

More specific drugs are given to those patients whose symptoms persist despite the use of NSAIDs. Myocrisin (Gold) injections are a very common RA treatment but can be dangerous if not taken under very careful supervision. It is dangerously toxic, and can also cause skin rashes or ulcers, and kidney damage. Penicillamine is an orally administered preparation and is similar in its effects though potentially worse in its side effects, to gold.

The most powerful RA drugs are the Corticosteroids. These can give immense relief to almost any RA patient, and were hailed as the miracle drugs when first applied in rheumatology some 50 years ago. They are still used today, but the range of side effects that these drugs can cause has meant they are used sparingly and with caution. Side effects range from the swollen 'moon' face, and facial hair, to perforated and bleeding gastric ulceration. Further, these

drugs may reduce pain and swelling in the short term, but in no way cure the disease, and are, in general, useless in the long term. Low dosages of the corticosteroid prednisone are both harmless in terms of side effects and can reduce the pain and swelling of many RA sufferers.

Surgery is the final option generally available from established medicine. Surgery is undertaken to remove inflamed synovial tissue (*Synovectomy*), or to replace parts of joints or whole joints that have become deformed (*Arthroplasty*) with plastic prostheses, or to fix swollen and painful joints in a good functional position (*Arthrodesis*), so as to relieve pain.

2.2.3. Migraine

Headaches and giddiness are the most commonly presented neurological symptoms, (Rubenstein and Wayne, 1985)². Migraine is an episodic ailment that affects approximately 10% of the population, although in many cases the migraines are very infrequent and of short duration. Migraines usually begin at puberty and last until middle age. Women are more prone to migraine attacks than men. There is a tendency for the headaches to occur during periods, and to cease during pregnancy (Adams, 1984). There is substantial evidence that migraines are familial. It has been estimated that 70% of

2. There are a number of head pains similar to migraine, though these are not studied here. For a full account of the extent and variations in types of head pain presented see Waters (1986).

sufferers are the offspring of migraine suffering parents, (Goodell, Lewontin and Wolff, 1954), though the mechanisms responsible for this remain unclear.

Two related syndromes have been identified: *classic* or *neurologic migraine* and *common migraine*. The classic type begins with little or no pain, but with feelings of drowsiness or elation, thirst or a craving for sweet foods. Neurological symptoms then develop, such as visual disturbance ('visual aura'), aphasic behaviour (i.e. speech difficulties), and hemiparesis (mild paralysis down one side of the face or body), with little or no pain. These symptoms last approximately half an hour in the typical case, and then blend into hemicranial or global throbbing, which lasts anything from an hour to a couple of days. The attacks are often associated with nausea and vomiting. In common migraine there are no neurological disturbances indicating onset, though vomiting and nausea are still common during the attack itself, which can typically last anything from an hour to a few days, and are characteristically lateralised (i.e. occur on one side of the head only). A related ailment to those discussed above is *migraineous neuralgia*, or cluster headaches, which appear in the form of migraine, in that they are typically lateralised, though typically centered around an eye, and affect sight and may cause vomiting. Attacks, however, occur in clusters, every twelve to twenty-four months and typically strike at night or early

evening. The headaches are, like migraines, of varying duration, though the cluster periods last about one to four weeks. The cause of the clustering is unknown. Unlike migraine the incidence of cluster headache syndrome is far more common in men (4:1). Its relationship to migraine is conjectural and unclear (Adams, 1984), and no incidences of it are reported in this study.

It should be noted that the headache patterns and symptoms outlined above are typical examples of migraineous attacks, but there is substantial variation. It is possible to experience neurological symptoms such as giddiness, flashing lights, aphasic behaviour etc without any pain whatsoever.

The exact mechanism that triggers migraine is unclear. It is generally agreed that the disorder is a neurovascular one, concerning both intracranial and extracranial vessels. Circulatory changes occur (Oleson, Larson and Lauritzen, 1981), that cause excessive constriction of blood vessels running through the brain, and then subsequent and excessive vasodilation of the blood vessels. The pain in migraine is experienced at this stage, when the blood vessels are excessively dilated for an atypically long period. The actual headache pain has been attributed to excessive pulsation of extracranial, and possibly intracranial, arteries. Blood platelets also aggregate, and this, it has been suggested, is what may cause the stroke-like aspects of

migraine (aphasia, paralysis of facial muscles etc), (Couch and Hassanein, 1977). It remains unclear why some individuals are prone to migraine, although it has been suggested that cranial vessels of the migraine sufferer are hypersensitive.

Not only is migraine an illness of uncertain aetiology, but it is also not known what are the factors that trigger an attack, nor why the illness is so unpredictable in its course, with certain periods in the life of a sufferer clear of migraines and others dominated by them. Enzymes in certain foods such as red wine, chocolate, and cheese have been posited as likely triggers of migraine, as has stress, tiredness, exercise, sunlight, and the use of oral contraceptives. However, while these certainly are precipitatory causes for some sufferers they are not for all. Certainly the migraine sufferers interviewed in this study had nearly all, at some time, avoided these (and other mooted) triggering agents, with no impact on their headache suffering.

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Numerous treatments exist for migraine, just as they do for RA: avoidance of certain foods, biofeedback, acupuncture and relaxation techniques are amongst the most commonly cited. As with rheumatoid arthritis the results of such methods are

ambiguous, and the medical profession limits itself, for the most part, to analgesic and other drug treatments.

The most important aspect of treatment for headache is to determine the nature of the ailment. Some headaches are indicative of major neurological diseases, and it could be fatal to diagnose such pains as tension headaches, or migraine. Treatment of migraine, therefore, involves three steps. The first is to determine that the headaches are migraines and not indicative of a different or more sinister complaint; the second stage is, in many cases, to convince the sufferer this is the case, and, then, at the third stage, to treat the illness with suitable drugs. Some patients require no more than the information that the illness is not a tumor, or likely to become one. Many patients present knowing what things bring on the illness and attend for information about the illness, and support that they should avoid the triggering mechanism. Patients who present with neurological aura alone are rarely treated, and in general the information that they are suffering from migraine attacks is the most important information they could receive.

Drug treatments for migraine vary in both their usefulness to sufferers and in their side effects. The time to treat the oncoming headache is during the neurological aura. If the attacks are mild then aspirin will generally suffice,

but for all the migraine sufferers reported here the pain could not be controlled to any extent by such medication. Very high levels of success are claimed for ergot preparations, sometimes mixed with caffeine (cafergot). Ergot preparations are available in tablet form, but if vomiting prevents oral administration then they can be taken in suppository form. Side effects of this drug are prolonged vascular spasm, and the drug can be dangerous if administered to pregnant women. Further, ergot can, rather ironically, cause headaches if taken in sufficiently large doses or for very long periods of time. In individuals with very frequent migraine, attempts at prevention are often made. Phenobarbital, propranolol and methysergide are drugs administered to frequent sufferers. Retroperitoneal fibrosis (i.e. the formation of excessive fibrous tissue behind the peritoneum (i.e. the membrane lining the abdominal and pelvic cavities), and peptic ulcers, can result from constant use of such drugs. Clonidine is sometimes administered prophylactically, but can aggravate depression and cause insomnia.

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CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

The research undertaken here seeks to find what factor or complex of factors affect the impact of painful chronic illness upon mental health. Social (including economic), psychological, and demographic factors are studied. The intention of the study is to discover a group of factors that may influence the impact of painful chronic illness upon mental health. Two groups of chronically ill patients are being studied: firstly individuals suffering from Rheumatoid Arthritis (RA), and secondly individuals suffering migraine.

This chapter provides an outline of the research methodology adopted in this work and information on the questionnaires used, and the reasons they were chosen.

3.2. SAMPLE AND DATA COLLECTION

3.2.1. Reasons for the Selection of the Illnesses Under Study

The reasons for comparing these two illnesses, (Rheumatoid Arthritis (RA) and Migraine), is that both are typically chronic (i.e. as opposed to acute) illnesses. Both have acute phases (e.g. flare up in RA, and migraine attacks), but the illnesses are chronic ailments with no guaranteed methods of cure. Neither illness is normally considered to be associated with mortality, although advanced forms of RA, can lead to complications in a small number of cases and this can cause death.

The two illnesses are similar insofar as they are typically very painful and episodic. That is, periods can be spent with relatively little or no discomfort being caused by the illness. However, the ailments are sufficiently different to permit a comparison of coping strategies across two different illnesses. RA often causes physical deformation, and can, as noted above, be life threatening. Migraine cannot cause physical deformation and is very rarely directly life threatening.

The two illnesses, are characterised by chronic pain, and unpredictability (see Section 2.2.). RA has greater implications for overall health status. Thus, comparisons can be made between coping strategies adopted by the two

groups of sufferers, and mental health. The comparison will make it possible to see if coping strategies are illness specific, and whether good mental health is associated with chronic pain alone, or chronic pain combined with other aspects of the illness. This comparison would not be possible between two illnesses characterised by pain only (e.g. migraine and back pain) or illness with pain and other illness manifestations (e.g. osteoarthritis and RA).

3.2.2. Sample Source

Both illnesses are more common in women, and so the sample was composed from women. This enables the effects of sex to be controlled out in this study. The subjects were gained from three populations: (1) Rheumatoid Arthritis in-patients at the Rheumatology Ward (Seddon Ward) at the Nuffield Orthopaedic Centre (NOC) in Headington, Oxford, (2) out-patients presenting at the Arthritis clinic at NOC, and (3) out-patients presenting at the Migraine Clinic at the Department of Neurology at the Radcliffe Infirmary, Woodstock Road, Oxford. All interviewees were diagnosed as suffering from one of the two ailments by medical specialists, (i.e. a Consultant Neurologist and a Consultant Rheumatologist).

The two populations from which samples were drawn for this research were rheumatoid arthritics and migraine sufferers. No individual currently suffering both illnesses was

interviewed. Patients were randomly selected from patients attending out-patient clinics or as inpatients.

A second study was undertaken as part of the research on a sample of individuals not selected due to illness. This permitted comparison with the patient groups. The study of a sample of non chronically ill individuals was selected from the University of Oxford Department of Experimental Psychology Subject Panel. All the subjects chosen were women between the ages of 18 and 80 years of age. Whilst these subjects comprise a group referred to as 'not chronically ill' there were some who suffered chronic illness. However, the subjects in this study were not selected because they suffered illness, but it would be surprising not to find a proportion of ill people in a randomly selected sample of the population. Whilst this sample is not strictly randomly selected, they were not selected for this research on any health related criterion, as were those in the main study. Comparisons between the two groups are thus made cautiously, or alternatively the data from the Subject Panel is used to explore distinct hypotheses.

3.2.3. Method of data collection for the sample of chronically ill individuals

Data was collected by means of structured interviews, in which patients were asked to respond to questions with a pre-determined response set. This method was chosen in

preference to unstructured interviewing to enable comparisons to be made on the basis of standardised questions. Further, it was chosen in preference over a self completion questionnaire design for two reasons: firstly, the number of questionnaires to be completed was extensive, and differing methods of completion were necessary. In order to avoid confusion in the minds of the recipients it was decided it was advisable to have someone present to administer the questionnaires verbally, thereby enabling explanations and clarifications to be made to patients. Some RA patients were also so deformed with their illness that completing a questionnaire would have been a difficult and painful task, whereas reading responses from a card was easier for them. All patients were presented with a copy of the relevant questionnaire to follow, and were asked to read out their responses.

Comparisons within and between groups were made by administering the General Health Questionnaire (GHQ), the McGill Pain Questionnaire (MPQ), the Nottingham Health Profile (NHP), and the Multidimensional Health Locus of Control Scale (MHLC), (see Appendix Ia-Id), and an instrument developed for this research (see Appendix Ie) to study patient's beliefs/attitudes/knowledge of their illness, and how they construed and coped with the pain. These questionnaires were administered verbally by the researcher. It was intended that these questionnaires should

provide a profile of patients in terms of the nature of the pain experienced, their mental health (ie depressive symptomology), and what factors may effect these variables.

At the beginning of each interview subjects were told the reasons for the research, and it was stressed that the research would neither have any bearing upon their treatment, nor would results be fed back to the the medical staff treating them. Requests from interested nursing staff to sit in on the interviews were always refused.

Overall the interviews took on average about two hours, the shortest interview taking thirty-five minutes, and the longest four and a half hours. Variations in the time taken to complete the interviews are accounted for by the wide variations in the nature of patient's replies; some answered the questions simply by reference to the specified range of answers, whilst others gave long, discursive replies, and further questionning was necessary to gain a reply from the specified response set.

3.2.4. Method of data collection for the sample of Subject Panel respondents

Questionnaires were sent to Subject Panel respondents for self completion and return in a pre-paid envelope. The questionnaires were a selection of those administered in the chronically ill patients interviewed, together with a short

form questionnaire seeking information concerning general health state and demographic data. The Subject Panel respondents could not be interviewed due to the prohibitive costs involved. It is possible that mode of administration may influence results, as greater self-disclosure may be gained from respondents who are not having face to face interviews. However, it is suggested here that health is an area in which people are more willing to self disclose whatever method of administration is used.

3.3. THE ASSESSMENT OF MENTAL HEALTH

3.3.1. Introduction

The General Health Questionnaire (GHQ) is one of the most widely used mental health screening questionnaires, (Hunt, McEwen and McKenna, 1986). Developed by Goldberg, (1972), the questionnaire is used as a screening test to detect non-psychotic psychiatric disorder, and it is the questionnaire used in this work to assess psychological disturbance. In the main RA/Migraine study it was administered to all subjects upon interview, and then sent to a small sub-sample for self completion four weeks later.

The GHQ comes in a variety of formats, and a number of suggestions were put forward by Goldberg as to the method of scoring. The questionnaire is available in 60, 36, 30, 20 and 12 item lengths. The 30 item GHQ was chosen for use in this project as it has been found to be very consistent in test-retest studies, and also to correlate well with psychiatrists' assessments of patients (Goldberg, 1972). Reliability of the longer versions is slightly better, but the length of time needed for completion increases with additional items, and, as the GHQ was to be sent out in a follow up, length was taken to be a potential aspect that may discourage participation. The GHQ is generally administered as a paper and pencil schedule, but in the RA/Migraine study it was administered verbally. A copy of the GHQ was handed to each patient and the items read out.

The patient followed the questionnaire through selecting each response to each question.

The GHQ in the format used in this research consisted of 30 statements with four available responses to each item. Subjects are asked to compare their perceived state of health over the last few weeks with their health *in general*, on each of the items listed. Thus, an item in the GHQ reads: *Have you over the last month been able to face up to your problems?* The possible set of answers to this question are: *More so than Usual, The Same as Usual, Less Able than Usual, Much Less Able*. There are three possible ways of scoring the responses on the GHQ. The first is to score each item on a Likert type scale (0,1,2,3, or 1,2,3,4), the second to score it as a Modified Likert type scale (0,0,1,2,) and the third, and the one recommended by Goldberg, is to score it on a '0' or '1' basis, known as the 'GHQ score'. Goldberg found little advantage to adopting the Likert approach and recommended the simpler approach, (Goldberg and Hillier, 1979; McDowell and Newell, 1987). Indeed, Goldberg recommends the simple GHQ raw scores as an index of assessing whether psychological treatments are successful. He suggests the GHQ can be administered before and after

treatment, and if the treatment is successful the raw score should be lower (Goldberg, 1972).

Throughout the GHQ the first two responses to each statement are seen as indicating a positive state of mental health whilst the second two statements are indicative of a symptom problem in that given area. The higher the total score the greater the likelihood of psychological disturbance. When a certain proportion of statements (usually 20%) have received a score of one then psychological disturbance is indicated. The cut off point in the 30 version questionnaire is 4/5, with scores of 5 and over coded as indicating possible non-psychotic psychiatric disorder. The GHQ is not generally scored so as to give any idea as to the extent of psychological disturbance, although extent of psychological ill-health has been inferred from the raw data score in some studies (e.g. Warr and Jackson, 1987), and Goldberg has suggested raw GHQ scores can give an indication of state of psychological ill health (Goldberg, 1972). A problem of the GHQ subjects are often unaware of the specific time reference required by the instrument, and respond in general terms about their feelings rather than their state of health over just the last month (Hunt, McEwen and McKenna, 1986). In view of these two points it was decided to find whether the GHQ results would tally with those of another screening questionnaire;- The Beck Depression Inventory (BDI) (Beck, et al, 1961). Both the BDI and the GHQ are state rather than

trait measures. The BDI is composed of 21 groups of items, each group consisting of four possible response items. Subjects choose one response per group. Each response has a value of either 0, 1, 2, or 3, and all the choices made by subjects are summed to give a single overall value. This value indicates extent of depression, (e.g. not at all, mildly depressed etc (see section 3.3.3. for a full account of the method of scoring)). Possible use of the BDI for the major part of the study was given up as one of the doctors in the survey disapproved of it's use and felt it could do psychological harm. A copy of the GHQ, together with a copy of the BDI, are to be found in Appendix Ia.

3.3.2. Study to compare results gained on the GHQ against those gained using the Beck Depression Inventory

The study was undertaken upon in-patients suffering Rheumatoid Arthritis and students in their exam term at the University of Oxford. For reasons given above migraine patients could not be included (i.e. the migraine consultant felt it unwise to administer the BDI to patients).

Subjects were presented with a copy of the BDI and a copy of the GHQ for self completion. They were asked to complete both in accordance with the instructions at the top of each questionnaire. The GHQ instruction read:

The following Questions ask you about your general health over the last few weeks. After each

statement ring the answer that seems most appropriate.

whilst the instruction for the BDI read:

The following questionnaire asks you questions about how you have felt over the last few weeks or so. Ring one statement per group that you feel applies to you at the moment. There are 21 groups with four statements each.

To avoid order effects the order of the two questionnaires was alternated between subjects.

3.3.3. Results

Data was collected from 53 individuals, (mean age 39.0 years, S.D. 20.38). Twenty four of the subjects were in-patients in the rheumatology ward at the Nuffield Orthopaedic Centre (mean age=57.6, S.D. 16.71) and 29 were individuals with no history of major or chronic illness (mean age=23.7, S.D. 1.85). Twenty-four of the subjects were male (6 in-patients and 18 'normals').

Caseness on the GHQ was taken to be indicated by those individuals who had over four positive scores. Caseness on the BDI was taken as those who scored nine points or over. The method of scoring the BDI was that suggested by Burns and Beck (1978). Scores of 0-9 indicate no depression, 10-14 indicate borderline depression, 15-20 indicate mild depression, 21-30 indicate moderate depression, 31-40

indicate severe depression and 41-63 indicate very severe depression. In this study 16 (30.2%) individuals scored in excess of 9 on the BDI, but only two of the sixteen scored above 21 (moderate depression), and no-one scored above 30. Hence depression scores were found to be low, with no subject suffering severe depression as measured with this instrument.

TABLE 3.1. HERE

Table 3.1. shows the consistency of classification as 'cases' on both instruments. Overall 14 (26.4%) subjects were classified as 'cases' by both the GHQ and the BDI, and 28 (52.8%) subjects were classified as disturbance-free on both measures. Incongruent classifications occurred in eleven cases, nine (17.1%) of which were classified as 'cases' on the GHQ, and not on the BDI, and two (3.8%) for which the opposite was true. Overall congruent classification on both measures was indicated, and this was supported statistically (Chi Sq=15.03, $P < 0.05$, $df=1$, two tailed test). However, congruence of measured 'caseness' was greater for the sample of arthritics than for the 'normals'. Nine (31.03%) 'normals' were inconsistently classified (all but one scored as a case on the GHQ, but not on the BDI,

		Caseness on the BDI	
		Case	Not-Case
Caseness on the GHQ	Case	14 (26.4%)	9 (17.1%)
	Not-Case	2 (3.8%)	28 (52.8%)

Table 3.1.

Scores on the General Health Questionnaire (GHQ) and the Beck Depression Inventory (BDI) in terms of 'caseness' and 'non-caseness'.

whilst one scored as a case on the BDI and not on the GHQ). Two RA patients were classified inconsistently; one as a case on the GHQ and not on the BDI and one for whom the opposite was true.

Pearson Product moment correlation coefficients were then calculated for the scores on the GHQ and on the BDI. For the data overall a correlation of 0.77 ($p < 0.001$, $n = 53$) was found from simple numerical scores on both the GHQ and the BDI. A score of 0.84 ($p < 0.001$, $n = 24$) was obtained for the RA patients and 0.73 ($p < 0.001$, $n = 29$) for the 'normals'.

3.3.4. Discussion

Analysis of the data provides evidence for the congruence of scores on the GHQ with scores on the BDI. The tendency for 'normals' to score more frequently as cases on the GHQ rather than the BDI may be due to the fact that their problems are more short lived and infrequent, and do not develop into more major symptoms of depression, which would be picked up by the BDI, and, further, that the GHQ detects a wider range of psychiatric morbidity than the BDI which is only used to detect depression. However, no individual in this study fell into the category of severe depression as measured by the BDI (scores of 31 or more). It might also be noted that the correlations of scores on the GHQ and BDI were high, indicating that the higher the score on one, then the higher the score on the other. This was true for the

'normals' as well as the RA patients. Thus, whilst scores of 'normals' on the BDI did not fall into the area designated as depression the scores were none-the-less elevated above those who did not score on either questionnaire. The consistency of the two questionnaires, in determining non-psychotic psychiatric disturbance was also supported in the Subject Panel study. In this study the BDI and the GHQ were included for self completion. One hundred and sixty questionnaires were returned. 113 subjects (70.63%) were placed by both the BDI and the GHQ as free of depressive symptoms, whilst 25 subjects (15.63%) were classified as 'cases' on both instruments. Overall, therefore, there was agreement on 86.26% of the questionnaires as to who were cases and who were not. Seventeen subjects (10.63%) were classified as cases by the GHQ and yet not by the BDI, and for another 5 subjects (3.13%) the opposite was true. Raw scores on both instruments were also found to have a high correlation (Pearsons' $r=0.78$, $p<0.0001$, $n=160$).

From the data presented here, the two instruments are shown to be highly consistent in determining those likely to be suffering non-psychotic psychiatric disturbance and those not. As one might predict the GHQ identifies more people as cases, partly because of the fairly low cut off point (i.e. any score above 4 is regarded as a case), and partly because of the nature of the items on the two questionnaires. Items on the BDI include statements concerned with suicide, and

permanent changes. The GHQ is less severe in its items. Transient and therefore less severe changes may be picked up by the GHQ which go unchecked by the BDI.

In both studies the correlation between raw scores on both instruments were high. Whilst the BDI indicates *degrees* of psychological ill-health the GHQ is rarely used to do so. However, the GHQ is sometimes used to indicate extent of disturbance. That is, total scores on the GHQ are calculated and the greater the score the greater the psychological ill-health (Goldberg, 1972; Warr and Jackson, 1987). The results of the study reported here, showing a high correlation between scores on the BDI and the GHQ, would support such a use of the GHQ, rather than just using it as a method of arriving at a dichotomous result (disturbance or not). In the main RA/migraine study reported here both measures from the GHQ will be used.

3.4. THE ASSESSMENT OF PAIN

3.4.1. Introduction

The major thrust of this thesis concerns the impact and response of sufferers of chronic illnesses to pain. It is, therefore, important to be able to provide some form of assessment of the pain suffered by an individual. For this purpose, the McGill Pain Questionnaire (MPQ)¹ was administered to all subjects in the study. A copy of the MPQ is reproduced in Appendix Ib.

The MPQ attempts to elicit an account of the nature of pain experienced by sufferers. It differs from most pain assessment tools in that it treats pain as a multidimensional experience and not simply as an experience with varying levels of intensity. Rating scales are the most commonly reported measure in clinical pain research, but certainly do not permit for differentiation of types of pain, (Reading, 1984). In contrast, there are 78 pain descriptor words included in the MPQ gained from a study in which subjects were asked to sort pain descriptor words into piles differentiating aspects of the experience of pain, (Melzack and Torgersen, 1971). Three general classes emerged: Sensory aspects of pain, affective qualities of

1. The McGill Pain Questionnaire is sometimes referred to as the Melzack Pain Questionnaire. These questionnaires differ only in name, the former referring to the University from which the instrument originated, and the latter referring to its principal inventor, Professor Ronald Melzack. There also exists a short form McGill (Melzack) Pain Questionnaire for clinical use when there is insufficient time to administer the longer form, (see Melzack, 1987).

pain, and the evaluative experience of pain. The MPQ yields two main scores. The first of these is a Pain Rating Scale, (PRS), which is the summed rank of the values of all the words chosen in the MPQ, and the second is the Present Pain Intensity Score (PPI) which measures overall intensity of the pain. Scores can also be calculated for the various aspects of the pain experience mentioned above; i.e. Sensory, Affective and Evaluative aspects. The MPQ has been found to be reliable over time, (Graham, et al, 1980; Hunter, et al, 1979), despite arguments that suggest that pain recall is difficult due to the tendency to repress memory for painful events, (Jones, 1957). However, studies of the reliability of pain recall have tended to administer the MPQ to subjects in pain, and then readminister it at a later date with the request to subjects to recall the pain reported at the initial MPQ administration. It is suggested here, however, that individuals may be accurate as pain reporters in general. Thus, pain that is regularly experienced by an individual may be reported consistently on the MPQ, even if the subject is not required to recall a specific instance of the pain.

In the RA/Migraine study the MPQ is administered in order to assess the nature and severity of the pain experienced by sufferers during painful flare ups. However, for the most part patients were not experiencing pain during the interview. The question of reliability of pain recall is

difficult to assess empirically, as pain is a subjective experience (i.e. it is an open question whether individuals are reliable whilst actually in pain). However, it may reasonably be assumed that there is a common language of pain, with general agreement as to what pain descriptor words refer to (i.e. the description 'a 'stabbing' pain in the head' can to some extent be 'understood' by those not experiencing one at the time of hearing this statement, and, indeed, who have never experienced one). Whilst we may tacitly assume that pain description is in some way reliable it is more debatable whether reports of past pain are consistent, and hence reliable. Thus, in the RA/migraine study it is possible that individuals describing their pain did so in a hazy and ad-hoc fashion, and if re-tested would give different responses). Before administering the MPQ to the chronic pain sufferers it was decided to see if responses of a specific pain group (headache sufferers) were consistent, as measured on the MPQ on two separate occasions. The following study attempts to determine whether the McGill Pain Questionnaire can be used to elicit consistent reports of pain (in this case, headache pain). It was hypothesised that individuals could consistently report pain from headaches, even if they had not suffered head-pain in the very recent past.

3.4.2. Study upon the consistency of scores on the McGill Pain Questionnaire over time

The research reported in this section examines the reliability of reports of headache pain in a sample of students. The headaches under study here are those that would not usually be regarded by sufferers as sufficiently worthy of medical treatment. This is partly due to the limited amount of distress caused by the headache, and partly because the cause of the headache is known to the sufferer, i.e. the headaches are known to be caused by certain behaviours the sufferer has engaged in. For example, the headaches reported here are associated with lack of sleep, eye strain, alcohol etc. The purpose of the study is to see if individuals are consistent in their recall of past headaches. In order to assess accuracy of pain recall the McGill Pain Questionnaire (MPQ) was administered, (Melzack, 1975).

Headache suffering is a commonplace phenomena. In a survey in Pontypridd, for example, it was found that nearly 72% of a randomly selected population suffered headaches, and nearly one quarter of the entire sample reported they suffered migraineous headaches (Waters, 1974). Further, it was found that headache suffering decreased with age. Hannay (1978), undertaking research on the extent of illness in the population, found that 20% of a random sample had suffered

headaches in the two weeks before being interviewed. Surveys have shown headache suffering to be extensive amongst University students (Andrasik, et al, 1979, Martin, 1987) although in most instances they do not consult a doctor, (Martin, 1987). It seems that individuals screen themselves, and regard themselves as having an insufficiently grave malady to present.

3.4.3. Method

Thirty six students were approached of whom thirty three (mean age 23.7 years with a sex ratio of 22 males to 11 females) reported experiencing headaches. Those who reported experiencing headaches were asked to complete the MPQ. All of those questioned had suffered at least one headache in the last three months, and the regularity of headache suffering varied from one headache per day to one per month. Headaches were experienced weekly or even more regularly by 37.5% of the sample. All of those questioned reported that the headaches they experienced most frequently were both similar in intensity and in qualitative aspects. Further, they had similar causes. Thus, headache suffering was associated with tiredness, stress, pre-menstrual tension, alcohol etc. The headaches were not seen as in any way indicative of a more sinister complaint.

Subjects were given the 20-subclass MPQ pain descriptor scale and asked to report the nature of the pain experienced

in the most common headaches they suffered. They were also asked to describe any discomfort they were feeling at the time of the MPQ administration. After the administration of the MPQ they were then asked to select randomly ten words from the MPQ and commit them to memory. They were given one minute to commit this randomly selected list to memory, and then to try and recall the words they had chosen. No subject chose the same words as initially selected from the MPQ: generally subjects ticked, and attempted to memorise, the first ten words on the MPQ. One week later subjects were then asked to try and recall the randomly selected list. Then, the MPQ was readministered to the subjects, once again asking them to report the most common pain they experienced as headaches. A very small proportion reported having had such a headache since the last administration of the MPQ. The purpose of the random word selection was twofold. Firstly, it was hypothesised that students may simply recall the words they had chosen in the first MPQ test whilst they were completing the second administration of the MPQ. Thus, any consistencies that may be found would be due to memory recall of words, rather than of pain. However, if subjects could not recall the words on the random list then it is less likely they would remember words chosen on the MPQ. Secondly, it was hypothesised that the requirement to commit to memory randomly selected pain words would interfere with the memory that subjects had for words chosen on the first administration of the MPQ. This is a method of memory

distortion, referred to as retroactive interference (Underwood, 1957).

Values that can be gained from the MPQ are the Pain Rating Intensity (derived from the Pain Rating Scale, (PRS)) calculated from the rank values of the words summed, the Number of Words chosen (NWC), and three values that indicate sensory (PRI (Sensory)), affective (PRI (Affective)) and evaluative (PRI (Evaluative)) aspects of the pain. These latter scores are obtained from the summed rank scores of certain sub groups of the MPQ. Further assessments of pain at its least and at its maximum can be gained. The Present Pain Intensity Scale was not applicable, as subjects in this study were not in pain at the time the MPQ was administered to them.

Subjects who took part in this study reported experiencing headaches, but were not in any discomfort through head pain at the time of the test. This research sought to find whether recall of pain associated with recurrent headaches was accurate, assuming the headaches were similar in profile and extent.

3.4.4. Results

Mean headache intensity at its worst on first administration was 2.85 (S.D. 0.97), and on the second administration a week later was 2.54 (S.D. 0.83), as rated on a 1-5 point

scale. These values are, as might be expected, lower than those reported in studies of cluster and migraine headache (Hunter, 1983). The pain experienced from headache at its mildest was assessed on a similar 5 point scale: subjects mean reports on the two administrations of the MPQ were 1.27 (S.D. 0.45) and 1.36 (S.D. 0.49). This is hardly surprising as subjects are typically reporting no more than the fact that at least their headache pain is 'mild'.

The values were then calculated for the first section of the questionnaire, consisting of the 20 word-lists. The data obtained from this analysis is summarised in Table 3.2.

TABLE 3.2. HERE

The number of words chosen on both administrations was highly consistent, with the mean number chosen on the first application being 8.7 (S.D. 3.55) and on the second, 8.2 (S.D. 2.97). The maximum number of words chosen on the first administration of the MPQ was 16, whilst on the second it was 14. The smallest number selected on both administrations was 2. There was a high degree of consistency in the scores reporting the qualitative dimensions of headache (see table 3.2). Differences were found to be statistically insignificant by means of t-tests. However, subjects did not necessarily choose the same words on both administrations,

	Pain Rating Dimensions				
	PRI	NWC	Sensory	Affective	Evaluative
First Administration					
Mean	18.87	8.73	11.27	2.77	2.00
S.D.	9.95	3.61	6.24	2.56	1.17
Second Administration					
Mean	18.53	8.23	11.30	2.83	1.83
S.D.	10.01	3.01	7.52	1.76	1.05

Table 3.2.

Means and Standard Deviations for results gained from the McGill Pain Questionnaire adjective check lists on two administrations, over the period of a week, to the same Subjects for assessment of headache (n=33).

although the scores gained were consistent. That is, different words may be chosen that have the same score value and are hence similar to those initially chosen. Despite this, however, there was consistency in the words chosen most frequently to describe the pain, with 'Tiring' (Chosen by 51.5% of the sample on the first administration, and 63.6% of the sample on the second administration), 'Nagging' (54.5% and 45.4% respectively), 'Dull' (39.4% and 39.4% respectively) and 'Throbbing' (39.4% and 39.4% respectively) being the most frequently chosen words on both administrations of the MPQ). Only the word 'Annoying' was chosen substantially more times in one administration than the other (48.2% and 24.2% respectively).

The random word recall test adds further support to the claim that words were not simply remembered, as recall on the second test was substantially lower than on the first (7.2 and 1.2 respectively). A paired t-test supported this observation ($t=20.89$, $df=31$, $p<0.001$).

3.4.5. Discussion

The results reported here support the hypothesis that the reporting of pain by subjects is consistent. One particular potential criticism, however, needs to be addressed. Subjects were asked to report on their own headache suffering. Evidence has suggested that individuals are superior at recall of ego based information than other

information (Keenan and Baillet, 1980). It could be argued subjects could *remember* the words themselves that they used to describe their pain on the first administration of the questionnaire, because they had an emotional stake in the description being made of their pain. If this is so then it is hardly surprising individuals remembered the pain descriptors better than the randomly selected list. In other words, individuals at the second administration of the MPQ, simply recalled words that they used to describe their pain at first administration, rather than choosing words that described the memory of headaches they suffered. However, it should be borne in mind that whilst scores on the MPQ were similar on both administrations the choice of words was not identical for the PRI, NWC, and the Evaluative, Sensory and Affective Pain Rating Dimensions. It is possible to gain the same overall scores on these areas of the MPQ by choosing different words. It must be recalled that the test measured *consistency of scores* on the MPQ, and these are taken to indicate the nature of the pain experience, not the choice of words per se. Indeed only one subject made the same choice of words on both administrations, although a small number of words were, as has been noted above, consistently chosen on both occasions.

This study has provided support for use of the MPQ to subjects not in pain at the time of the administration. The data gained was consistent on both applications of the MPQ.

That the larger study upon long chronic pain sufferers, indicates higher score levels is hardly surprising, as the MPQ is an instrument that not only has the function of differentiating type of pain, but also extent of pain experienced with different ailments.

In conclusion, then, it is argued here that people are generally good at recall of past pain. It is not necessary to ask people to recall a specific event of pain, but to ask what their pain is like when they have a given painful complaint (flare-up in RA, migraine attack, or, as here, headache). The MPQ is used in the main body of the research here to gain a profile of what the pain felt in migraine or a flare up is like *typically*.

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3.5. THE ASSESSMENT OF HEALTH STATUS

3.5.1. Introduction

Chronic illness can have major implications for one's life (Bury, 1982; Locker, 1983). A major area of potential importance for mental health is that of health status. Health status refers to the general health of an individual, and in this research health status is measured using a number of criteria, using both conventional medical measures and scores from a subjective health status measure.

3.5.2. The Nottingham Health Profile

A number of instruments exist to assess subjective perceptions of health status, the most notable are the Sickness Impact Profile (SIP) (Bergner, et al 1981), of which the British equivalent is the Functional Limitations Profile (FLP) (Charlton, Patrick and Peach, 1983), and the British Nottingham Health Profile (NHP) (Hunt et al, 1981; Hunt, et al, 1986)². The NHP is, like the SIP and FLP, a subjective health status measure and is the instrument chosen for use in this research³. It provides scores for the

2. A full account of the development of the Nottingham Health Profile is to be found in Hunt et al (1986). A comprehensive section on health status questionnaires, and their uses and applications can be found in McDowell and Newell (1987). The development of the FLP from the SIP is covered in Patrick and Peach (1989). A fully up to date account of the state of health status measures is to be found in Walker and Rosser (1988), and an account of their uses takes up an entire supplemental volume of 'Medical Care', March, 1989.

3. Health status measures such as the SIP/FLP and NHP are used to assess subjective perceptions of health in any illness, and the NHP has been cited as useful for detecting the extent of ill-health in populations (Hunt, McEwen and McKenna, 1986). Some, such as the Arthritis Impact Measurement Scale (AIMS) (Meenan, et al, 1980), are disease specific. Some authors, such as Williams (1990, in press), argue that research in health assessment should address the issue of disease specific measures more seriously than at present. There are, he argues, few disease specific measures, and demands of illnesses vary so dramatically that no single scale could hope to cover all illnesses. The problem here arises of how to compare perceived health status between illnesses when the measures themselves vary.

effect of illness upon various aspects of sufferers' lives: energy, pain, emotional reactions, sleep, social relationships, and physical mobility. There are 38 questions in the questionnaire. There is no indication on the questionnaire that particular questions relate to particular categories. Individuals indicate perceived health status by responding 'yes' or 'no' to the questions. Scores for each of the six topic areas are calculated by summing weighted values given to each positive response. The weights are provided by the designers of the NHP (Hunt, McEwen, and McKenna, 1986), and were derived using Thurstone's method of paired comparisons, (Thurstone, 1927a and 1927b). The NHP was chosen in preference to the SIP/FLP as it is considerably shorter, and hence quicker to administer. This was a major consideration due to the number of questionnaires being administered, and the overall amount of time required to work through all of the questions.

A number of studies have shown the instrument to be reliable (Hunt, McKenna and Williams, 1981; Hunt et al, 1982), as well as to provide valid results of health status, (Hunt et al, 1980; Hunt et al, 1981).

A copy of the NHP is to be found in Appendix Ic.

3.5.3. Medical Measures

A number of medical measures of the disease process were gained in order to provide as universal an assessment of sufferers' state as possible.

In the case of the Rheumatoid Arthritis patients, clinical information was gained in as many cases as possible from the patients' notes, and from the Doctor's assessment. However, records were often incomplete or out of date and information was, therefore, not always available. However, attempts were made to gain ESR (Erythrocyte Sedimentation Rate) scores, Haemoglobin Counts, and information concerning Rheumatoid Factor, from the notes (see Section 2.2. for an explanation of these terms). Medical personnel (Doctors, Nurses and Physiotherapists familiar with the patient) were asked to give an assessment of the severity of rheumatoid arthritis on the 'Steinbrocker', this being the most widely used instrument to indicate the severity of illness in rheumatoid arthritis, and the impact of the disease upon the sufferer's life, (Steinbrocker, Trager and Buttermann, 1949). The Steinbrocker is the classificatory scheme adopted by the American Rheumatology Association, and is scored, quite simply, from 1 to 4. The scores are associated with the following assessments:

- (1) *The patient has complete ability to carry on all duties without handicaps.*
- (2) *The patient's state of health is adequate for normal activities, despite handicap, or discomfort, or limited motion.*

- (3) *The patient is limited only to little or none of the duties of usual occupation or self-care.*
- (4) *The patient is incapacitated, largely or wholly, bedridden or confined to a wheelchair, with little or no self care.*

(ARA Classificatory Schema,
Steinbrocker et al,
1949)

Unfortunately, none of the measures outlined above or, indeed, utilised in clinical practice, provide a definitive record of the extent or severity of rheumatoid arthritis. The Steinbrocker is a simple descriptive instrument, whilst E.S.R. rates and blood counts are measures of underlying disease processes and are acknowledged medically not to be closely associated with patients experience of the problem. For example, rheumatoid factor is present to such an extent in some individuals who develop no other signs of the disease (joint swelling or pain, for example), that they are categorised as Sero-Positive. Alternatively not all rheumatoid arthritics score a sero positive, though by other clinical and medical measures they are regarded as suffering the disease, (see Gilliland and Mannik, 1984).

Migraine sufferers were asked to provide information about the extent of their migraines. A chart, provided routinely by the doctor, was available in most cases. On this chart patients are asked to indicate when they have migraines, and how long they last. Such charts generally cover a three month period. Patients were asked how often they had migraine, and this was checked against the chart. If a discrepancy existed, and it rarely did, patients were asked

why they had had fewer (never more) migraines in the last three months than they thought they had generally. Any variations were accounted for by patients by the use of a new drug, which had reduced the headaches in severity, but which they were uncertain was going to have this effect in the long run. Essentially migraine sufferers were pessimistic about the long term chances of success, mainly because most had had the illness for a considerable length of time, and had had too many disappointments previously. All patients who were interviewed in this study were regarded by the Consultant to have broadly the same severity of migraine.

3.6. MEASUREMENT OF PERCEIVED CONTROL

The concept of locus of control was formulated by Rotter (1966), and is an attempt to formalise the extent to which individuals believe they have personal power to influence the outcomes of their behaviour. An 'external locus' implies a fatalistic approach, whilst an 'internal locus' implies that events can be controlled by personal behaviour. Wallston and Wallston (1976) refined Rotters' notion, and applied it to behaviour directed at health related phenomena, with the Health Locus of Control (HLC) scale. Subsequently, they redeveloped their own scale, and incorporated not two dimensions of powerfulness, but three. The Multidimensional Health Locus of Control (MHLC), (Wallston, Wallston and DeVellis, 1978) was designed to assess beliefs about efficacy and control individual's hold in relation to their health. The MHLC measures an individuals' control, fate, and belief in 'powerful others'. These areas are referred to by Wallston et al as *Internality (IHLC)*, *Chance Externality (CHLC)* and *Powerful Others Externality (PHLC)*. Internality, as measured on the MHLC, refers to where individuals perceive their state of health as dependent upon their own actions and habits. Externality refers to individuals who regard their health as being determined by luck, fate or chance, and, belief in powerful others refers to where individuals regard their health as determined and controlled by persons able to exert power over their health (e.g. doctors, family, friends etc). The

MHLC is comprised of eighteen statements, each followed by a six point Likert-type format response set varying from *Strongly Disagree* to *Strongly Agree*. Six statements each refer to the three areas of internality, fate and powerful others. The three areas are not dealt with in order, but are mixed together within the questionnaire. A copy of the questionnaire is to be found in Appendix Ic. The questionnaire gives three separate scores, unlike Rotter's (1966) Locus of Control Scale which places respondents on a continuum from 'internality' to 'externality'. Instead, the MHLC, as the name suggests, treats locus of control as a multidimensional concept, with aspects of the locus of control construct being measured separately:

The questionnaire is essentially designed for paper and pencil completion, but for the reasons outlined in Section 3.2.3., it was decided to administer the questionnaire verbally. Respondents were handed a copy of the questionnaire to read in conjunction with the researcher speaking the statements aloud. Thus, the alternative responses were always in front of the respondent. A copy of the MHLC is to be found in Appendix Id.

3.7. THE ASSESSMENT OF PAIN COPING STRATEGIES

3.7.1. Introduction

A questionnaire designed for this research was administered. Questions relating to coping strategies adopted whilst in pain requested responses in terms of the frequency certain behaviours were undertaken, and were completed on seven point Likert type scales, with responses ranging from 'Never' to 'Always'. A copy of the questionnaire is reproduced in Appendix 1e. As with all the other questionnaires used in this research this instrument was administered verbally with patients provided with a copy to follow, so that the alternative responses were constantly in their mind.

3.7.2. Choice of Items for the Coping Questionnaire

Section six contains questions relating to the coping strategies adopted by individuals when in severe pain. This section of the questionnaire consisted of questions relating to the strategies adopted, both active and passive, as well as information concerning long term planning and attitudes. Some of the items were similar to those used by Brown and Nicassio (1987). They adopted the definition of coping as 'specific thought and behaviours people use to manage their pain or their emotional reactions to pain', and this definition also guided the choice of items chosen for this research. Once again, responses to the 'coping items' were given on a seven point scale. Patients rated the frequency that particular

strategies were used when their pain reached severe levels of intensity, such as during a 'flareup'.

Two preliminary studies were undertaken to ensure the questionnaire was easily understood by respondents, and hence not ambiguous or unintelligible. The questionnaire was piloted on eight in-patient rheumoid arthritics at the beginning of the project. After this initial application of the questionnaire a number of items were added to the schedule, and other questions were rephrased. The questionnaire was then administered to another fourteen in-patients. This was a follow up study where the questionnaire was administered on two occasions, while the subject was in hospital. The second interview took place exactly one week after the first. This made it possible for the consistency of items on the questionnaire to be assessed. Consistency of items was shown to be fairly high on test retest. Pearson Product Moment Correlation Coefficients and paired t-tests were calculated for all items. Approximately .76% of the items measured on the seven point Likert type scales gave significantly high correlations ($r > 0.50$, $p < 0.05$). The consistency of the questionnaires was further supported by paired t-tests, where it was found it was not possible to reject the null hypothesis at the 5% level on approximately 96% of the items. On this small pilot study, therefore, the consistency of responses to items over a short period of time was found to be high.

3.8. OTHER VARIABLES COLLECTED FOR THIS RESEARCH

The questionnaire designed to assess coping strategies had included within it a number of other sections seeking information concerning social and psychological factors. The first section contains questions relating to demographic variables. The second section consists of items concerning the length individuals had suffered from their illness, and whether or not they had been an in-patient in the last year, and if so, for what reason, and also whether alternative methods of cure had been sought at *any* time. The third section consists of items pertaining to how individuals explain their having the illness. There is mounting evidence that people's attributions for serious illness and other major threatening life events are often associated with emotional well being, health related behaviours and their belief in their ability to control the problem (Affleck, et al, 1987, Loewry, Jacobsen and Murphy, 1983). Attributions for the cause of the illness are sought in this study, in an attempt to find whether such attributions are associated with perceptions of helplessness (as measured on the Health Locus of Control), and mental health. Section four of the questionnaire deals with perceptions of social support. Social support is an important aspect in adaptation to

chronic illness, and has been posited as a factor that can prove instrumental in retaining good mental health (Fitzpatrick et al, 1988b) Section five contains a measure of pain at the time of the interview. Patients were asked to mark the line to indicate the extent of pain they were currently in. Section five also contains questions covering the effects the illness has had upon the sufferer's life. On seven point Likert type scales (with responses ranging from 'Never' to 'Always') patients were asked how often the illness had affected aspects of their life (e.g. problems with relationships, the effect of illness upon hobbies etc.). The section is split into two parts, the second of which relates specifically to the impact that pain has had upon the respondent: answers to the questions were once again made on seven point scales with responses ranging from 'Never' to 'Always'. A few questions were asked about the impact of stiffness on sufferers' lives, as this can be a major aspect of RA.

CHAPTER 4

COMPOSITION OF THE SAMPLES WITH REFERENCE TO MENTAL HEALTH AND MEDICAL MEASURES OF HEALTH STATE

4.1. INTRODUCTION

This section provides an outline of the samples in terms of demographic details in relation to mental health scores. It provides data from both the study of the chronic pain patients, and from the survey of Subject Panel respondents. The Subject Panel respondents did not complete all the questionnaires completed by the ill patients in this study for two reasons. Firstly, every attempt was made to keep the postal questionnaire as short as possible, whilst still providing information on central themes in this research (health status, locus of control etc), and secondly, not all questionnaires were relevant to the Subject Panel respondents (questions related to coping with chronic pain are not relevant to most of the subject panel respondents). Therefore the data gained from one sample is not always available for the other group.

4.2. DEMOGRAPHIC COMPOSITION OF THE SAMPLES

4.2.1. Introduction

This section provides information concerning the demographic compositions of the two samples (i.e. the sample of chronically ill individuals, and the Subject Panel respondents), and the two sub-samples (migraine and RA) which comprise the chronically ill group.

4.1.2. Age and length of illness

The sample of chronically ill patients consisted of two groups, one of which had two sub-samples. In total, 160 chronically ill individuals were interviewed (mean age=51 years, S.D. 13.55). The minimum age was 21 years and the maximum was 83. The sample of migraine sufferers came from the Out-Patients Neurology clinic at the Radcliffe Infirmary, Oxford, between the 16th February 1987 and the 21st March 1988. All of the subjects were women, and had been diagnosed by the consultant at the Radcliffe Infirmary as suffering migraine. Ninety seven patients were asked if they would take part, of which 80 (82.47% of those approached) agreed to do so (mean age=44 years, S.D. 11.03, minimum age=21 years, maximum age=79 years). Eighty was the target number of respondents. Those who refused to take part usually said they could not because they had transport to catch, or meetings to attend. The mean length of illness for migraine sufferers was 18.85 years (S.D. 12.13), with length of illness varying from 1 year to 66 years.

The sample of RA sufferers were recruited from both an in-patient ward at the Nuffield Orthopaedic Centre in Headington, Oxford, and from an out-patient clinic at the same hospital. Both the clinic and the ward were overseen by the same consultant. The sample consisted of eighty women with an age range from 21 to 83 years (mean age=58 years, S.D. 11.19),, forty of whom attended the out-patients clinic, (with an age range from 21 to 71 years, mean age=56 years, S.D. 11.10) and forty who were inpatients (age range from 37 to 83 years, mean age=60 years, S.D. 11.14). Length of illness of the RA sample varied considerably, from 1 year to 49 years (mean=14.95, S.D. 10.52). The inpatient sample had a mean length of illness of 14.18 years (S.D. 8.69), and the outpatient sample a mean of 15.73 years (S.D. 12.14). Both samples were deliberately composed of women alone. The interviews of in-patients were undertaken between the 12th January 1987 and 3rd of August 1987, whilst out-patients were interviewed between the 31st July 1987 and the 25 March 1988. No person interviewed as an in-patient was interviewed as an out-patient or vice versa. Forty four in-patients were asked if they would take part, of which four (9.09%) declined to do so. Three gave no reason for declining, whilst one said she was very tired and would be happy to do it at another date. Forty out-patients were asked if they would take part, and all of them agreed to do so.

4.2.3. Qualifications and social class

Overall, 91 (56.6%) of the entire sample had no formal qualifications, or at most a few CSE's or equivalent. Of those suffering arthritis 62 (78.8%) had no formal qualifications or a few CSE's or equivalent, whilst of the migraine sufferers the proportion in this group was 41.3% (n=33). The difference in educational qualifications held between the two groups was found to be significant, the migraine sufferers having significantly more qualifications ($\chi^2=37.42$, $df=7$, $p<0.001$). Likewise, migraine sufferers reported having stayed within formal education for a longer period of time than the RA sufferers (mean age of migraine sufferers leaving education=16.28 years S.D. 1.35; mean age of RA sufferers leaving education=15.10 years, S.D. 1.44; $t=5.33$, $df=158$, $p<0.0001$).

There has been considerable debate as to the most appropriate method of assessing social class. It has been suggested that the most commonly used measure (that of the Registrar General) contains classes that are not homogeneous and which allocate some individuals into classes which neither reflect their status, nor economic rewards (Bland, 1979). Other attempts to measure social class such as the Hope-Goldthorpe scale (Goldthorpe and Hope, 1974) used in the Oxford Mobility Study (see Goldthorpe, 1980, 1987), and the Bedford measure used in the early Bedford College studies of depression (see

Brown and Harris, 1978) have also met with criticism (Bland, 1979). It was decided that the most simple method of grading social class would be that of the Registrar General. For most of the respondents to both surveys married womens' class was calculated by husbands' employment. The 1980 version of the Registrar General's Classification of Occupations does include jobs generally taken by women, which previously had not been the case, and this enabled class position to be calculated for unmarried women, who were not living with their parents. Widowed respondents who had not remarried were assessed for social class position by the last occupation held by the respondent's husband when alive. Those who were remarried (either due to death of previous husband or divorce) were assessed for social class position by their present husband's occupation. In cases where women were living with parents, the father's job, or last job if retired at the time of the survey, was used as an index of class. Respondents' social class position was not determined solely by their own employment because many claimed to be 'housewives', and such a title conceals major differences in household income between those whose husbands are classified into the professional category, and those classified lower down the social class scale. Further, the growth in womens' employment in part-time work, and also the increase of womens' presence in certain sectors of the occupation sector means that a

woman's occupation per se is not always a clear indication of social class (Barron and Norris, 1976)¹.

The social class distribution, (according to the Registrar General's Classification of Occupations, 1980), of the R.A. and migraine samples is shown in table 4.1. There was a significant difference in the social class composition of the two illness groups, the migraine sample having on average a considerably higher social class position than the RA patients. A higher than expected proportion of patients of background was noted in a previous study of referrals to neurologists for headache in South East England (Fitzpatrick and Hopkins, 1981).

TABLE 4.1. HERE

Education and class position were only moderately associated. For the sample as a whole qualifications and social class were significantly correlated ($r=0.23$, $n=160$, $p<0.01$), as they were for RA sufferers also ($r=0.23$, $n=80$, $p<0.05$). However, the correlation of qualifications and class was not significant for migraine sufferers ($r=0.17$, $n=80$, N.S.). The age at which individuals left formal education was found to be

1. The marital status of the patients in the study was as follows. RA patients; 5 (6.3%) single, 55 (68.8%) married, 6 (7.5%) divorced, 14 (17.5%) widowed. No RA patients were cohabiting or separated. Migraine patients; 12 (15%) single, 62 (77.5%) married, 3 (3.8%) divorced, 3 (3.8%) widowed. No migraine patients were cohabiting or separated.

Social Class	Overall	RA	Migraine
	n (%)	n (%)	n (%)
1	27 (16.9)	7 (8.8)	20 (25.0)
2	54 (33.8)	28 (35.0)	26 (32.5)
3 <i>Non- Manual</i>	17 (10.6)	10 (12.5)	7 (8.8)
3 <i>Manual</i>	51 (31.9)	27 (33.8)	24 (30.0)
4	8 (5.0)	7 (8.8)	1 (1.3)
5	3 (1.9)	1 (1.3)	2 (2.5)

Table 4.1.
Distribution of chronic pain sufferers overall and by illness,
by social class, as defined by the Registrar General (1980).

associated with occupational class for the sample as a whole ($r=0.23$, $n=160$, $p<0.001$), and for migraine sufferers ($r=0.36$, $n=80$, $p<0.001$), but not for rheumatoid arthritics ($r=0.20$, $n=80$, N.S.).

The sample of 'non-chronically ill' subjects was chosen from the University of Oxford Department of Experimental Psychology Subject Panel. This is a panel of people living in the Oxford area who have agreed to take part, for a small fee, in studies for the Department. They are not, therefore, a strictly random sample. One hundred and seventy one questionnaires were sent to Subject Panel members of which 164 (95.91%) were returned. One of these was returned unmarked, whilst the other three arrived after the target of 160 had been reached and were not included in the sample for analysis. All those approached for this survey were women. The age range of the 160 Subject Panel women included in the data set for analysis was from 18 to 80 years, with a mean of 47 years, S.D. 12.52. Respondents to this postal survey were not requested to give information concerning qualifications, but questions were included concerning occupation. Table 4.2. summarises this data. As can be seen the social class distribution is skewed to the upper classes, with over 60% coming from social classes 1 and 2.

TABLE 4.2. HERE

Social Class	n	%
unknown*	1	.
1	49	30.8
2	49	30.8
3 <i>non-manual</i>	35	22.0
3 <i>manual</i>	14	8.8
4	12	7.5
5	0	0

* *respondent did not complete relevant question*

Table 4.2.

Distribution of Subject Panel respondents by social class, as defined by the Registrar General (1980).

Due to the fact that the social class composition of the Subject Panel is skewed to the upper classes it cannot be viewed as a typical random sample of the population, although it is worth bearing in mind that evidence for social class association with psychological ill health is inconclusive (Marks et al, 1979).

4.3. HEALTH MEASURES

4.3.1. Introduction

Clinical measures of health state were obtained from the migraine sufferers and a sub-sample of the Rheumatoid Arthritis sufferers, and some laboratory measures were also gained for a sub-sample of the RA sufferers.

4.3.2. Rheumatoid Arthritis

Section 3.5. provides information concerning the measures taken. Information concerning clinical and laboratory measures was not obtained on all RA patients partly due to incomplete or unavailable notes, and partly because some measures had not been taken for some time, and were possibly out-of-date. The fact that measures were often out of date may be a reflection that such measures are viewed as only the broadest guide to health state in RA, and not an accurate indicator of the disease process. Steinbrocker measures were taken when the consultant was available to give his assessment. Of the 44 individuals whose notes were suitable, 26 (59.1%) were sero-positive. Scores on the Steinbrocker (n=49) are outlined in the table below:

Steinbrocker Category	n	%
Category 1	2	4.1
Category 2	26	53.1
Category 3	19	38.8
Category 4	2	4.1

(The meanings of the Categories on the Steinbrocker are explained in Chapter 3 of this thesis. Category 1 indicates little functional impairment due to the disease, whilst 4 indicates considerable impairment)

The mean haemoglobin count was 11.98 (S.D. 1.49, n=44), and the mean ESR count was 42.85 (S.D. 26.82).

4.3.3. Migraine

Information was obtained from patients concerning the length and frequency of the attacks. All patients were asked by the consultant to indicate on a chart when they had attacks, and for how long they lasted. These charts covered a three month period, and were used as the basis for gaining information on frequency and duration. Table 4.3. summarises this information.

TABLE 4.3.

Frequency	Length of migraine attack				Total
	1-2 hours	half a day	A day	A Few days	
Less than one per month	0	3 (3.75%)	5 (6.25%)	13 (16.25%)	21 (26.25%)
Once per month or more	1 (1.25%)	1 (1.25%)	8 (10.0%)	14 (17.5%)	24 (30.0%)
Once per week or more	3 (3.75%)	6 (7.5%)	15 (18.75%)	11 (13.75%)	35 (43.75%)
TOTAL	4 (5.0%)	10 (12.5%)	28 (35.0%)	38 (47.5%)	80 (100%)

Table 4.3.

Frequency of migraine attack cross tabulated against length of attack.

4.4. MENTAL HEALTH ASSESSMENTS

4.4.1. Extent of Non-Psychotic Psychiatric Disturbance in the Samples

This section documents the extent of non-psychotic psychiatric disturbance in the samples of Rheumatoid Arthritics (RA) and migraine sufferers, as well as in the Subject Panel respondents. The General Health Questionnaire (G.H.Q.) was administered to all subjects in the study. The method of scoring adopted was that suggested by Goldberg (1972). It was scored from 0-30, with any score over 4 being taken to indicate disturbance, (see section 3.3. for a discussion of the G.H.Q. and method of scoring).

4.4.2. G.H.Q. Scores for Chronically Ill Subjects

In the study of chronically ill patients, 89 (55.6%) of the 160 respondents scored as a 'case' on the G.H.Q. (i.e. they had a score of over 20% positives). The mean raw score on the G.H.Q. overall was 7.98 (S.D. 6.18), though the mean G.H.Q. raw score for those who were found to be 'cases' on the G.H.Q. was 12.33 (S.D. 4.88), and for those categorised as not 'cases' the mean was 2.54 (S.D. 1.66, n=71).

Breaking the data down into the sub-samples revealed 56 of RA sufferers scored as 'cases' (70%), of which 30 were in-patients and 26 were outpatients. That is, 75% of in-patients, and 65% of out-patients, scored as 'cases'.

Thirty three (41.3%) migraine sufferers scored as 'cases' on the G.H.Q. Table 4.4. summarises the data of raw G.H.Q. scores. A χ^2 test revealed the differences in numbers of cases between the migraine and RA groups to be significant ($\chi^2=13.40$, $df=1$, $p<0.01$), with RA patients scoring more frequently as 'cases'.

TABLE 4.4. HERE

Age, length of illness, years of schooling, formal qualifications and social class were not found to correlate significantly with GHQ scores, or with NHP scores for emotional reactions. Age and length of illness were entered into a regression using GHQ raw scores as the dependent variable. The resulting R^2 was low ($R^2=0.026$). Clinical measures of disease activity, and frequency and length of migraine were not significantly associated with GHQ scores and 'caseness'.

4.4.3. G.H.Q. Scores for Subject Panel Study

One hundred and sixty questionnaires were included for analysis in the Subject Panel study. Forty two (26.3%) of the sample scored on the G.H.Q.² The mean score was 3.93 (S.D. 5.96). The mean raw score of those classified as

2. This score is in keeping with that of Goldberg et al (1974), who, using the GHQ, found that 23.3% of women in a sample drawn from the general population of South Manchester, scored as 'cases'.

Subjects	n	Mean	S.D.
G.H.Q. Cases			
RA In-patients	30	12.80	5.07
RA Out-patients	26	11.88	4.13
Migraine	33	12.24	5.32
G.H.Q. Non-Cases			
RA In-patients	10	2.30	1.57
RA Out-patients	14	2.71	2.01
Migraine	47	2.53	1.59

Table 4.4.
Mean raw G.H.Q. scores by 'cases' and 'non-cases' and
Illness Group, (Total n=160).

'cases' was 12.48 (S.D. 5.61, n=42) and for 'non-cases' it was 0.89 (S.D. 1.31, n=118).

4.4.4. Comparison of raw G.H.Q. scores between Samples and Sub-Samples.

Comparisons were made between raw scores on the G.H.Q. gained from the different samples. A significant difference was found between scores on the G.H.Q. gained from the Subject Panel respondents and the chronically ill subjects ($t=48.53$, $df=318$, $p<0.001$, one tailed test). The mental health of the chronically ill was measured as 'worse' than that of the subject panel. The difference between raw scores on the G.H.Q. was also significantly different for the R.A. and migraine sufferers ($t=15.19$, $df=158$, $p<0.001$, one tailed test), G.H.Q. scores being higher for R.A. patients than for those suffering chronic migraine. Differences between the in and out patient samples of the R.A. sufferers were also found to be significant, ($t=3.25$, $df=78$, $p<0.001$, one tailed test), in-patients scoring higher on the GHQ than outpatients. The difference was not as great as that between migraine and RA patients. The difference between the RA in and out patients may be explicable in terms of their state of illness being worse (in-patient RA sufferers had often been brought into hospital because they were so ill), or alternatively, even more salient for mental health, the experience of being an in-patient may have been sufficiently distressing in itself.

4.5. DISCUSSION

The data presented here confirms the results of other studies indicating elevated mental health scores for RA sufferers, (Anderson et al, 1985; Zaphiropoulos and Burry, 1974; Rimon, 1969), and headache patients, (Cox and Thomas, 1980; Ziegler et al, 1978). Demographic variables and medical measures of health state were not found to be significantly associated with mental health scores. The remaining chapters of this thesis will examine some of the possible factors that may, in both illnesses, be associated with psychological distress.

CHAPTER 5

ANALYSIS OF COPING STRATEGIES AND ASSOCIATED BEHAVIOURS AND THEIR ASSOCIATION WITH MENTAL HEALTH

5.1. COPING STRATEGIES

5.1.1. Introduction

Research has suggested that individuals who experience long term chronic pain attempt to develop ways of reducing or tolerating the pain, (Copp, 1974; Tan, 1982). Such efforts made by patients to deal with the pain of their illness are called coping strategies, (Rosenstiel and Keefe, 1983). There is evidence to suggest that the coping strategies that individuals adopt may be important in determining how they adapt to the demands made of them by the chronic pain of their illness, (Brown and Nicassio, 1987; Rosenstiel and Keefe, 1983).

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This section documents and analyses the reported strategies of sufferers of chronic painful illnesses to adjust to the demands of the pain of their illness. This section, therefore, is an analysis of the reported methods of coping the sufferers in this study said they adopted.

5.1.2. Issues of Definition

Coping is a term that has been subject to a variety of interpretations, although perhaps the most famous treatment of this issue is that undertaken by Lazarus and his colleagues. For Lazarus and his colleagues the central theme in their definition is that of 'effort'. That is, coping is seen as '...efforts, both action orientated and intrapsychic to manage, (that is master, tolerate, reduce, minimise) environmental and internal demands, and conflicts among them, which tax or exceed a person's resources' (Lazarus and Launier, 1978). Coping is seen as the process of managing demands, be they external to the individual, or internal, that are perceived and appraised by the individual as taxing or exceeding the available resources of that person, (Lazarus and Folkman, 1984). As Ray, Lindop and Gibson (1982) remark, coping is '... action directed at the resolution or mitigation of a problematic situation.' Coping is not seen as an outcome of efforts manifested to deal with a situation, but is the very process of dealing with the demands¹.

It is assumed by Lazarus and his colleagues that action taken in coping is purposeful. Coping is viewed as a series of transactions between individuals, who have at their

1. This differs from the view adopted by other researchers of coping in which it is seen as 'successful adjustment' to the demands of the illness (Haan, 1977). In the definition offered by Lazarus, adjustment is seen as the successful outcome of the coping process. The difference may seem to simply lie in semantics. However, how it is that one successfully adjusts (or in Haans' terms 'copes') with illness is an area of considerable debate.

disposal various commitments, resources, attitudes, etc., and the environment in which they find themselves. This environment may simply be a mundane day to day life without any obvious threat, or it may be characterised by great pain, discomfort and worry due to the demands of an illness from which they may be suffering. Thus, the environment individuals find themselves in makes demands upon peoples personal resources, (Lazarus and Launier, 1978). The environment is constantly changing and the coping strategies adopted develop and change over time. Thus, coping is seen as an active and dynamic process.

Individuals, argue Lazarus and his colleagues, focus their 'coping effort' at two possible outcomes; emotional and practical, (Cohen and Lazarus, 1979; Folkman, Schaefer and Lazarus, 1979; Folkman and Lazarus, 1984). Thus coping efforts are aimed at reducing emotional harm, and attempting to ensure practical needs are met. In emotion-focussed coping (the 'palliative function'), actions are taken to assess and control the emotional impact of the stress. An example of such a strategy would be denying, or in some other way, redefining the problem or the significance of the problem. On the other hand, problem-focussed coping (the 'instrumental function') refers to actions aimed at dealing with some of the practical problems of the stress. Examples of problem-solving coping behaviour would be seeking professional expert medical advice for an illness or, if one suffers from a painful disorder, taking medication to reduce the pain. Obviously

these two different types of coping are not mutually exclusive. It is perfectly possible to attempt to minimise the seriousness of one's disorder, and take medication in order to relieve pain.

Coping effort argue Lazarus and his colleagues can be aimed at either emotional or practical problems. There are many different actions that individuals may adopt in order to cope, and these are referred to as 'Coping Strategies' (Cohen and Lazarus, 1979; Lazarus and Folkman, 1984), and a number of attempts have been made to systematise the possible coping strategies an individual might employ. Cohen and Lazarus, (1979), suggest five broad groups which categorise, roughly, all possible coping behaviours. These are information seeking, direct action, inhibition of action, intrapsychic efforts and turning to others.

I. Information seeking involves gathering information that relates to the stressful event. In the case of a patient with rheumatoid arthritis, (RA), for example, this may take the form of asking the nature of the disease, the form it takes and how it may change, possible actions that may prevent pain or discomfort etc. Information so gathered may be utilized for either or both emotion regulation and problem solving. The RA patient may seek knowledge in an attempt to reduce anxiety, or to guide action.

II. Direct action is, as the name suggests, a problem solving activity. For example, taking medication in the hope of reducing pain mobility.

III. Alternatively, inhibition of action may also be a coping strategy. RA patients may not take medication as they may be fearful of the consequences (e.g. they may fear that taking drugs may have adverse side effects).

IV. Intrapsychic efforts are processes such as denial where an individual may attempt to intellectualise the problem, or deny its existence. This emotion based coping may occur in cases where, for example, an RA patient denies the existence of pain in the joints. This strategy may be adopted if there is nothing that doctors feel they can do for the patient (due to age, or drug allergies, or in cases of terminal illness). Such a strategy may be inappropriate in cases where individuals ignore stressors that are indicative of underlying problems. It may be possible to treat a disease at an early stage but continued denial of symptoms, and hence unwillingness to present, may mean the illness becomes too far advanced for a practitioner to deal with if the sufferer presents at a later date, or is brought in after the symptoms have got such that they are impossible to ignore.

V. Turning to others for help and support is the final category in Lazarus' schema. This involves mobilising a social support network. This may include family and friends, as well as medical personnel. There is a considerable body of research that indicates that social support can enhance the likelihood of successful adjustment, (Frankel and Turner, 1983; Ben-Sira, 1984).

Alternative categorisations have been put forward such as that offered by Ray, Lindop and Gibson, (1982) in which the coping strategies of women with breast cancer were examined. Categories of Rejection, Control, Resignation, Minimisation, Avoidance and Dependency were documented. Broadly speaking the strategies documented were similar to those outlined by Lazarus and his co-workers, with the exception of Rejection, which seems from the definition offered by Ray et al. to be more a pessimistic acknowledgement of the futility of any action (and consequent depression and bitterness), than a coping strategy. Likewise, Rosenstiel and Keefe (1984) in their study of the coping strategies of patients with low back pain include items on 'catastrophizing', helplessness and lack of control as coping behaviour. Indeed, they note that those high on these items were more depressed and more impaired than those who did not. In the context of the research undertaken for this thesis such behaviour would be seen as a measure of outcome, and not a 'coping strategy'. Adopting the categorisation offered by Lazarus, behaviour leading to depression, bitterness, or catastrophizing, is regarded as an indication of unsuccessful adjustment. Coping strategy categorisations such as those offered by Ray, Lindop and Gibson (1982), and Rosenstiel and Keefe (1984) further differ from that of Lazarus (outlined above) in that coping behaviour is not restricted to deliberate action, a theme that is central to the definition given by Lazarus. In the definitions of coping offered by researchers such as Rosenstiel and Keefe (1983) it is

possible for individuals to engage involuntarily in coping behaviour that is unsuccessful. This thesis draws a more distinct line between outcome measures and coping behaviours. Behaviour that is consciously engaged in and aimed at the pain of the illness is regarded here as coping behaviour. It is further suggested here that the distinction made by Lazarus et al, that coping effort can be either emotion or problem directed is an unnecessary distinction. Whether an action is aimed at emotional or practical problems is less relevant for the purposes of outcome measurement. The success of any coping behaviour is dictated by whether it is associated with good psychological adjustment. Thus, problem based coping may be influential upon mental health, just as much as coping directed directly at emotional demands. The practical decision to take medication, aimed at the problem of pain, may reduce pain, and thereby influence psychological state. For the purposes of this thesis the success of any coping strategy is determined by its association with 'caseness' and raw score on the General Health Questionnaire, (Goldberg, 1972, outlined in Chapter 3, Section 3).

5.1.3. Research on Coping Strategies²

Coping strategies require the individual to acknowledge the problem and adopt a strategy to deal with it. There is evidence to suggest that no one strategy is good for all occasions, (Menaghan, 1982), and coping research attempts to uncover which strategies are the most successful for particular occasions. For example, seeking information is a possible strategy for coping with illness. Information may be used for psychological support, (e.g. to subdue fears), or may be used for practical purposes (e.g. to reduce pain by following medical advice). Andreassen, Noyes and Hartford, (1972) noted how active information seeking aided patients with severe burns, and helped them to cope with the demands of the illness. Felton, et al, (1984), in a longitudinal study of 170 patients with one of four different chronic diseases (Rheumatoid Arthritis, Diabetes Mellitus, Cancer, Hypertension) found that the success of coping was not related to illness diagnosis, but rather it was related to the coping strategy adopted by patients. That is, cognitive strategies, such as information seeking, were associated with successful coping, whilst emotional strategies, such as avoidance, blame, or emotional 'ventilation', were associated with unsuccessful coping. Of course, it is perfectly possible for individuals to adopt more than one strategy for any one stressor. However, there is a tendency for emotion-focussed coping strategies to be

2. It is worth noting that not all coping research is concerned with finding which strategies are the most successful (or unsuccessful) for adaptation to the illness; see for example Viney and Westbrook, 1981, 1982.

directed at health related stressors, and problem focussed strategies to be aimed at work situations, (Folkman and Lazarus, 1980). This may be taken as indicative that individuals feel they can exercise personal power over work related phenomena, but feel less powerful in their efficacy when it comes to illness³.

5.1.4. Coping and Chronic Pain

Whilst a number of studies have addressed the issue of coping and chronic illness there has been something of a paucity of research that has focussed upon coping with chronic pain in particular. This seems something of an omission in coping research when there is evidence to suggest that pain is one of the major concerns of patients in illness (Melzack, 1973). In the two illnesses studied here there is evidence to suggest that pain and depression are strongly associated, (Cox and Thomas, 1981; Ziegler et al, 1978). Available evidence suggests that the use of coping strategies, as part of cognitive-behavioural interventions, can be helpful in reducing pain reports and reducing psychological distress (Brown and Nicassio, 1987). Brown and Nicassio (1987) suggest that the grouping of coping strategies into as many categories as researchers such as Lazarus is unnecessarily, and that coping is either action based or passive. They hypothesise that action based strategies are the most influential in terms of good

3. This perhaps has to do with the tendency of individuals to see illness as somehow an unnatural state of affairs caused by events beyond their control, (Herzlich, 1973).

psychological adjustment. Indeed they refer to active strategies as 'adaptive'. They suggest that '...patients...use active or adaptive pain coping strategies when attempting to control their pain or to function in spite of the pain. Alternatively, patients may use passive or maladaptive pain coping strategies when relinquishing control of their pain to others, or when allowing other areas of their lives to be adversely affected by pain'. However, they do suggest that passive strategies may be more useful for acute flare-ups of illness. They remark that the coping questionnaire used in their research⁴,

'...is designed to assess the methods that patients use to cope with pain of a chronic nature. While our study did not distinguish between chronic pain and the acute, intense and unpredictable pain characteristic of an RA flare-up, it is possible that passive coping methods may be more adaptive for flare ups than for chronic pain. It is standard rheumatology practice, for example, to prescribe rest and to have patients restrict physical activity and use of affected joints when they flare.' (Brown and Nicassio, 1987, p61)

The purpose of this chapter is to explore the relationship between pain coping strategies and pain reports and mental health. It is hoped to discover whether specific coping strategies exist that are adaptive to the experience of long term pain suffering.

4. They termed their questionnaire the Vanderbilt Pain Management Inventory.

5.2. HYPOTHESES

This section provides analysis of empirical data from the chronically ill patients interviewed for this study. The specific 'coping questions' in the questionnaire designed for this research are to be found in Section 6 of the 'Coping with Pain Questionnaire', (see also Table 5.1.). Choice of items was guided by the work of Brown and Nicassio (1987). However the coping questionnaire used by these researchers was regarded as too long to administer amongst the large number of questionnaires that were to be used in this study, and so the questionnaire used here contained fewer items.

This thesis has argued that pain is one of the most salient dimensions of illness. In this study patients are asked how they cope with episodes of pain (RA flare-ups or migraine attacks) of the diseases, and what anticipatory strategies they adopt in order to cope with the demands of the illness. It has been argued that anticipatory coping strategies can be adopted by individuals in an attempt to deal with stressful events they are aware await them in the future, (Lazarus, 1975; Lazarus and Launier, 1978).

It was hypothesised that coping strategies to deal with pain during a flare-up of RA or a migraine attack may exist. That is, there may be specific coping strategies adopted by individuals in order to focus their attention away from the pain, or to reduce it. It was realised that not all coping strategies that may be available to migraine

patients may be available to RA patients. For example, an RA patient may not be able to go for a walk to take their mind off the pain due to deformation, but this is not the case with migraine. Hence it was decided to exclude potentially illness specific strategies, and include instead some questions of a slightly more general nature (ie do you engage in an activity you enjoy when you have a flare up). Such a statement seems to indicate active strategies aimed at ignoring the pain, without falling into the trap of being illness specific.

In this thesis acute and longer term anticipatory strategies are analysed separately. Lazarus and his colleagues (see Section 5.1. of this thesis) have regularly suggested that coping is a changing and dynamic process, that is influenced by numerous factors. Certainly in the illnesses studied here there are periods when patients suffer immense pain and discomfort, and long periods of inactivity. It is hypothesised that coping behaviours may be undertaken during remission from pain, that anticipate further attacks of migraine or flare-ups of RA. Little work in the coping literature has been aimed at this issue, and research undertaken in the area of coping with chronic pain has ignored the issue altogether. Brown and Nicassio (1987) do suggest the possibility that active strategies may be undertaken during remissions of pain flare ups in RA, and more passive strategies may be taken during flare-ups. It was therefore decided to ask patients about both coping strategies during a flare-up of RA or a migraine attack,

and specifically undertaken during remission from pain. Thus, anticipatory action orientated coping strategies, such as storing food and domestic goods for times when one is in pain, may result in less distress on the part of the sufferer, partially because they are manifesting some control over the demands of their illness, and partially because such preparations may make a flare-up or attack less distressing. The demands of a painful flare-up would seem to be greater when individuals are poorly prepared. During a flare-up, however, patients may undertake more passive strategies so as not to exacerbate the pain. RA patients may attempt to keep still so as not to move painful swollen joints and migraine patients may attempt to keep away from stimuli such as bright lights that may aggravate the attack. The possibility of action based strategies of an anticipatory nature being undertaken whilst in remission, and more passive strategies during painful episodes will be explored in this section.

5.3. METHODS AND MATERIALS

Coping questions were all measured on a seven point scale. There were 23 coping questions in total on the questionnaire (from question 6e to question 7a). Question 6b (concerning whether sufferers took medication prior to a flare up) may be regarded as constituting a coping item, but was not answered by all participants (because they did not know when a flare up was about to occur), and so was omitted from the analysis. The coping items included for analysis are listed in table 5.1. An outline of the

administration of the questionnaire is to be found in Chapter 3. A copy of the questionnaire is to be found in Appendix 1e (the coping questions are to be found in Section 6 of the questionnaire).

5.4. ANALYSIS OF COPING QUESTIONS

5.4.1. Basic Statistics

Basic statistics were computed for the coping items for all chronically ill subjects (RA and migraine) (see Table 5.1.(I)), and for RA and migraine sufferers as distinct groups (see Table 5.1. (II) and (III))

TABLE 5.1. (I, II, III) HERE

The most frequently reported coping strategies for both RA and migraine patients were, during a painful episode, taking medication to relieve pain, trying to avoid company and trying to ignore the pain. The most commonly reported anticipatory strategies were trying to avoid certain foods, thinking themselves generally fortunate (positive self image), avoiding discussing the illness with others, trying to portray to others a positive attitude about one's state of health and making a positive effort to gain information from Doctors after treatment. Significant differences were found to exist between the coping strategies adopted by RA as opposed to migraine sufferers on some coping domains. When in pain migraine sufferers indicated they would wish to be left alone more frequently than RA sufferers ($t=6.13$,

Coping Item	n	Mean	SD
Do you			
Q67. take anything to reduce pain?	160	6.16	1.79
Q68. seek out company?	160	1.38	1.91
Q69. try to avoid company?	160	5.17	2.56
Q70. try to stay active?	160	4.84	2.52
Q71. engage in some activity you usually enjoy to take your mind off the pain?	160	3.41	2.57
Q72. become frustrated or angry?*	160	4.06	2.28
Q73. deliberately engage in thoughts about how much worse one's situation could possibly be (minimising impact of one's own situation)?	160	3.39	2.41
Q74. watch TV?	157	2.43	1.79
Q75. listen to radio?	157	2.53	1.91
Q76. try to read?	160	2.51	1.96
Q77. think about other things?	160	4.12	2.35
Q78. try to ignore the pain?	159	3.78	2.27
Q79. store up food and other goods for days when you can't get them yourself?	156	2.88	2.65
Q80. try to avoid certain foods?	158	3.74	2.58
Q81. read medical books?	158	2.08	1.28
Q82. avoid people because you do not wish to be a burden to them?	157	2.25	1.84

This Table (Table 5.1.(I).) Continued Over

Table 5.1.(I). continued from previous page

Q83. pray for your condition to improve?	158	3.33	2.25
Q84. compare yourself with others and think you have been unfortunate with your health?	158	2.31	1.81
Q85. do you think of yourself as generally fortunate?	159	5.11	1.91
Q86. discuss the problems of the illness with others?	160	2.18	1.65
Q87. avoid discussing the illness with others?	160	4.92	2.36
Q88. try to portray a positive attitude about your health to others?	159	5.78	1.91
Q89. make a positive effort to gain information from Drs after treatment?	160	4.46	2.65

* This item excluded from the analysis of coping items. See footnote 5.

Table 5.1.(I).

Means and Standard Deviations for all chronically ill individuals in the study (not all subjects answered all questions) on coping items in the questionnaire.

Coping Item	n	Mean	SD
Do you			
Q67. take anything to reduce pain?	80	5.95	2.11
Q68. seek out company?	80	1.68	1.61
Q69. try to avoid company?	80	4.05	2.79
Q70. try to stay active?	80	5.93	2.10
Q71. engage in some activity you usually enjoy to take your mind off the pain?	80	4.68	2.48
Q72. become frustrated or angry?*	80	4.46	2.20
Q73. deliberately engage in thoughts about how much worse one's situation could possibly be (minimising impact of one's own situation)?	80	3.99	2.45
Q74. watch TV?	77	3.47	1.90
Q75. listen to radio?	77	3.45	1.99
Q76. try to read?	80	3.68	2.00
Q77. think about other things?	80	4.15	2.72
Q78. try to ignore the pain?	79	3.78	2.22
Q79. store up food and other goods for days when you can't get them yourself?	76	3.53	2.80
Q80. try to avoid certain foods?	78	3.23	2.50
Q81. read medical books?	78	1.95	1.28
Q82. avoid people because you do not wish to be a burden to them?	77	2.03	1.58

This Table (Table 5.1.(II).) Continued Over

Table 5.1.(II) continued from previous page

Q83. pray for your condition to improve?	78	3.44	2.16
Q84. compare yourself with others and think you have been unfortunate with your health?	78	2.59	1.92
Q85. do you think of yourself as generally fortunate?	79	5.00	2.05
Q86. discuss the problems of the illness with others?	80	2.18	1.76
Q87. avoid discussing the illness with others?	80	5.34	2.27
Q88. try to portray a positive attitude about your health to others?	79	6.24	1.42
Q89. make a positive effort to gain information from Drs after treatment?	80	4.36	2.77

* This item excluded from the analysis of coping items. See footnote 5.

Table 5.1.(II).

Means and Standard Deviations for RA sufferers in the study (not all subjects answered all questions) on coping items in the questionnaire.

Coping Item	n	Mean	SD
Do you			
Q67. take anything to reduce pain?	80	6.36	1.37
Q68. seek out company?	80	1.09	0.33
Q69. try to avoid company?	80	6.29	1.70
Q70. try to stay active?	80	3.75	2.45
Q71. engage in some activity you usually enjoy to take your mind off the pain?	80	2.15	1.96
Q72. become frustrated or angry?*	80	3.65	2.29
Q73. deliberately engage in thoughts about how much worse one's situation could possibly be (minimising impact of one's own situation)?	80	2.79	2.23
Q74. watch TV?	80	1.44	0.90
Q75. listen to radio?	80	1.64	1.30
Q76. try to read?	80	1.35	0.99
Q77. think about other things?	80	3.73	2.38
Q78. try to ignore the pain?	80	3.78	2.33
Q79. store up food and other goods for days when you can't get them yourself?	80	2.28	2.38
Q80. try to avoid certain foods?	80	4.24	2.57
Q81. read medical books?	80	2.20	1.28
Q82. avoid people because you do not wish to be a burden to them?	80	2.45	2.05

This Table (Table 5.1.(III).) Continued Over

Table 5.1.(III) continued from previous page

Q83. pray for your condition to improve?	80	3.23	2.34
Q84. compare yourself with others and think you have been unfortunate with your health?	80	2.01	1.67
Q85. do you think of yourself as generally fortunate?	80	5.23	1.76
Q86. discuss the problems of the illness with others?	80	2.17	1.54
Q87. avoid discussing the illness with others?	80	4.50	2.36
Q88. try to portray a positive attitude about your health to others?	80	5.33	2.21
Q89. make a positive effort to gain information from Drs after treatment?	80	4.55	2.55

* This item excluded from the analysis of coping items. See footnote 5.

Table 5.1.(III).

Means and Standard Deviations for migraine patients on coping items in the questionnaire.

df=158, $p<0.001$, two tailed test). RA sufferers attempted to stay active more frequently than migraine sufferers when in pain ($t=6.03$, df=158, $p<0.001$, two tailed test), and to engage in an activity they enjoyed ($t=7.13$, df=158, $p<0.001$, two tailed test). Watching television ($t=8.52$, df=158, $p<0.001$, two tailed test) and listening to the radio ($t=7.13$, df=158, $p<0.001$, two tailed test) were the only other areas in which significant differences existed.

No significant zero order correlations were found between any of the MPQ scale scores (or the present state linear pain measure) and the coping statements.

The coping scores of the migraine and RA sufferers on the coping items were correlated with both NHP subjective health status scores and medical measures. Zero order correlations were found for RA sufferers between the NHP score for energy and the coping question (question 69) 'During a flare-up do you try to avoid company?' ($r=0.31$, $p<0.01$, $n=68$). A correlation was also found between the coping question 'During a flare-up do you try to stay active?' and the NHP score for pain, ($r=0.26$, $p<0.05$, $n=68$). These correlations would tend to indicate that tiredness may influence individuals willingness to seek company, and that attempts at activity whilst having a flareup cause pain. This latter finding would be in keeping with items on the NHP, which tend to characterise pain as conditional upon movement. Thus those reporting attempts at remaining active would also be expected to score on the NHP

pain scale⁵. Likewise, there was a modest correlation between the mobility score on the NHP and question 69 ('When having a flare-up do you try to avoid company?'), ($r=0.28$, $p<0.02$, $n=68$), indicating that mobility problems influence people not to seek out company.

Pearson Product Moment Correlation Coefficients were calculated for all coping questions against scores on the NHP emotional reactions scale score, and raw score on the GHQ, and caseness as indicated on the GHQ at interview. No significant correlations were found between coping items and measures of psychological state for the RA patients⁶, although for the migraine patients the item 'Do you compare yourself to others and feel unfortunate with your state of health' (question 79) was found to be correlated with caseness as indicated on the GHQ ($r=0.35$, $p<0.01$, $n=80$), and raw scores on the GHQ ($r=0.38$, $p<0.0001$, $n=80$). Correlations were further found between praying for one's condition to improve and 'caseness' on the GHQ ($r=0.42$,

5. The association of the pain items with aspects of mobility in the Nottingham Health Profile has been noted elsewhere, (see Kind and Carr-Hill, 1987; Jenkinson et al, 1988; Jenkinson and Fitzpatrick, 1990).

6. A significant correlation was found between feelings of frustration and anger during a painful flare up and 'caseness' as indicated on the GHQ ($r=0.41$, $p<0.0001$, $n=68$) for the RA sample, and with raw scores on the GHQ ($r=0.40$, $p<0.0001$, $n=68$). For the migraine sample scores on the item 'During an attack do you feel frustrated and angry?' was not found to be associated with mental health scores on the GHQ. However, this item was removed from the analysis as it was decided that this was an outcome measure (of unsuccessful coping) and not a coping strategy. A similar item was removed from the coping questionnaire developed by Brown and Nicassio (1987) because it did not load highly on any factor. When the item was included in analyses in this research it, likewise, did not load significantly on any factor.

$p < 0.0001$, $n = 80$), as well as the GHQ raw score ($r = 0.48$, $p < 0.0001$, $n = 80$).

Analyses were undertaken to determine whether particular sub-groups of the samples undertook particular coping strategies that were associated with mental health scores. Pain scores as measured on the MPQ, mobility (for RA patients only) as measured on the NHP, and length of illness were broken into two groups by means of a median split, and the mean scores of the coping strategies for these groups were correlated with mood as measured by the GHQ. However, these analyses provided no significant results, thereby indicating that no interaction effects were present in the data on these dimensions.

Various coping schemas have been documented in this thesis (see Section 5.1. above). In these schemas the universe of possible coping strategies is categorised into more analytical or theoretical groups (e.g. active or passive strategies). It was therefore decided to factor analyse the data to determine whether theoretically meaningful underlying dimensions existed. The items included for this analysis were Q67 to Q78, (see Table 5.1.)⁷.

7. It was decided to exclude Q72, ('Do you become frustrated and angry?') as this may in fact reflect coping responses more than a coping strategy (see footnote 6, Chapter 5, above).

5.4.2. Factor analysis of coping strategies undertaken during a flare-up of RA or a migraine attack

Factor analyses were performed separately for the two illness groups. Firstly the set of coping items were analysed in which patients described how they dealt with symptom episodes. Principal components factor analysis followed by varimax rotation was performed on the coping items. Using the scree test the results suggested 2 and 3 factor solutions for migraine and RA respectively. Tables 5.2. and 5.3. summarise these analyses.

TABLES 5.2. & 5.3. HERE

Two factors emerged from the analysis of the migraine sufferers' coping questions. The first factor accounted for 22.8% of the variance, and loaded upon the items concerned with remaining active, attempting to think about something else and trying to ignore the pain. The underlying dimension may be attempting to cope with the pain by ignoring it by engaging in other activities. This seems to be an active coping strategy. The second factor, accounting for 15.7% of the variance, loaded most positively on the item 'do you try to avoid company?', and, unsurprisingly therefore, a negative loading was gained for the item as to whether sufferers sought out company. A negative loading was gained on the item 'do you take anything to reduce the pain?' There was a further negative loading on listening to

Component measures	Factor loadings	
	1	2
<i>Factor 1</i>		
Q69. try to avoid company?	-0.84	0.71
Q70. try to stay active?	0.73	-0.03
Q71. engage in some activity you usually enjoy to take your mind off the pain?	0.76	-0.06
Q77. think about other things?	0.69	-0.13
Q78. try to ignore the pain?	0.65	-0.18
<i>Factor 2</i>		
Q67. take anything to reduce pain?	0.13	-0.79
Q68. seek out company?	-0.08	-0.23
Q69. try to avoid company?	-0.84	0.71
Q75. listen to radio?	0.29	-0.55
<i>Items not loading on either factor</i>		
Q73. deliberately engage in thoughts about how much worse one's situation could possibly be (minimising impact of one's own situation)?	-0.15	-0.23
Q74. watch TV?	-0.12	-0.03
Q76. try to read?	-0.08	-0.03

Table 5.2.

Factor Analysis (varimax rotation) of Short Term Coping Items in Questionnaire for migraine patients.

Component measures	Factor loadings		
	1	2	3
<i>Factor 1</i>			
Q70. try to stay active?	0.47	-0.03	0.09
Q71. engage in some activity you usually enjoy to take your mind off the pain?	0.81	0.06	-0.02
Q74. watch TV?	0.21	0.06	0.05
Q76. try to read?	0.45	-0.16	0.55
Q77. think about other things?	0.69	0.07	-0.01
<i>Factor 2</i>			
Q67. take anything to reduce pain?	0.17	0.42	-0.01
Q68. seek out company?	0.18	-0.75	-0.17
Q69. try to avoid company?	0.32	0.74	-0.25
<i>Factor 3</i>			
Q73. deliberately engage in thoughts about how much worse one's situation could possibly be (minimising impact of one's own situation)?	-0.04	-0.18	0.74
Q76. try to read?	0.45	-0.16	0.55
Q78. try to ignore the pain?	-0.11	0.35	0.63
<i>Item that did not load on any factor</i>			
Q75. listen to radio?	-0.09	-0.17	0.02

Table 5.3.
Factor Analysis (varimax rotation) of Short Term Coping Items in Questionnaire for Rheumatoid Arthritis subjects.

the radio. The factor has elements of withdrawal, but it could also be interpreted as avoidance of noise, thereby explaining the negative loading of the item 'Do you listen to the radio?'

Factor analysis was undertaken on the arthritis group, with the first factor (accounting for 17.8% of the variance) loading upon factors concerned with remaining active (Q70 and Q71), trying to think about something else, and trying to read. Watching television gained a moderate positive loading. As with the migraine group this first factor could be characterised as an active strategy, but with elements of cognitive coping and suppression. In this respect it is similar to the results of Rosenstiel and Keefe (1983). The second factor (accounting for 15% of the variance), loaded on similar items as the second factor of the migraine group, but in this instance RA sufferers indicated they would take medication to reduce the pain. This seems a strategy of both direct action and withdrawal. A third factor was also obtained for the arthritis group. This factor accounted for 13.2% of the variance and loaded on the items 'thinking how worse the situation could be during a flare-up', 'trying to read during a flare-up', and 'trying to ignore the pain'. This seems to be a coping strategy based upon cognitive restructuring.

The results obtained from these analyses were used to construct scale scores. Thus, items which loaded on the factors and seemed to provide evidence of an underlying

factor were summed together⁸. These new variables were thus constructed from existing variables with assumed communality that was taken to indicate an underlying dimension. The scores gained from this procedure were then correlated with emotional reactions scores on both the GHQ (both for raw scores and 'caseness'), and the NHP but no significant correlations were found. Furthermore, no significant correlations were discovered between pain measures (either on the MPQ or the present state linear scale) and the newly constructed scale scores.

5.4.3. Factor analysis of coping strategies undertaken whilst in remission (anticipatory coping strategies)

Factor analysis was undertaken on migraine and RA patients as separate groups for the longer term (anticipatory) coping strategies of chronic pain patients. There were eleven coping items in this analysis (Tables 5.4. and 5.5. indicate the contents of the anticipatory coping items).

Five factor solutions were obtained for both the RA patients and the migraine patients as distinct groups using the principle components method, and these factors were extracted for rotation using the Kaiser criterion. Whilst five factors were retained using the Kaiser criterion, the fourth and fifth factors had eigenvalues only marginally

8. Items with weak loadings were not incorporated into the scale scores. Thus, the item 'Do you watch TV?' was not incorporated into the scale constructed from factor analysis of RA subjects, and neither was 'Do you seek out company' included in the scale score based upon the second factor gained from the analysis of the migraine respondents data.

above one, and, hence, only the first three factors were retained for rotation.

The factor analyses did not provide any evidence for theoretically interesting underlying coping strategies. Only relatively small amounts of variance were explained by each of the factors, and, more importantly, the factors were regarded as theoretically uninteresting. For the RA sample the first factor explained 19.0% of the variance, the second 16.1% of the variance and the third 13.1% of the variance. The number of items with high loadings was low in each case. For the migraine sample the first factor explained 18.0% of the variance, the second 15.0% of the variance and the third 13.0% of the variance. The number of items with high loadings was, once again, low in each case. The number of items loading on each was small and did not provide support for underlying factors in the data. See tables 5.4. and 5.5.

TABLES 5.4. & 5.5. HERE

5.3. DISCUSSION OF COPING STRATEGIES

The results of this study lend support to the thesis that migraine sufferers adopt more passive coping strategies than do RA sufferers. Migraine sufferers reported that they wished to be left alone when in pain more frequently than did RA sufferers, whilst RA patients more frequently reported that they attempted to stay active, engage in an

Component measure	Factor loadings		
	1	2	3
Q79. store up food and other goods for days when you can't get them yourself?	0.11	0.02	-0.19
Q80. try to avoid certain foods?	0.46	0.25	0.61
Q81. read medical books?	-0.19	0.02	0.12
Q82. avoid people because you do not wish to be a burden to them?	-0.07	-0.48	0.53
Q83. pray for your condition to improve?	-0.13	-0.06	0.82
Q84. compare yourself with others and think you have been unfortunate with your health?	0.16	-0.68	0.28
Q85. do you think of yourself as generally fortunate?	0.08	0.85	0.15
Q86. discuss the problems of the illness with others?	-0.89	-0.11	0.09
Q87. avoid discussing the illness with others?	0.90	-0.13	0.09
Q88. try to portray a positive attitude about your health to others?	0.01	0.02	-0.11
Q89. make a positive effort to gain information from Drs after treatment?	-0.27	-0.09	0.16

Table 5.4.

Factor analysis, after varimax rotation of Long Term Coping Items in Questionnaire, for Rheumatoid Arthritis patients in the study.

Component measure	Factor loadings		
	1	2	3
Q79. store up food and other goods for days when you can't get them yourself?	0.79	0.04	0.03
Q80. try to avoid certain foods?	0.10	0.29	0.54
Q81. read medical books?	-0.04	0.11	-0.01
Q82. avoid people because you do not wish to be a burden to them?	0.76	0.19	0.03
Q83. pray for your condition to improve?	0.42	0.60	0.09
Q84. compare yourself with others and think you have been unfortunate with your health?	0.21	0.77	0.04
Q85. do you think of yourself as generally fortunate?	0.33	-0.45	-0.11
Q86. discuss the problems of the illness with others?	-0.15	0.55	-0.62
Q87. avoid discussing the illness with others?	-0.10	-0.04	0.82
Q88. try to portray a positive attitude about your health to others?	-0.21	0.12	-0.20
Q89. make a positive effort to gain information from Drs after treatment?	0.06	-0.11	-0.12

Table 5.5.

Factor analysis, after varimax rotation, of Long Term Coping Items in Questionnaire, for migraine patients in the study.

activity they enjoyed, watched television and listened to the radio than did migraine sufferers. The stereotyped image of the migraine sufferer as someone who is forced to retreat to bed in a darkened room would, from this data at least, not seem to be altogether removed from the truth. Migraine suffering is a disabling condition that necessitates almost complete withdrawal from the world whilst the sufferer is in pain. Engaging in activities in order to take one's mind of the pain is impossible, it would seem, and radio listening or television watching would only further exacerbate the situation. A number of the patients remarked that they would be unable to listen to or watch anything when they were in pain through migraine. Activities such as reading and indeed seeking company when in pain seemed unpopular strategies for both RA and migraine sufferers.

From the data gained in this study there seems only limited support for the claim that the use of pain coping strategies may enable individuals to adapt to their illness. Certainly no individual coping strategy was found to be highly correlated with mental health scores. No evidence was found for the hypothesised link between self reported pain and self reported coping behaviour. However, the results were similar in this respect to those of Rosenstiel and Keefe, (1983), and Turner and Clancy, (1986), who found that coping strategies were not associated with positive psychological adjustment, (see Tables 5.5. and 5.6.).

TABLES 5.6. & 5.7. HERE

They found behaviours that were related to poor adjustment, but the items constituting these strategies were highly negative. Indeed they themselves remark,

"The results of the present study...tend to agree with those previous studies that used self report technique to assess pain coping strategies. Both studies⁹ found that success in dealing with pain is more a function of refraining from use of a catastrophizing strategy than use of any particular coping strategy. The present study also suggests that the tendency to catastrophize is related to poorer emotional adjustment as assessed by anxiety and depression, but not pain ratings. Considered overall, this pattern of findings suggests that counselling (-sic) patients to decrease their use of catastrophizing may be useful.

The pattern of results raises questions about applying the term 'coping' to the strategies we have assessed. Although patients report using these strategies to help them 'cope' with pain, in fact many of the strategies seem to be maladaptive. The term 'coping' implies that a strategy is related to positive adjustment. In the present study, frequent use of certain coping strategies was related to poor adjustment", (Rosenstiel and Keefe, p43, 1983).

In conclusion the evidence presented here would not provide support for the hypothesised link between coping and adaptation, when utilising GHQ score as the measure of outcome. Further this research provided scant evidence for the adoption of action based strategies for anticipatory coping and more passive coping in a flare up of RA or a

9. The studies referred to here are those by Chaves and Brown (1978), and Spanos, et al, (1975).

Component measures	Factor loadings		
	1	2	3
<i>Factor 1 (Cognitive coping and suppression)</i>			
Reinterpreting pain sensations	0.69	-0.09	0.49
Coping self-statements	0.85	-0.24	0.00
Ignoring pain	0.86	-0.21	0.39
<i>Factor 2 (Helplessness)</i>			
Catastrophizing	-0.08	0.67	0.43
Increasing activity	0.45	-0.53	0.50
Ability to control pain	0.45	-0.83	0.03
Ability to decrease pain	0.06	-0.75	0.17
<i>Factor 3 (Diverting attention and praying)</i>			
Diverting attention	0.37	-0.24	0.82
Praying or hoping	0.18	0.08	0.82

Table 5.6.

Factor analysis (oblique rotation) of coping strategy questionnaire. Results taken from Rosenstiel and Keefe, 1983.

Component measures	Factor loadings		
	1	2	3
<i>Factor 1 (Denial of Pain)</i>			
Ignoring pain	0.65	0.13	-0.04
Reinterpreting pain sensations	0.81	0.16	0.43
Ability to decrease pain	0.74	-0.17	-0.25
<i>Factor 2 (Diverting attention and praying)</i>			
Diverting attention	0.16	0.81	-0.10
Praying or hoping	-0.21	0.75	0.13
Increasing activity	0.32	0.67	-0.12
<i>Factor 3 (Helplessness)</i>			
Catastrophizing	0.11	0.13	0.75
Ability to control pain	0.46	-0.11	-0.60
Coping self-statements	0.05	0.38	-0.69

Table 5.7.

Factor analysis (oblique rotation) of coping strategy questionnaire. Results taken from Turner and Clancy, 1986.

migraine attack. From the raw data scores there is evidence that migraine sufferers adopt more passive coping during a flare up than RA patients, but these coping items were not associated with psychological state.

No evidence was sought here for maladjustive 'coping' behaviours that would be associated with poor psychological state. Catastrophizing, getting upset, depressed, frustrated or angry were regarded as indications of unsuccessful adjustment and not coping strategies¹⁰. In conclusion it is argued here that the evidence for coping strategies for chronic painful illness that permit adaptation to the demands of the pain and demands of the illness is weak. This finding has been supported by the results of a recently published study by Revenson and Felton (1989) who, in a study of RA patients, found little support for the hypothesised link between coping strategies and psychological well being. The results of other studies have led writers to argue that whilst there is relatively little evidence for adaptive pain coping strategies, there is some evidence that certain behaviours are mal-adaptive. However, as data from such studies is obtained from self report it is possible that psychologically distressed individuals are simply reporting manifestations of distress rather than any particular strategy. It is, for example,

10. However, it is worth noting that the item excluded from the coping analysis (Q72, Do you become frustrated and angry during a flare-up/attack?) was correlated with mental health for the RA patients in this study (see results section, footnote 6). However there was no such correlation for migraine patients, perhaps because such expressive emotions might exacerbate the pain of an attack.

possible that depressed people catastrophize, and not, as Rosenstiel and Keefe (1983) assume, that catastrophizing leads to psychological problems. Thus, treatment should not be aimed so much at the strategies patients adopt to prevent psychological maladjustment, as Rosenstiel and Keefe (1983) suggest, but it might be aimed directly at the depression itself.

CHAPTER 6

PROFILE OF PERCEIVED HEALTH IN THE SAMPLES AND ITS RELATION TO MENTAL HEALTH

6.1. INTRODUCTION

Perceived health status refers to individuals' own subjective evaluation of the impact of illness on their daily lives. As Hunt et al (1986) remark, it has sometimes been suggested that perceived health status may simply be no more than a subjective assessment determined more by social and psychological factors than by any basis in actual illness state. However, they also remark that belief about illness is an intervening variable between objective health (ie health status as measured clinically by the medical profession) and the adoption of what Parsons (1951) refers to as the sick role, (cf also Maddox, 1964).

Perceived health status has received relatively little attention in research upon the psychological impact of illness. It has been argued that the relative contribution of disability and other aspects of health status has not been closely studied, (Newman, et al, 1987, 1989). For example, in one study of RA patients it was found that

depressed state was associated most strongly with a number of factors, of which self reported disability was the most significant (Newman, 1987, 1989). It has been suggested that quality of life measures, such as those made by the NHP, should be incorporated into clinical assessments (Berry et al, 1987).

Berry et al (1987) remark that improvement in quality of life is an important and major concern for arthritis sufferers. This case could be made for all chronically ill individuals. Individuals have expectations about the sort of life they hope to live. It seems reasonable to assume that adaptive preference formation (Elster, 1983) does occur among the chronically ill. That is, individuals suffering chronic illnesses have lower expectations in areas affected by their illness than do healthy people, although there is no doubt variation in expected quality of life amongst the sick.

The question we may ask is this: is an individual with a severe chronic illness worse off in terms of mental health than someone who has perfect health? The answer seems to be 'yes'. Indeed empirically such a claim is justified, because reports of mental health among the chronically ill generally support this view; depression is far more widespread among the long term ill than in the population at large. Thus, chronic illnesses such as RA can adversely affect one's

ability to live the life one would choose to live. If one's ability to function is in some way deficient, as is the case in RA, then capabilities are also affected, and this may affect mental health. It is suggested that individuals assess their capability to live the life they regard as the best possible for them, and some aspects of their lives do not live up to these assessments. Such assessments of capability, in the context of health status, are partially conditioned by expectations. It is when assessments of capability are incongruent with lifestyle that depression may manifest itself. This is not an area to which the medical model addresses itself. Pincus et al (1983), in a study of rheumatoid arthritics, remark that patient satisfaction is largely influenced by perceived change in disability, with the least satisfied patients stating that they had perceived a change in difficulty in activities of daily living.

Medical assessments of patients are, in large measure, determined by a range of conventional clinical, radiological and laboratory measures. In the RA sufferer clinical measures include morning stiffness, pain, and functional abilities such as walking. Migraine patients are typically asked about the frequency, duration and character of attacks. What is rarely taken into account in medical assessment is the impact of an illness on an individuals quality of life, and subjective perceptions of health state.

6.2. HYPOTHESES TO BE EXPLORED IN THIS SECTION-OVERVIEW

The point has already been made that the social and psychological literature on the impact of chronic illness upon mental health has paid relatively little attention to the notion of perceived health status. However, it is argued here that how ill individuals perceive themselves to be is closely bound up with their mental health. Thus, as well as gaining clinical 'objective' data from medical personnel and patients, it was also decided to obtain data on perceptions of illness. Two questionnaires were used to assess perceptions of health: the McGill Pain Questionnaire (MPQ) and the Nottingham Health Profile (NHP), whilst a third, (a section from the questionnaire designed specifically for this research) concerns the impact of the illness upon a sufferer's daily life. The MPQ provides a profile of the pain experienced at specified times (eg during a flare up), whilst the NHP provides a more general measure of the perceived impact of illness. A full account of the development and validation studies carried out upon these questionnaires is to be found in Chapter 3.

The NHP is a questionnaire designed to provide a profile of perceived health in the areas of sleep, social isolation, energy, mobility, pain and emotional reactions. The results from this questionnaire for the R.A./migraine study and also for the Subject Panel study are provided here. The

questionnaire designed specifically for use in this research contains a section on the impact of illness upon the daily lives of sufferers, and this is also discussed here.

It is hypothesised here that pain is not a major determinant of mental health, as is often suggested, but that the impact an illness has upon daily life for sufferers is the most salient dimension. RA suffering is an illness which has pervasive consequences on the lives of sufferers, and migraine suffering can be regarded as an illness with implications for overall health status, insofar as it can be totally debilitating when during an attack, and can have major implications for a sufferers life. In addition, the very unpredictability of migraine may be a cause for distress, due to the inability of sufferers to have control over their lives. Perceived health refers to the impact of an illness upon a sufferer's daily life, and pain only illnesses can have such an impact. It is hypothesised that perceived health assessments are associated more strongly with mental health assessments than with pain reports per se.

6.3. METHOD AND MATERIALS

Information concerning the NHP, the MPQ, the questionnaire designed for this research, and the method of administration in this study is to be found in Chapter 3.

6.4. PAIN PERCEPTION AND MENTAL HEALTH

6.4.1. Results

The McGill Pain Questionnaire was administered to obtain a profile of the types and severity of pain suffered by all individuals surveyed in the RA/Migraine study. One hundred and fifty four of the chronically ill patients in the sample interviewed completed the MPQ (74 RA patients and 80 migraine patients). The main reason for failure to complete was tiredness. Table 6.1. summarises the results from the administration of this questionnaire.

TABLE 6.1. HERE

Significant differences were found as to the nature and extent of the pain reported between the RA and migraine groups. T-tests for the three sub-scales of the MPQ were found to reveal significant differences between RA and migraine sufferers (sensory sub-scale $t=2.70$, $p<0.01$, affective sub-scale $t=1.87$, $p<0.05$, and evaluative sub-scale $t=2.69$, $p<0.01$), with migraine coming out as an illness characterised by more painful flare ups, as reported on the

	Arthritis		Migraine	
	Mean	S.D.	Mean	S.D.
Sensory	16.72	6.83	19.60	6.37
Affective	6.12	3.50	8.45	10.43
Evaluative	3.12	1.52	3.78	1.48
Pain Rating Index	29.45	11.27	35.75	11.51
No Words Chosen	12.14	3.82	13.23	3.36

Table 6.1.

Scores on the McGill Pain Questionnaire (MPQ) for rheumatoid arthritis (n=74) and migraine (n=80) sufferers.

MPQ, than RA. The overall pain rating intensity scale (PRI) score on the MPQ supported these findings ($t=3.42$, $p<0.001$), as did the number of words chosen (NWC) on the MPQ ($t=1.87$, $p<0.05$).

Over 40% of RA patients picked the following words to describe their pain; throbbing, shooting, aching, tender, exhausting, sickening and nagging. Previous studies have found similar pain profiles for RA sufferers, (Burckhardt, 1984; Parker et al, 1988). Migraine patients had a slightly different pain profile to the RA patients, with 40% of patients choosing the following words to describe their pain; stabbing, sharp, heavy, splitting, exhausting, sickening, blinding, unbearable and nauseating. In both illnesses the words tiring and exhausting (both coming from the same word group on the MPQ) were the most chosen words, with 90% of the both groups of sufferers picking one or other of these two descriptors. From this result it would seem that tiredness caused by long term chronic pain suffering is a major element in the perception of the disease. However, t-tests revealed that on no dimension was 'caseness' or 'non-caseness' as measured by the GHQ found to be associated with pain reporting on the MPQ.

6.5. PERCEIVED HEALTH STATUS AND MENTAL HEALTH

6.5.1. Nottingham Health Profile: Results from the R.A./Migraine Study

One hundred and forty-eight of the 160 patients interviewed completed the NHP. Twelve RA patients did not complete this questionnaire, because of tiredness. The mean age for the subjects who completed the NHP was 51 years, (S.D. 13.6). The youngest patient interviewed was 21 and the oldest was 83. Sixty eight patients suffered from RA (mean age=58 years, S.D. 11.7, minimum age=21, maximum age=83), and 80 patients were migraine sufferers (mean age=44 years, S.D. 11.8, minimum age=21, maximum age=79).

Basic scores on the NHP are summarised in Table 6.2. with norms provided for three age groups from a general practice population (Hunt et al, 1986). The results were higher on all dimensions, for the RA sample, than the general population norms provided by the designers (Hunt, et al, 1986), and also those provided by Wilkin et al (1987). The migraine sample likewise had more elevated scores than the norms on all dimensions other than physical mobility (1986).

TABLE 6.2. HERE

If the mean scores of the chronically ill individuals in this survey are examined in terms of sub-groups by age and

	NHP Domains					
	Energy	Pain	Emotional Reactions	Sleep	Social Isolat- ion	Physical Mobility
OVERALL (n=148)						
Mean	52.1	44.6	30.4	44.6	20.8	27.4
S.D.	38.5	31.6	26.3	31.6	25.7	30.0
R.A. SUFFERERS (n=68)						
Mean	64.5	62.9	31.8	51.7	26.5	55.1
S.D.	35.1	27.1	26.7	31.6	27.4	20.8
MIGRAINE SUFFERERS (n=80)						
Mean	41.6	18.5	29.2	38.6	15.9	3.8
S.D.	38.3	19.2	26.0	30.5	23.2	8.8
NORMATIVE DATA						
<i>(Women between 20-24)</i>						
Mean	16.6	1.1	14.3	8.4	5.5	1.4
<i>(Women between 40-44)</i>						
Mean	12.6	5.9	10.0	11.9	5.0	3.3
<i>(Women between 55-59)</i>						
Mean	18.6	14.5	7.7	11.7	3.4	3.7

Table 6.2.

Mean scores on the six domains of the NHP for all chronic pain patients and for RA and migraine sufferers as specific groups. Norms are those provided by Hunt et al, (1986).

social class, and then compared to population data of the same age and social class then the differences are even greater¹. Table 6.3. summarises the data broken down by social class and illness, whilst Table 6.4. summarises the data for age and illness.

TABLES 6.3. & 6.4. HERE

RA came out as an illness with greater implications for health status than migraine on all topic domains. These differences were significant for the NHP scores of energy ($t=3.8$, $p<0.001$), pain ($t=11.3$, $p<0.0001$), mobility ($t=19.0$, $p<0.001$) social support ($t=2.5$, $p<0.01$) and impact on sleep ($t=2.6$, $p<0.01$). However the difference were not significant for emotional reactions. T-tests were undertaken for all domains on section one of the NHP for in-patient scores against out-patient scores. Only one of these analyses was significant, that being on the domain of mobility ($t=3.3$, $p<0.001$), with in-patients reporting greater problems with movement than out-patients.

1. The originators of the NHP provide norms for the instrument from surveys of the general population, and other non-clinical populations. This work is fully summarised in Hunt et al (1986). Wilkin et al (1987) provide norms for the NHP from a population survey in Manchester and likewise the results are lower than those reported here. See also the data gained from the University of Oxford Subject Panel (see Chapter 6.6. and Figure 6.1. of this thesis).

NHP Dimensions

Social Class	Energy	Pain	Emotional Reactions	Sleep	Social Isolation	Mobility
Rheumatoid Arthritis sufferers (n=68)						
I & II n=35	56.82 (35.34)	57.66 (28.07)	28.88 (25.53)	46.09 (30.48)	21.33 (25.15)	49.48 (20.94)
III-V n=33	71.74 (33.69)	67.86 (25.65)	34.49 (27.92)	67.86 (25.65)	31.43 (28.89)	60.46 (19.41)
Migraine sufferers (n=80)						
I & II n=46	38.85 (41.19)	17.13 (17.88)	24.97 (22.85)	35.04 (27.63)	13.89 (23.07)	3.98 (7.84)
III-V n=34	45.35 (34.28)	20.44 (20.99)	35.00 (29.14)	43.41 (33.82)	18.53 (23.56)	3.59 (10.09)

Table 6.3.

Scores on the Nottingham Health Profile broken down by illness and social class.

Social Class	NHP Dimensions					
	Energy	Pain	Emotional Reactions	Sleep	Social Isolation	Mobility
Rheumatoid Arthritis sufferers (n=68)						
21-59 n=34	63.38 (33.87)	69.76 (23.63)	37.62 (27.12)	51.38 (32.34)	28.94 (28.14)	52.65 (20.93)
60-83 n=34	65.62 (36.68)	56.06 (28.89)	25.91 (25.40)	52.00 (31.33)	24.12 (26.87)	57.62 (20.61)
Migraine sufferers (n=80)						
21-45 n=39	43.39 (37.70)	16.72 (17.41)	31.67 (28.50)	45.67 (25.07)	18.56 (25.07)	4.26 (9.37)
46-79 n=41	39.93 (39.28)	20.27 (20.56)	26.93 (23.54)	26.93 (27.90)	13.29 (21.35)	3.39 (8.34)

Table 6.4.
Scores on the Nottingham Health Profile broken down by
illness and age group, determined by a median split.

A Spearman correlation coefficient was calculated between the emotional reactions item on the NHP and the score on the GHQ. The resulting correlation was found to be quite high, ($r=0.61$, $p<0.0001$, $n=68$). High correlations were also found between the emotional reactions scale of the NHP and scores on the GHQ for both sub-samples (with a correlation of $r=0.59$ ($p<0.0001$, $n=80$) for RA sufferers and $r=0.65$ ($p<0.0001$, $n=154$) for migraine sufferers. The GHQ indicated 'caseness' in terms of non-psychotic psychiatric disorder in 55.4% of the respondents ($n=82$); 33.1% ($n=49$) were suffering RA, and 22.3% ($n=33$) migraines.

The NHP categories were then correlated to determine how distinct the dimensions were, for the data as a whole (see table 6.5.), for RA sufferers alone (see table 6.6.) and for migraine sufferers alone (see table 6.7.). Pain and mobility were found to be highly correlated, and it has been suggested that items in these two domains are perhaps tapping aspects of the same illness dimension (Kind and Carr-Hill, 1987, Jenkinson, et al, 1988). Pain as measured on the NHP was not found to be correlated with pain measures on the MPQ or the linear scale of present pain intensity².

2. Siegrist and Junge (1989) erroneously claim that high correlations have been found between pain domains in studies on the NHP and MPQ as reported by McDowell and Newell, (1987). However, McDowell and Newell (1987) report correlations for the instrument preceding the NHP, the Nottingham Health Index. The Nottingham Health Index (NHI) was the forerunner of the more widely used Nottingham Health Profile. Little work has been done using the NHI. For further information on the NHI see McDowell et al (1978), and McDowell and Newell (1987).

TABLES 6.5. - 6.7. HERE

A discriminant function analysis (see Klecka, 1980) was used to determine whether scores on the NHP could be used to predict illness suffered (RA or migraine), in order to determine whether perceptions of (ill-) health in the two groups were different. Scores from the six subject areas of the NHP were included. A stepwise method of selecting variables was used. This method selects a subset of the variables to produce a discriminant model using stepwise selection. The only variable so selected in the analysis was the NHP score for mobility (Wilks lambda=0.27). The variable which minimises the Wilks lambda is included at each step. The Wilks lambda value of 0.27 (significant at the 0.0001 level) indicates that the function was quite successful in distinguishing between the two illnesses. A linear discriminant function analysis was undertaken, and the posterior probability of 'membership' of each illness was calculated. 148 cases were included in this calculation (68 RA and 80 migraine) and 86.7% (n=59) of RA sufferers and 96.3% (n=77) of migraine sufferers were correctly reclassified. This procedure was repeated using the same data, but removing the NHP score for mobility. This variable was the only one that had made a significant contribution in differentiating illness groups, as RA patients score far

	Pain	Sleep	Energy	Social Isolation	Emotional Reactions
Mobility	0.76 (0.0001)	0.29 (0.001)	0.41 (0.0001)	0.29 (0.0001)	0.07 N.S.
Pain		0.35 (0.0001)	0.34 (0.0001)	0.26 (0.001)	0.07 N.S.
Sleep			0.31 (0.0001)	0.33 (0.0001)	0.29 (0.001)
Energy				0.42 (0.0001)	0.44 (0.0001)
Social Isolation					0.55 (0.0001)

Table 6.5.

Correlations (Spearman) of category areas on the Nottingham Health Profile, for all chronically ill patients in the study who completed the NHP (n=148). The significance levels are those figures in brackets (N.S.=Not Significant).

	Pain	Sleep	Energy	Social Isolation	Emotional Reactions
Mobility	0.42 (0.001)	0.30 (0.01)	0.39 (0.001)	0.28 (0.02)	0.07 N.S.
Pain		0.28 (0.05)	0.29 (0.02)	0.07 N.S.	0.04 N.S.
Sleep			0.31 (0.01)	0.34 (0.005)	0.33 (0.01)
Energy				0.31 (0.01)	0.29 (0.01)
Social Isolation					0.55 (0.0001)

Table 6.6.

Correlations (Spearman) of category areas on the NHP, for RA patients (n=68). The significance levels are those figures in brackets (N.S.=Not Significant).

	Pain	Sleep	Energy	Social Isolation	Emotional Reactions
Mobility	0.63 (0.0001)	0.13 N.S.	0.27 (0.01)	0.12 N.S.	0.04 N.S.
Pain		0.32 (0.01)	0.11 N.S.	0.30 (0.01)	0.06 N.S.
Sleep			0.22 N.S.	0.25 N.S.	0.25 N.S.
Energy				0.45 (0.0001)	0.57 (0.0001)
Social Isolation					0.56 (0.0001)

Table 6.7.

Correlations (Spearman) of category areas on the NHP for migraine patients, (n=80). The significance levels are those figures in brackets (N.S.=Not Significant).

higher in this area than migraine patients, as would be expected. The linear discriminant function correctly placed 78.0% (n=53) of RA cases and 96.3% (n=77) of the migraine cases in the correct illness category. Using stepwise discriminant analysis a Wilks lambda value of 0.52 (significant at the 0.0001 level) was gained, with pain being the only variable that significantly contributed to the discriminant analysis. Whilst the value of Wilks lambda is somewhat high, it is still significant, and, further, the linear discriminant function was successful in allocating cases to the correct groups. This would tend to indicate that whilst mobility is an area of obvious significance in telling the NHP scores for migrainers and RA sufferers apart, there are still other differences between the groups. It would seem that migraine sufferers report better health than RA sufferers, as may be expected.

6.5.2. Association of NHP Scores with Mental Health

Scores on the NHP were correlated with mental health scores (GHQ raw score and NHP emotional reactions score) for both RA and migraine patients. The emotional reactions score on the NHP was found to be significantly correlated with raw score on the GHQ for both the RA sample ($r=0.59$, $n=68$, $p<0.0001$) and the migraine sample ($r=0.65$, $n=80$, $p<0.0001$). Scores on other domains of the NHP were then correlated with mental health scores. Tables 6.8. (I & II) summarise these analyses. The strongest correlations were found between

energy, sleep and social relationships with mental health scores for both samples.

TABLE 6.8. (I & II) HERE

A multiple regression analysis was undertaken for all the pain patients in the study who had completed the NHP (n=148). The dependent variable was, in the first regression, the NHP score for 'emotional reactions', and in the second multiple regression analysis it was raw GHQ score. NHP variables were entered into the regression by stepwise selection. R^2 values of 0.40 and 0.38 respectively were obtained. Tables 6.9. and 6.10. summarise this analysis.

TABLES 6.9. & 6.10. HERE

NHP scores are associated with emotional reactions scores as measured on the NHP itself, and raw scores on the GHQ. Energy and social relationships were the significant independent predictors of NHP emotional reactions scores. NHP scores for energy, sleep, and social relationships were found to be independent predictors of GHQ scores in the second regression analysis. Length of illness and age were added to the regression analysis, but did not significantly alter the results gained from NHP scores alone, e.g. the R^2 value for NHP scores plus age and length of illness against

NHP Domains	Mental Health Scores	
	GHQ Raw Score	NHP Score
Mobility	0.16 N.S.	0.07 N.S.
Pain	0.24 (0.01)	0.04 N.S.
Sleep	0.49 (0.0001)	0.33 (0.01)
Energy	0.49 (0.0001)	0.29 (0.01)
Social Isolation	0.40 (0.001)	0.55 (0.0001)

Table 6.8. (I)

Correlations (Spearman) of mental health scores (raw GHQ score and NHP emotional reactions score) and domains measured on the NHP for the Rheumatoid Arthritis patients (n=68). Significance levels are those figures in parentheses.

NHP Domains	Mental Health Scores	
	GHQ Raw Score	NHP Score
Mobility	0.01 N.S.	0.04 N.S.
Pain	0.19 N.S.	0.06 N.S.
Sleep	0.27 (0.02)	0.25 N.S.
Energy	0.39 (0.001)	0.57 (0.0001)
Social Isolation	0.52 (0.0001)	0.56 (0.0001)

Table 6.8. (II)

Correlations (Spearman) of mental health scores (raw GHQ score and NHP emotional reactions score) and domains measured on the NHP for the Migraine patients (n=80). Significance levels are those figures in parentheses.

NHP Variables	Beta Coefficient	Std Err	F	p
Social Relations	0.45	0.08	36.63	0.0001
Energy	0.21	0.05	16.91	0.0001
Mobility	-0.19	0.06	-9.32	0.0028
Sleep	0.10	0.06	2.68	0.1027
Constant	11.15			

n=148

$R^2=0.40$

* All variables with p values less than 0.15 were entered, which is the default value for the SAS package.

Table 6.9.

Stepwise multiple regression analysis for items on the NHP on NHP score for emotional reactions (unstandardised regression coefficients).

NHP Variables	Beta Coefficient	Std Err	F	p
Social Relations	0.07	0.02	15.50	0.0001
Energy	0.05	0.01	14.30	0.0001
Sleep	0.04	0.01	9.80	0.0017
Constant	2.12			

n=148

$R^2 = 0.38$

* All variables with p values less than 0.15 were entered, which is the default value for the SAS package.

Table 6.10.

Stepwise multiple regression analysis for items on the NHP on raw GHQ score (unstandardised regression coefficients).

the dependent variable of GHQ score was 0.36. The dummy variable of illness was entered into the regression, but, surprisingly, did not contribute to it.

6.5.3. Medical Assessments of Health Status

Analysis was undertaken upon the medical data gained from the notes of RA patients and from the frequency charts completed by migraine sufferers. In the RA patient group the following data was available: Haemoglobin counts, Erythrocyte Sedimentation Rate, assessments on the Steinbrocker, and information concerning whether patients were rheumatoid factor positive or negative. This material is summarised in Section 4.2. No association was found between domains on the NHP and length and frequency of migraines, or medical measures in RA.

The Steinbrocker scores were correlated with NHP scores for mobility, ($r=0.62$ ($p<0.0001$, $n=48$)). This relatively high correlation would tend to indicate that mobility as measured clinically on the Steinbrocker is strongly associated with individuals' own perceptions of their functional impairment. None of the medical measures were highly associated with any measures of psychological disturbance.

6.6. HEALTH STATUS AND MENTAL HEALTH IN THE SUBJECT PANEL

6.6.1. Hypotheses

It has been argued that the modal response of the NHP is zero when used in the general population (Kind and Carr-Hill, 1987). In part this could be accounted for by the tendency of the general population to describe its health as good (Curtis, 1983), and hence for an instrument such as the NHP (designed to uncover the chronically ill in populations) to be insensitive to minor health problems (which are common in the general population, see Hanny, 1979). The administration of the NHP to the subject panel was undertaken to see to what extent ill health was reported on this questionnaire by a sample of individuals who were not specifically selected due to health problems. Further, it enabled a check to be undertaken on scores on the NHP, insofar as NHP scores could be associated with psychological state, as in the previous study, to see if health state was associated with psychological well being.

6.6.2. Nottingham Health Profile Results from the Subject Panel Study

As with the RA and migraine sufferers, the NHP was completed by the Subject Panel participants (n=160). All Subject Panel participants completed the questionnaire. Scores were found to be, predictably, significantly lower for subject panel participants on all domains compared with

all chronically ill patients. The only non-significant difference was, as one might expect, on the domain of mobility between migraine sufferers and Subject Panel participants. The results gained were similar to those reported for samples of the general population (re. Hunt et al, 1986; Wilkin, et al, 1987). Tables 6.11. and 6.12. summarise the results of the NHP scores.

TABLES 6.11. & 6.12. HERE

Figure 6.1. shows mean results gained from the administration of the NHP (first section) for the RA, migraine and subject panel. This figure shows graphically the differences between the groups.

FIGURE 6.1. HERE

A multiple regression analysis was undertaken on the Subject Panel data using the NHP scores as the predictor variables (excluding the score for emotional reactions), against the dependent variables of the NHP score for emotional reactions, and, secondly, the GHQ raw score. R^2 values of 0.49 and 0.57 respectively were gained. Tables 6.13 and 6.14. summarise this data. The main independent predictors

	NHP Domains					
	Energy	Pain	Emotional Reactions	Sleep	Social Isolat- ion	Physical Mobility
<i>OVERALL (n=160)</i>						
Mean	15.9	6.9	10.7	13.7	8.6	4.5
S.D.	30.3	18.1	18.5	19.6	19.1	10.7

Table 6.11.
 Scores on the six domains of the NHP for all Subject Panel participants.

	Pain	Sleep	Energy	Social Isolation	Emotional Reactions
Mobility	0.70 (0.0001)	0.26 (0.001)	0.42 (0.0001)	0.09 N.S.	0.17 N.S.
Pain		0.29 (0.0001)	0.34 (0.0001)	0.17 N.S.	0.21 (0.01)
Sleep			0.26 (0.001)	0.21 (0.01)	0.41 (0.0001)
Energy				0.52 (0.0001)	0.54 (0.0001)
Social Isolation					0.69 (0.0001)

Table 6.12.

Correlations (Spearman) of category areas on the Nottingham Health Profile, for all Subject Panel respondents in the study (n=160). The significance levels are those figures in brackets (N.S.=Not Significant).

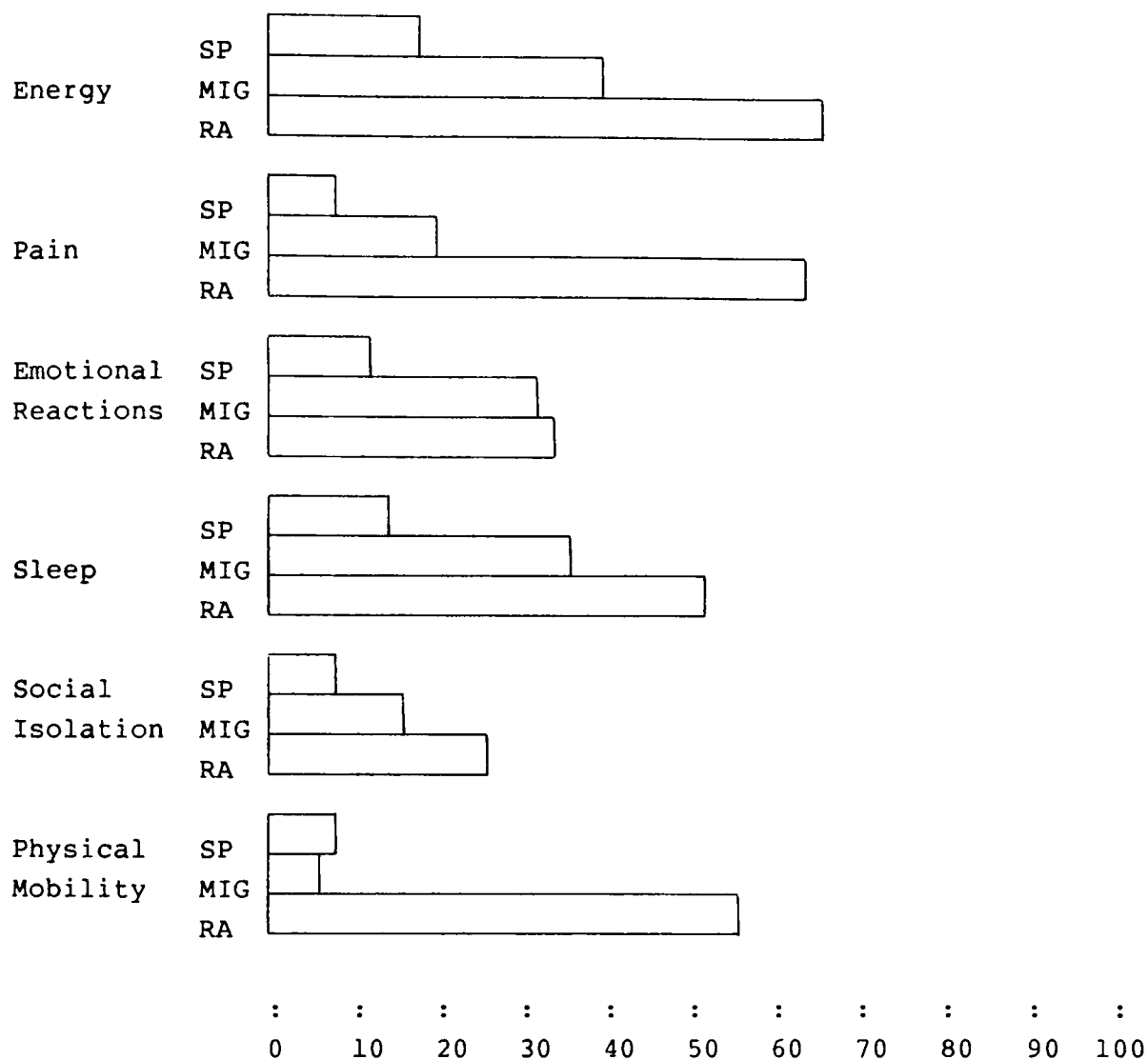


Figure 6.1.

NHP category scores for the three separate groups of respondents.

SP Subject panel respondents (n=160)

MIG Chronic migraine sufferers (n=80)

RA Chronic rheumatoid arthritis sufferers (n=68)

of the dependent variable on both analyses were energy, social relationships, and sleep.

TABLES 6.13 and 6.14. HERE

As with the results gained from the chronically ill, the Subject Panel participants were found to report higher levels of non psychotic psychiatric disturbance when perceived health status scores were elevated. NHP domains most significantly contributing to the regression were in the same areas as for chronically ill individuals (i.e. energy, sleep and social relationships). Thus individuals with high NHP scores felt their present state of health had contributed to their having poor sleep, loss of energy, and an impairment in their social functioning.

6.7. THE PERCEIVED IMPACT OF ILLNESS UPON INDIVIDUALS' DAILY LIVES

As part of the questionnaire designed specifically for this research it was decided to include a section aimed at tapping areas of potential concern to patients in their daily lives that may have been affected by chronic illness. Section 5 contains these questions (see appendix).

The questions from Section 5 of this section were correlated with GHQ raw scores and NHP emotional reactions scores.

NHP Variables	Beta Coefficient	Std Err	F	p
Energy	0.03	0.01	6.60	0.0111
Sleep	0.08	0.02	17.61	0.0001
Social Relations	0.15	0.02	52.18	0.0001
Constant	1.04			

n=160

$R^2=0.49$

* All variables with p values less than 0.15 were entered, which is the default value for the SAS package.

Table 6.13.

Stepwise multiple regression analysis for items on the NHP on GHQ raw score for subject panel data (unstandardised regression coefficients).

NHP Variables	Beta Coefficient	Std Err	F	p
Energy	0.12	0.04	10.27	0.0016
Sleep	0.23	0.05	20.21	0.0001
Social Relations	0.52	0.06	75.29	0.0001
Constant	1.04			

n=160

$R^2=0.57$

* All variables with p values less than 0.15 were entered, which is the default value for the SAS package.

Table 6.14.

Stepwise multiple regression analysis for items on the NHP on NHP score for emotional reactions for subject panel data (unstandardised regression coefficients).

Tables 6.15. and 6.16. summarise this data (only items providing significant correlations are included in the tables).

TABLES 6.15. & 6.16. HERE

Table 6.17. provides basic statistics on those items that were found to significantly correlated with the emotional reactions scores.

TABLE 6.17. HERE

Variables that correlated with GHQ scores for RA and migraine samples were then summed into a single variable: one for the RA sample, and one for the migraine sample. These scales were then correlated with GHQ scores for RA and migraine samples respectively. A correlation of 0.35, ($p < 0.001$, $n = 68$) was found for RA patients when the scale was correlated with GHQ raw score, and for migraine sufferers $r = 0.44$, ($p < 0.0001$, $n = 80$) for the relevant scale correlated with GHQ raw score.

<i>Does/did the illness:</i>	R.A.	Migraine
Effect your work?	0.23 (0.05) 80	N.S.
Cause problems to domestic relationships?	0.24 (0.05) 80	0.39 (0.001) 80
Make you feel you had no power over your life?	0.23 (0.05) 80	0.40 (0.001) 80
Make you worry you might be bothersome to friends and relatives?	0.29 (0.01) 79	0.29 (0.01) 80
Make you worry you might be bothersome to people in general?	0.29 (0.01) 79	0.31 (0.001) 80

Table 6.15.

The effect of illness upon peoples perceptions of their lives correlated with mental health as measured on the GHQ (Pearson Product Moment Correlation Coefficients. The number in brackets is the probability value. NS=Not Significant).

<i>Does/did the illness:</i>	R.A.	Migraine
Cause problems to domestic relationships?	0.35 (0.001) n=68	0.41 (0.001) 80
Cause you to worry about what other people think of you (eg putting the symptoms on etc)?	N.S.	0.24 (0.05) 80
Make you feel you had no power over your life?	0.24 (0.05) 68	0.49 (0.0001) 80
Make you worry you might be bothersome to friends and relatives?	N.S.	0.40 (0.001) 80
Make you worry you might be bothersome to people in general?	N.S.	0.24 (0.05) 80

Table 6.16.

The effect of illness upon peoples perceptions of their lives correlated with mental health as measured on the emotional reactions scale of the NHP (Pearson Product Moment Correlation Coefficients. The number in brackets is the probability value. NS=Not Significant).

<i>Does/did the illness:</i>	R.A.	Migraine
Effect your work?	4.51 (2.03) 80	3.78 (1.42) 80
Cause problems to domestic relationships?	2.21 (1.52) 80	2.40 (1.35) 80
Cause you to worry about what other people think of you (eg putting the symptoms on etc)	2.61 (1.82) 80	2.41 (1.63) 80
Cause you to worry you might be bothersome to friends and relatives	3.61 (2.19) 79	2.88 (1.80) 80
Make you feel you have no power over your life?	2.83 (1.99) 80	2.86 (1.77) 80
Make you worry you might be bothersome to people in general?	2.85 (2.22) 79	2.18 (1.52) 80

Table 6-17

Mean scores, and standard deviations of scores on questions related to peoples perceptions of their lives and the impact of their illness upon it (min score=1, max score=7) (from the 'Coping with Pain Questionnaire')

6.8 DISCUSSION OF THE IMPACT OF PERCEIVED HEALTH STATUS UPON MENTAL HEALTH.

It is interesting to note that in their work on coping, Lazarus and his colleagues acknowledge the importance of the perceptual element in influencing how an individual perceives and reacts to stressful events, (Cohen and Lazarus, 1979, Lazarus and Folkman, 1984). Their research has been concerned with behaviour that occurs *after* the perception of stress, and the importance of the initial perception of the event remain unanalyzed. However, the perception of stress, it is argued here, is a major aspect in the adaptation of individuals to their illness.

The evidence presented here from the RA/Migraine study and the subject panel study suggests that assessments of perceived health status can provide insights into the impact of an illness upon an individual that standard medical measures cannot. The results indicate that individuals' perceptions of the impact of their health upon their life vary enormously. This variation, however, is not associated with many of the measures used in 'objective' medical assessment. Clinical assessment as measured on the Steinbrocker was found to be highly associated with individuals' own assessments of mobility. In part such a clinical assessment is a rather simple descriptive one and the congruence in assessment is largely attributable to the

fact that medical personnel have access to much the same information as do patients. For example, doctors can see the impact that RA has had upon individuals' ability to walk. There is, in the terminology of contemporary social psychology, no divergence in perspective between the 'observer' (in this case the medical practitioner or other assessor) and the 'actor' (in this case the RA patient), (Farr and Anderson, 1983). In radical behaviourism such a result is to be expected: the information available to oneself is similar to that available to others (Bem, 1967, 1972). Whereas ESR and haemaglobin counts may provide measures of underlying disease processes, such as the degree of activity or severity of disease, the Steinbrocker provides a summary measure of the overall level of functional disability of the patient.

Certain aspects of the NHP do not lend themselves to easy verification from outside observers, although those individuals close enough to patients (eg members of a sufferer's family) may be able to substantiate the claims made by sufferers from external behaviour. However, certain information is simply not available to the outside observer, and hence cannot be substantiated externally. It is certainly possible that the elevated scores on aspects of the NHP in fact reflect psychological state. It has been suggested that poor mental health may lead to over reporting of illness symptoms, (Spiegel et al, 1988). Indeed, it has

been suggested that the NHP can be used as a measure of psychological state, when a number of the scale scores are collapsed together, (McKenna and Payne, 1989). However as McKenna and Payne argue, many aspects of illness are in large part determined by patients subjective assessment. The decision to go to the doctor is usually based on subjective assessment of ill health, and is reflective of concern about it. Further, it is hardly surprising that those who assess themselves as socially isolated, lacking energy (further supported by the results of the MPQ where the large majority of sufferers claimed the pain was either 'exhausting' or 'tiring'), and sleeping poorly also score as psychologically distressed. These are the attributes of others' lives that observers would claim were potentially depressing, and so it is hardly surprising that individuals experiencing them find them so. Of course such a claim may be countered by arguing that there are numerous stressors that may cause psychological disturbance, and the study undertaken here has not addressed other potential aspects of the sufferers' lives. However, the correlations for the NHP items with GHQ and NHP emotional responses scores seem to indicate that other stressors are not the most salient for the sample studied here. The original sampling frame determined that illness was likely to be the most salient stressor in the lives of the people studied here (in the RA/Migraine samples).

Results from the correlation of emotional state (both on the GHQ and the NHP) with questions concerning the impact of the illnesses upon the daily lives of the sufferers tended to indicate that individuals were most concerned about the effect of the illness upon others with whom they came into contact with (e.g. they were concerned about being bothersome to friends and relatives, etc), and the extent of powerlessness individuals felt due to the illness. It is interesting to note that powerlessness was more strongly associated with non psychotic psychiatric disturbance amongst migraine than RA sufferers. This result is explicable in terms of the tendency of migraine to flare up at unpredictable times, and totally demobilise an individual, whereas, for the most part, RA follows a somewhat more predictable course on a week to week basis. These results can be interpreted as supporting those of the NHP discussed above. Those whose illnesses make considerable demands upon them are less likely to be able to live a 'normal' life, to feel powerless, and hence suffer higher levels of psychological disturbance. The following section will explore possible associations between control and fatalism with illness state and mental health.

CHAPTER 7

FATALISM AND CONTROL IN PAINFUL CHRONIC ILLNESS

7.1. Locus of Control

7.1.1. Introduction

Rotter (1966) proposed that an individual's potential for carrying out a behaviour is in large measure determined by the expectation that the person has of his or her own ability to bring about a particular outcome, and further the value that the individual places upon that outcome. He suggested that those individuals who have the generalized belief that they can influence events and outcomes have an 'internal locus-of-control', whilst those individuals who believe that outside forces beyond their own control (such as fate/chance and powerful others) determine outcomes have an 'external locus-of-control'.

Individuals' perceptions of control over their lives may be severely affected by painful chronic illness. Control, in this context, refers to people's belief that the source of the outcomes of their behaviour lies either with themselves (an internal locus of control), the environment (e.g. 'powerful others' such as doctors) or chance ('chance' or sometimes referred to as 'fatalism'). People regard both themselves and others as being either what DeCharms (1968)

termed 'origins' or 'pawns' of outcomes in the social environment.

7.1.2. The Locus-of-Control construct: a review, and formulation of hypotheses.

The purpose of this chapter is to explore the relationship between mental health and health locus of control. It will examine perceptions of helplessness and control, as measured by the Multidimensional Health Locus of Control scale, (MHLC), in both of the chronically ill samples, and also in the Subject Panelrespondents.

Evidence suggests that locus of control acts as a mediator, influencing the relation between life stressors and impairment of mental and physical well being, (Lefcourt, et al, 1981). An internal locus-of-control, can have an effect upon the impact of stressors, (Parkes, 1984). For example, external locus-of-control and intolerance of ambiguity were found to be related to tension at work, and this was not the case for those with an internal locus, who felt they had some control over ambiguity in the work situation (Keenan and McBain, 1979). Additionally, individuals exposed to real life stressors not only experience less distress if they have an internal locus-of-control than do externals, but also achieve better outcomes, (Anderson, 1977). Individuals with an internal locus of control are more likely to engage in health promoting behaviours than are externals. Seeman and Seeman (1983) found that individuals with a low sense of personal control generally showed less optimism about their

treatment, and reported a poorer level of health as well as more episodes of ill health, than those exhibiting a greater sense of control.

Further, evidence suggests that health behaviour is related to locus of control; Seeman and Evans (1962), for example, found hospitalised tuberculosis patients who held internal locus of control beliefs knew more about their condition, actively sought information from the medical staff treating them and were more dissatisfied by the information made available to them than externals. Likewise, DuCette (1974), studying a sample of newly diagnosed diabetics, found that internals had a greater knowledge of their illness than did externals. It has been generally accepted that a high sense of personal control is beneficial for adjustment to the demands of chronic illness. Patients are believed to be able to adjust to the demands of their illness better if they have a sense of control over their illness, (Janis and Rodin, 1979). In a large scale community survey it was found, for example, that self-reliant individuals adjusted better to the demands of their illness than did those individuals who relied on others for help, (Brown, B.B. 1978).

Wallston and Wallston (1981) note that it is '...reasonable to expect that patient status (i.e. actually being a patient) would increase external health expectancies' (text in parentheses added). Further, they argue that '...most internal samples tend to be those exhibiting preventative

health behaviours...and college samples; *both tend to be middle to upper class*' (Wallston and Wallston, 1981, p215, italics added). Wallston and Wallston summarise a number of studies in which the MHLC has been used (many of which are unpublished) and the general findings seem to be that externality is associated with age (i.e. the older one is the more likely one is to be external) and, also, that lower levels of education, and also social class, are associated with externality.

More recently, it has been suggested that it may not always be beneficial for adaptation to chronic illness to have an internal locus of control. Indeed, Reid (1984), argues that locus of control studies do not examine the ramifications of living in a state of external control, except insofar as they assume externals to manifest a profound sense of helplessness, hopelessness and depression. However, the association of depressed state with external locus of control ('chance'/'fatalism' or a belief 'powerful others' may be influential) is perhaps too narrow a characterisation of the role played by peoples' belief in their own power. Put bluntly, it may be useful sometimes to concede defeat. Reid argues that externality in accepting that one's disease is not one's responsibility in origin may be adaptive, especially if one combines responses by assuming internality on some other dimension, such as seeking medical information and medication. Optimally, therefore, a combination of externality and internality may prove adaptive. Affleck, et al, (1987) have suggested that in illnesses which have

proved impossible to control it may be adaptive to believe that one has little power over the course of the disease. The argument here is that an external locus of control will prevent individuals blaming themselves for their disease and their health state, and further they will not expend too much time and energy at wasteful attempts at control, which will only cause misery because they fail. Individuals who manifest external locus of control may well be in a better position to accept the status quo and adjust to it than those who manifest an internal locus. A parallel claim has been made by Young (1961), that educational attainment is perceived by some not to be an accurate and meritocratic judge of ability. External factors, such as inaccuracies of the examination system, the claim that the education system is designed to work in the interests of certain elite groups in society, etc are invoked for lack of success rather than internal attributes (e.g. stupidity). Invoking the latter may foster frustration, and cause individuals to lose their 'inner vitality', suggests Young. Likewise, assuming continuing ill health is a function of external factors may prevent individuals becoming dispirited because attempts at control continuously fail.

In summary, therefore, it seems that internality is most useful where an illness can be controlled and influenced by health related behaviours, whilst externality is most appropriate for those whose illnesses have resisted attempts at control and would reasonably be expected to continue to do so.

It was hypothesised that the longer individuals suffering RA had experienced their illness the greater would be their scores on externality (i.e. fate and powerful others), and that the lower would be their beliefs in personal control, because, following social learning theory, individuals will have more often experienced failure personally to modify or influence the course of their illness than individuals with a shorter history of illness. That is, individuals who have had their illnesses for longer periods may assume that they had no power over the illness, and would hence put the onus upon fate or powerful others. This hypothesis is based upon the work of Affleck, et al, (1987), mentioned above, who have suggested that in illnesses which have proved impossible to control it may be adaptive to believe that one has little power over the course of the disease. An external locus of control would act so as to prevent sufferers blaming themselves for their disease state, and prevent them expending great amounts of effort in trying to 'get well'.

It is possible that the extent and severity of illness can influence perceptions of control. Stress caused through illness may produce feelings of helplessness, and this helplessness may be 'learned' insofar as people see themselves as powerless in having controlled their illness in the past, and believe they will be powerless to exhibit any control over the illness in the future (Seligman, 1975). Indeed, in a reformulation of the theory of learned helplessness Seligman and his colleagues argued that

individuals may globalise their helplessness, and believe they are not only unable to influence their illness, but also other aspects of their lives (Abramson, Garber and Seligman, 1980). This would be in keeping with the hypothesis outlined above that lower class individuals may score higher on externality than those in the middle and upper classes. In the case of the two illnesses studied here these factors are closely bound up with the unpredictable nature of the diseases. Both illnesses have a large aspect of unpredictability about them, with RA patients not knowing the likely course of the disease, and when their illness will flare up again, whilst chronic migraine sufferers cannot predict the time and duration of future attacks. In both cases some degree of control can be manifested by avoiding factors that may trigger flare ups or headache attacks, but it is certainly not the case that keeping warm will prevent all flare ups of RA, or that avoiding chocolate, cheese and red wine will guarantee no future migraines. The manifestations of the two diseases that are studied here were severe forms of the illnesses that did not lend themselves to such 'common sense' cures. If 'externality' is associated with length of illness, it is argued, this may be adaptive to the demands of living with an uncontrollable disease.

Firstly, the internal consistency of the instrument will be examined, on both the chronic illness groups and also on the non-clinical sample of Subject Panel respondents. Then, scores obtained on the instrument will be correlated with

items included in the questionnaire designed specifically for this research which tap beliefs relating to the particular illness experienced by the individual. The question 'Do you think fate may be the cause of you suffering RA/Migraine?' (3b) relates to the dimension of chance on the MHLC, (chance) whilst the question 'Does the illness make you feel that only the medical profession could help you?' (5g) relates to the dimension of powerful others on the instrument. Section 7 of the 'coping' questionnaire concerns personal control by patients over their illness, in that it explores how much decision making they engage in in relation to their illness. Thus it asks questions concerning whether they actively seek information from the doctor, and whether they exert any control over the level of medication they take.

Evidence from previous studies has provided varying results concerning the internal reliability of scales on the MHLC. For example Wallston and Wallston (1984) and Nicassio et al (1978) report alpha values falling somewhere between 0.66 and 0.75, whilst lower values have been reported by, for example, Lewis et al (1978) who reported an alpha of just 0.36. It is possible that such differences may be accounted for by methodological differences. Wallston and Wallston (1984) suggest the low alpha value gained by Lewis et al (1978) may in part have been caused by the adoption of a four point response scales, rather than the six point scales suggested by the originators (Wallston et al, 1986), though they provide no theoretical claim as to why four point

scales would have such an effect on reliability, nor do they provide any empirical support for their observation (e.g. by means of comparing results of the MHLC gained by using different response formats). However, an alternative interpretation of Lewis et al's results might be that they administered the Health Locus of Control (the instrument from which the MHLC was developed) verbally rather than for paper and pen self completion. One possible reason why verbal administration may reduce reliability scores is that respondents may forget the response alternatives. It is suggested the method adopted in the RA/migraine study of showing patients the questionnaire and asking them to state their answers verbally should have overcome problems of individuals not recalling the available responses. Further, Wallston et al (1978) do not suggest that the questionnaire should be administered for only by pencil and paper completion. They acknowledge that interview responses may affect reliability, but provide no evidence for this observation, (Wallston and Wallston, 1981).

One explanation for the variation in reliability scores gained using the MHLC is that it is influenced by level of education. The data of Nicassio, et al, (1978), although obtained from an RA sample, was gained from patients who were attending a private clinic in America. In their paper the modal education level was 'high school graduate'. These subjects represent a somewhat more formally educated group than the RA group surveyed for this research. Likewise, Wallston and Wallston's data is gained from individuals

whose educational level is higher than that of the RA patients surveyed here. The hypothesis will be examined that individuals with a higher level of education are more consistent in their replies than those with less time spent in formal education, or fewer qualifications. It is possible that level of education may have some bearing on the level of consistency measured on the scales. This hypothesis will be explored using the RA/migraine data. It could be argued that those with a higher level of formal education are better at remaining consistent throughout this questionnaire. They may understand the questions better, and as such they may wish to be seen as consistent in their responses. There is a long and fruitful literature on 'demand characteristics' in psychological research (Orne 1962), and attempts by individuals to be regarded as 'good subjects' (Riecken, 1962), and in doing so attempt to validate the (perceived) hypothesis of the experimenter. One aspect of 'demand characteristics' is the wish to be seen as 'good subjects' and hence provide consistent answers. It would therefore be expected for migraine patients, with their higher overall level of education compared to the RA patients, to be more consistent and, for the data overall, for education to be associated with level of consistency on the MHLC scales.

7.2. METHOD AND MATERIALS

The Multidimensional Health Locus of Control (MHLC) was administered to all migraine sufferers in the study, and to all Subject Panel respondents. A small number of RA sufferers did not complete the questionnaire due to tiredness.

An outline of the administration of the questionnaire used in this research is to be found in Chapter 3, whilst a copy of the MHLC is to be found in Appendix 1d. It is a questionnaire comprised of 18 questions, of which six relate to the dimension of internality, six to the dimension of powerful others and six to the dimension of fate. Items relating to explanations for illness, and social support were administered in the questionnaire designed specifically for this research. These items are to be found in the questionnaire (Sections 3 and 4), and a copy of the instrument is to be found in Appendix 1e. The MHLC was sent to the Subject Panel respondents for self completion, and postal return.

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7.3. RESULTS

7.3.1. Internal Consistency of MHLC Scales

The MHLC was tested for internal reliability by means of the Cronbach's Alpha statistic. Table 7.1. summarises this data for both the illness groups (RA and migraine), as well as both the illness groups combined and also for the Subject Panel Sample.

TABLE 7.1. HERE

The results were somewhat more satisfactory for the Subject Panel Sample, perhaps indicating that this questionnaire lends itself better to self completion rather than as part of an interview schedule. The internal reliability scores for the domains measured by the instrument are not particularly high for the patient groups. There are a number of possible explanations for this difference. One possibility is the method of administration, whilst another is that the two patient groups were unclear as to the references made to health in the questionnaire. In part this may be due to the confusion in the minds of many sufferers as to what each individual statement referred. Often the patients asked whether the questionnaire related to their state of health overall, or their state of ill-health, (patients were advised that the questionnaire refers to state of health overall, and not to illness specific aspects, although some patients seemed to remain unclear even after having been informed of this).

Sample	n	Self	Powerful others	Chance
RA/Migraine	152	0.52	0.60	0.49
RA	72	0.53	0.50	0.47
Migraine	80	0.53	0.57	0.47
Subject Panel	160	0.83	0.62	0.62

Table 7.1.
Internal reliability of items in the Multidimensional Health
Locus of Control as measured by Cronbachs' Alpha.

Overall values of the MHLC scale scores were correlated with individual items for the relevant scale. The correlations show that individual items were associated with the overall scale score. These results are summarised in Tables 7.2. to 7.4.

TABLES 7.2. - 7.4. HERE

It had been hypothesised that years of formal education, and/or qualifications held would be associated with scores on the MHLC, and the reliability of scores on the MHLC. The effect of education, and educational qualifications, on the scores gained on the MHLC domains was tested on the RA/migraine sample by a MANOVA. A median split on the dependent variables of years of formal schooling and educational qualifications provided the levels for the independent variables. Significant results were gained for scores of the six 'powerful others' questions on years of formal education ($F=3.31$, $df=6$, $p<0.005$), and qualifications obtained ($F=5.39$, $df=6$, $p<0.001$). The higher the level of qualifications and years of formal education the lower was the score on 'powerful others' externality. Significant independent effects were found for all but one MHLC 'powerful others' question ('My family has a lot to do with me becoming sick or staying healthy'). However, MANOVA results for 'internality' and 'chance' were not significant.

	Sample		
	RA & Migraine n=152	RA n=72	Migraine n=80
Self 1	0.50	0.39	0.62
Self 2	0.55	0.63	0.47
Self 3	0.37	0.32	0.46
Self 4	0.60	0.63	0.58
Self 5	0.58	0.59	0.58
Self 6	0.63	0.67	0.67

Table 7.2.

Correlation coefficients (Spearman) of Internality items on the MHLC against the Internality scale score, for all chronically ill subjects either separately or combined together, ($p < 0.001$). See over for item content.

Self 1 (1): If I get sick it is my own behaviour which determines how soon I get well again.

Self 2 (6): I am in control of my health.

Self 3 (8): When I get sick I am to blame.

Self 4 (12): The main thing which affects my health is what I myself do.

Self 5 (13): If I take care of myself, I can avoid illness.

Self 6 (17): If I take the right actions, I can stay healthy.

Annex to Table 7.2.

Internality ('Self') items on the MHLIC. Responses are given on a 6 point scale. The number in brackets indicates the item's location amongst the eighteen items on the questionnaire.

	Sample		
	RA & Migraine n=152	RA n=72	Migraine n=80
P.O. 1	0.68	0.60	0.67
P.O. 2	0.71	0.74	0.67
P.O. 3	0.29	N.S.	0.58
P.O. 4	0.59	0.54	0.47
P.O. 5	0.62	0.63	0.51
P.O. 6	0.60	0.62	0.51

Table 7.3.

Correlation coefficients (Spearman) of Powerful Others items on the MHLC against the Powerful Others scale score, for all chronically ill subjects either separately or combined together, ($p < 0.001$). See over for item content.

Power 1 (3): Having regular contact with my doctor is the best way for me to avoid illness.

Power 2 (5): Whenever I don't feel well I should consult a medically trained professional.

Power 3 (7): My family has a lot to do with my becoming sick or staying healthy.

Power 4 (10): Health professionals control my health.

Power 5 (14): When I recover from an illness, it is usually because other people (e.g. doctors, nurses, family, friends) have been taking care of me.

Power 6 (18): Regarding my health, I can only do what my doctor tells me to do.

Annex to Table 7.3.

'Powerful Others' externality items on the MHLC. Responses are given on a 6 point scale. The number in brackets indicates the item's location amongst the eighteen items on the questionnaire.

	Sample		
	RA & Migraine n=152	RA n=72	Migraine n=80
Chance 1	0.43	0.39	0.49
Chance 2	0.59	0.60	0.54
Chance 3	0.46	0.40	0.49
Chance 4	0.59	0.64	0.50
Chance 5	0.47	0.47	0.52
Chance 6	0.63	0.65	0.60

Table 7.4.

Correlation coefficients (Spearman) of Chance/Fatalism items on the MHLIC against the chance/Fatalism scale score, for all chronically ill subjects either separately or combined together, ($p < 0.001$). See over for item content.

Chance 1 (2): No matter what I do, if I am going to become ill, I am going to become ill.

Chance 2 (4): Most things that affect my illness happen to me by accident.

Chance 3 (9): Luck plays a big part in determining how soon I will recover from an illness.

Chance 4 (11): My good health is largely a matter of good fortune.

Chance 5 (15): No matter what I do I'm likely to become ill.

Chance 6 (16): If it's meant to be, I will stay healthy.

Annex to Table 7.4.

'Chance' (fate) externality items on the MHLIC. Responses are given on a 6 point scale. The number in brackets indicates the item's location amongst the eighteen items on the questionnaire.

This provides some support for the hypothesis that educational qualifications and years of education may influence one MHLC scale score, although it is difficult to explain why only one dimension should be so effected.

Analysis of the scale scores on the MHLC by splitting the sample into two on the basis of school leaving age (the median falling at 15 1/2 years), and then calculating Cronbach's alpha for the subsamples, did not provide evidence for the hypothesis that those with more years of formal education were any more consistent on the MHLC. A similar analysis was undertaken using a median split on the number of qualifications obtained (the median falling between those with no qualifications whatsoever, and those with a CSE or more), and once again those with higher qualifications were not found to be more consistent on the MHLC scores. Table 7.5. (I & II) summarises these results.

TABLE 7.5. (I & II) HERE

7.3.2. Summary statistics from the MHLC

Mean scores on the MHLC are summarised in table 7.6. for both the chronically ill groups and the Subject Panel sample.

TABLE 7.6. HERE

	Years of education	
	Low (n=78)	High (n=75)
Self (IHLC)	0.41	0.60
Fate (CHLC)	0.50	0.54
Power (PHLC)	0.58	0.48

Table 7.5. (I)

Internal reliabilities for scales on the MHLC (Cronbach's alpha) by median split on school leaving age for all patients in the study.

	Qualifications	
	Low (n=86)	High (n=67)
Self (IHLC)	0.44	0.57
Fate (CHLC)	0.51	0.43
Power (PHLC)	0.54	0.57

Table 7.5.(II)

Internal reliabilities for scales on the MHLC (Cronbach's alpha) by median split on formal qualifications for all patients in the study.

	MHLC Domains		
	Internal	Powerful Others	Chance /Fate
RA/Migraine (n=152)	16.29 (4.19)	12.75 (5.39)	14.95 (4.57)
RA (all subjects) (n=72)	16.11 (4.22)	15.08 (5.19)	16.04 (4.66)
RA (In-patients) (n=36)	16.42 (4.74)	15.92 (5.90)	17.08 (3.97)
RA (Out-patients) (n=36)	15.80 (3.67)	14.25 (4.30)	15.00 (5.12)
Migraine (n=80)	16.40 (4.17)	10.65 (4.67)	13.98 (4.29)
Subject Panel (n=160)	18.12 (4.60)	9.98 (4.31)	12.51 (4.35)

Table 7.6.

Means of domains of the Multidimensional Health Locus of Control for all groups in the study (*standard deviations are those figures in parentheses*).

Significant differences were found between the scores on all the scales of the MHLC for the chronically ill sample as against those for the Subject Panel sample with the latter scoring significantly lower on Powerful others, ($t=4.76$, $p<0.001$), and Chance, ($t=4.46$, $p<0.001$), and significantly higher on Internality ($t=3.51$, $p<0.001$). Similar results were found for the RA patients alone, where significant differences were found between their scores on the MHLC and the scores of the Subject Panel respondents on all domains (Internal; $t=3.13$, $p<0.001$, Powerful others; $t=7.49$, $p<0.001$, and Chance; $t=5.01$, $p<0.001$). Among the RA sufferers out-patient scores were found to be significantly higher than Subject Panel scores on Powerful Others ($t=5.34$, $p<0.001$), and Chance ($t=2.73$, $p<0.001$), and significantly lower for scores on Internality ($t=3.13$, $p<0.01$). In patient scores were significantly different on two domains only. In patients scored significantly higher on both Powerful Others ($t=5.25$, $p<0.001$), and Chance ($t=4.61$, $p<0.001$).

Migraine patients were found to have significantly different scores to the Subject Panel respondents on two of the scales of the MHLC. The internality score for the Subject Panel respondents was higher than that of the migraine respondents, ($t=2.59$, $p<0.01$), whilst the opposite was true for the chance/fate score, ($t=2.38$, $p<0.02$). There was no significant difference on the domain of powerful others, however.

Differences between the two illness groups comprising the chronically ill sample were analysed. Significant differences were found on two domains of the MHLC, RA patients scoring significantly higher on both Powerful Others scale ($t=5.44$, $p<0.00$), and chance ($t=2.44$, $p<0.02$). There were, however, no significant differences for scores on the MHLC between RA in-patients and out-patients.

The three scale scores of the MHLC were correlated against one another to see how distinct the scores were. For the RA/migraine sample as a whole the only significant correlation between scales of the MHLC was between 'chance' and 'powerful others' ($r=0.28$, $p<0.0005$). Splitting this data down into the two illness groups showed that there were no significant associations for the RA sample, although 'chance' and 'powerful others' were found to be significantly correlated ($r=0.24$, $p<0.05$) for the migraine sample.

Domains on the MHLC were likewise correlated to determine how distinct the dimensions were for the Subject Panel data. 'Chance' and 'powerful others' were found to be correlated ($r=0.20$, $p<0.01$), and a small negative correlation was found between 'chance' and 'internality'.

7.3.3. MHLC scale scores and their association with related questions

Despite the relatively low level of internal consistency for domains on the MHLC, the score for 'chance'/'fatalism' was found to be significantly correlated with the score for the question on the 'coping' questionnaire which asked whether individuals thought they had contracted their illness due to fate (ie one of those things over which they had no control), (for the migraine sample $r=0.42$, $p<0.0001$, $n=80$, and for the RA sample $r=0.43$, $p<0.001$, $n=72$). However, the item asking sufferers if they felt only the medical profession could help them was not found to be correlated with the powerful others score on the MHLC. Internality as measured on the MHLC was correlated with scores for the question 'How often do you deviate from the routine of pill taking recommended by Doctors and take extra medication?' for RA sufferers ($r=0.42$, $p<0.001$, $n=72$), although not for migraine sufferers. Internals are thus making a decision to increase medication, although it is not clear as to why only the RA patients should adopt this strategy.

7.3.4. Demographic Variables and their association with the MHLC

A number of demographic variables were collected, and these were correlated with the scores from the MHLC. The predicted correlation between externality and social class was found only with the migraine sample on the domain of 'powerful others' ($r=0.39$, $p<0.001$). Thus, migraine sufferers with low

social class positions as measured on the Registrar General's Classification of Occupations (1980) felt that powerful others, such as doctors and friends, were influential in their health state. The 'chance' score was not found to be significantly correlated with class for the migraine sample. Neither externality score was found to be significantly correlated with social class for the RA sample. It had been hypothesised that length of illness may be associated with a more external locus of control, but it was neither associated with powerful others or fatalism on the MHLC. However, for the arthritis sample, age was found to be correlated with both powerful others ($r=0.36$, $p<0.01$, $n=72$) and chance ($r=0.37$, $p<0.001$, $n=72$), though not with internalism. Age was not significantly correlated with scores on the MHLC for the migraine sample. One possible explanation for these findings might be that the RA sample was significantly older and suffered more functional limitations than the migraine sample, and they may therefore see themselves as being dependent on powerful others such as doctors and relatives. Further, they may be more fatalistic about their state of health, assuming that as one gets older so one becomes more infirm, and there is very little one can do to prevent this. Indeed, these findings seem to gain further support from the results of the Subject Panel study, which is comprised of relatively healthy individuals, where correlations between age and MHLC domains were not significant.

7.3.3. MHLC scale scores and their association with related questions

Despite the relatively low level of internal consistency for domains on the MHLC, the score for 'chance'/'fatalism' was found to be significantly correlated with the score for the question on the 'coping' questionnaire which asked whether individuals thought they had contracted their illness due to fate (ie one of those things over which they had no control), (for the migraine sample $r=0.42$, $p<0.0001$, $n=80$, and for the RA sample $r=0.43$, $p<0.001$, $n=72$). However, the item asking sufferers if they felt only the medical profession could help them was not found to be correlated with the powerful others score on the MHLC. Internality as measured on the MHLC was correlated with scores for the question 'How often do you deviate from the routine of pill taking recommended by Doctors and take extra medication?' for RA sufferers ($r=0.42$, $p<0.001$, $n=72$), although not for migraine sufferers. Internals are thus making a decision to increase medication, although it is not clear as to why only the RA patients should adopt this strategy.

7.3.4. Demographic Variables and their association with the MHLC

A number of demographic variables were collected, and these were correlated with the scores from the MHLC. The predicted correlation between externality and social class was found only with the migraine sample on the domain of 'powerful others' ($r=0.39$, $p<0.001$). Thus, migraine sufferers with low

social class positions as measured on the Registrar General's Classification of Occupations (1980) felt that powerful others, such as doctors and friends, were influential in their health state. The 'chance' score was not found to be significantly correlated with class for the migraine sample. Neither externality score was found to be significantly correlated with social class for the RA sample. It had been hypothesised that length of illness may be associated with a more external locus of control, but it was neither associated with powerful others or fatalism on the MHLC. However, for the arthritis sample, age was found to be correlated with both powerful others ($r=0.36$, $p<0.01$, $n=72$) and chance ($r=0.37$, $p<0.001$, $n=72$), though not with internalism. Age was not significantly correlated with scores on the MHLC for the migraine sample. One possible explanation for these findings might be that the RA sample was significantly older and suffered more functional limitations than the migraine sample, and they may therefore see themselves as being dependent on powerful others such as doctors and relatives. Further, they may be more fatalistic about their state of health, assuming that as one gets older so one becomes more infirm, and there is very little one can do to prevent this. Indeed, these findings seem to gain further support from the results of the Subject Panel study, which is comprised of relatively healthy individuals, where correlations between age and MHLC domains were not significant.

A discriminant analysis was undertaken to see whether scores on the MHLC would be able to predict illness suffered. However, the analysis was unsuccessful in placing individuals in the chronically ill sample in their appropriate illness (RA or migraine) on the basis of scores on the MHLC.

No other significant associations were found between domains measured by the MHLC and other demographic variables, either for the RA/Migraine sample or the Subject Panel respondents.

7.3.5. Pain and MHLC Scores

Scores on the McGill Pain Questionnaire and the pain score on the Nottingham Health Profile were correlated with the values gained on the MHLC scales. However, no significant zero order correlations were found, either for RA/migraine subjects scores on the NHP and MPQ when correlated with the MHLC scores, or for Subject Panel respondents scores on the NHP correlated against the MHLC scales.

7.3.6. Mental Health and MHLC Scores

MHLC scores on all three dimensions were correlated with mental health raw scores, using both GHQ score and the emotional reactions score on the NHP, for RA patients and migraine patients as separate groups, and with the two patient groups combined. These correlations were not significant. The hypothesis that individuals may become more external the longer they suffer an illness, and that duration of illness might interact with health locus of

control in influencing current mood, was tested by means of ANOVA. GHQ raw score was used as the dependent variable and, in the first ANOVA, MHLC 'chance' scale score and length of illness were entered as independent variables, whilst in the second ANOVA, MHLC 'powerful others' and length of illness was used as the independent variables. ANOVA's were run on the data as a whole, and broken down by illness group, but no significant differences or interaction effects were found. Thus, no support could be found for the hypothesis advanced by Reid (1984) and Affleck, et al (1987) that externality occurs as a rational response to long term uncontrollable chronic illness and this response may act so as to prevent psychological disturbance.

A median split was performed on the scale scores of the MHLC, and on the total pain rating index of the MPQ. Raw scores on the GHQ were then entered into an ANOVA by each (median split) scale score on the MHLC together with the (median split) pain rating index score, to discover whether an interaction of MHLC scale scores and pain scores were associated with GHQ score. This analysis yielded no significant results, thereby indicating that pain and locus of control did not seem to influence mental health as measured by the GHQ.

MHLC scores on all three domains were entered into a discriminant analysis to see if they could predict 'caseness' on the GHQ. Discriminant analysis was unsuccessful in placing individuals in the appropriate category as

determined by the GHQ (i.e. a 'case' or 'non-case') for either migraine or RA, or for both groups combined.

MHLC scores on the three scales were correlated with mental health scores for the Subject Panel. As with the sample of chronically ill individuals there were no significant correlations, on either the Beck Depression Inventory or GHQ raw scores, or on indications of 'caseness', on either measure.

7.4. DISCUSSION

The internal consistency of the MHLC was found to be lower in this study than that reported by its designers (Wallston et al, 1978) and other researchers (e.g. Nicassio, et al, 1985) where values for Cronbach's alpha tend to fall around the 0.70 mark for all three domains (i.e. internal, powerful others and chance). Table 7.7. provides a summary of internal consistency results gained, from other studies, for the scales of the MHLC.

TABLE 7.7. HERE

The hypothesis that years of formal schooling, or educational attainment, may be associated with the lack of reliability gains scant support here.

The Subject Panel respondents were found to have significantly higher scores on 'internality' and significantly lower scores on the dimensions of 'powerful others' and 'chance'/'fate'. This would tend to support Herzlich's (1973) claim that people regard good health as something for which they are personally responsible, and bad health as caused by external factors for which they are not wholly responsible. The Subject Panel respondents had generally better health than the migraine and RA patients. It would seem this state of (good) health is regarded as a product of the individual. The chronically ill individuals had lower scores on internality and

	Alpha reliabilities		
	IHLC	CHLC	PHLC
Wallston and Wallston data (1984):			
College Students (n=88)	0.66	0.83	0.75
College Students (n=85)	0.80	0.70	0.73
College Students (n=115)	0.75	0.68	0.73
Individuals attending a Health Fair (n=89)	0.61	0.67	0.69
Nicassio et al data (1978)			
RA sufferers (n=219)	0.77	0.69	0.72

Table 7.7.

Internal reliabilities for scales on the MHLC (Cronbach's alpha), from data gained in other surveys. (Note: IHLC=Internal Locus of Control, CHLC=Chance/Fate Locus of Control, and PHLC=Powerful Others Locus of Control).

significantly higher ones on externality. This finding is in keeping with other research (Wallston and Wallston, 1981).

The hypothesised association between scores for externality (as measured by 'chance' and 'powerful others') with length of illness did not gain very much support from the data presented here. Indeed patients were not found to be significantly more external on either of the dimensions (i.e. chance and powerful others) in relation to length of illness. Patients continue to present their symptoms, therefore, but there is no evidence that they have greater beliefs in the efficacy of medical practitioners the longer they present. Thus, patients belief that powerful others, such as doctors and relatives can influence their health state does not seem to increase over time. It therefore becomes a puzzling question as to why patients continue to go to the doctor. Swanson, Maruta and Wolff (1986) note that head pain patients will continue to present their symptoms to medical practitioners for remarkably long periods of time. In part such patients may regard their behaviour as exhibiting some form of personal control over an illness that in all other ways is unpredictable. However, it is possible that there may have been successful attempts to deal with head pain previously, but that these treatments did not succeed for very long. A number of patients in this study remarked that they had

had periods of little or no pain during their treatments. Attempts to study this phenomenon systematically were discarded due to the difficulties in getting data (i.e. the accuracy of individuals' ability to recall past successes may be difficult to validate). However, during the interview a number of the patients mentioned there had been periods which were relatively pain free and this does provide some rationale as to why the patients continued to return to the doctor. Further, simply being aware that most of the population deal with head pain by taking drugs that can be easily bought over the counter may influence a sufferer to continue attending a clinic. They may hold a belief that headaches are essentially something that should be treatable. Further, patients may continue to present at a clinic despite modest medical efficacy for the simple reason they wish to obtain prescribed drugs, even if the drugs have only a limited impact on their suffering, (McIntyre and Oldman, 1977). In the case of RA, it may be necessary for patients to present in order not only to gain medication for pain killers and anti-inflammatories, but also to be in-patients for prostheses. RA patients were found to be significantly more external (on both 'chance' and 'powerful others') than migraine patients. This finding finds support elsewhere, where RA patients have been found to have elevated scores on helplessness, (Lowery et al, 1983; Skevington, 1983; Affleck et al, 1987).

Neither pain scores nor mental health scores were associated with MHLC scale scores. Much of the literature (see Sections 1.4. and 7.1.2) would tend to lead one to expect a possible association between fatalism as measured on the MHLC and psychological state as measured by an instrument such as the GHQ. This is not the finding of this study. Further, analysis of the data presented here did not provide support for the hypothesis by Reid (1984) that an external locus of control may be adaptive in circumstances where the illness has been unresponsive to treatment.

The inclusion of the MHLC in the schedules administered here was to find whether internality or externality was associated with length or severity of illness, and whether such scores would associate with psychological mood. The most significant results, however, have been related to social class and age. Thus, the older patients gained higher scores for externality than younger patients. Similarly Stein et al (1988) found scores on internality on the Arthritis Helplessness Index (Nicassio et al 1985) to be negatively associated with class. However, in keeping with other findings (Nicassio et al, 1985) there were no zero order correlations between length of illness and locus of control. There seems little support for the hypothesis that the longer individuals experience illness, the more 'external' they become, (Reid, 1984).

In conclusion it seems that the most salient dimensions for health locus-of-control are not actually related, in this survey, to health, but rather to social class factors and to age. Such findings, which have been recurrent in the literature (Wallston and Wallston, 1981) support a more general hypothesis that social class and age are major determinants of beliefs of personal efficacy. Age seems to be the major determinant of MHLC externality for RA, whilst social class features are more important for the migraine sample. It may be hypothesised that age is the dominant determinant of locus of control beliefs. Older sufferers attribute their state of ill health to external factors. Younger individuals, however, may vary in their attributions for their state of health as a function of social class, with the those of lower class backgrounds adopting a more external fatalistic view of health. Thus, younger individuals expect greater control over their health, and differences in expectations can be attributed to class, whilst older individuals fatalistically assume that, irrespective of class, health deteriorates as one gets older. RA is, further, an illness associated by many as associated with age. Pains and joint stiffness may, therefore, be associated with old age, over which individuals may fatalistically assume they are powerless.

CHAPTER 8

DISCUSSION AND CONCLUSIONS

8.1. INTRODUCTION

This thesis has set out to examine the hypothesis that pain may be a determinant of psychological disturbance amongst the chronically ill, and both direct and indirect links between pain and mental health were examined. It was argued that the experience of pain can influence other aspects of a sufferer's life, and that such biographical disruption may be the most influential factor in the development of psychological problems. The possible mediating aspect of certain social and psychological variables may act so as to prevent psychological problems, and this thesis has addressed this issue. This thesis has examined the possible part played by a number of social, psychological, and medical variables in psychological distress in two chronic painful illnesses (migraine and rheumatoid arthritis).

8.2. SOCIAL AND PSYCHOLOGICAL VARIABLES AND THEIR ASSOCIATION WITH MOOD STATE

8.2.1. Extent of Psychological Disturbance in the Samples

In keeping with other evidence for migraine (Cox and Thomas, 1981) and RA, (Anderson et al, 1985) the extent of psychological disturbance in the chronically ill samples studied here was found to be higher than for general population samples. Further, RA and migraine patients were found to score higher than Subject Panel respondents surveyed as part of this research on both the GHQ and the NHP emotional reactions scales.

8.2.2. Pain and Mood State

No correlations were found between pain and mood state, despite measuring pain on a number of indices (five pain scores from the McGill Pain Questionnaire, which has been shown to be a consistent measure of the experience of pain, both in his research (see Section 3.4. in this thesis) and elsewhere (Reading, 1980). Pain was also measured on the Nottingham Health Profile, and by means of a present pain intensity question).

Results from other studies as to the association of pain and mood state are contradictory. A number of studies have not found a relationship between pain and mood state (Kerns and Haythornwaite (1988); McFarlane and Brooks (1988); Newman et al (1989)), whilst other studies have found pain to be an

important explanatory variable of mood state, (Frank et al (1988); Parker et al (1988)). However pain and disability are so strongly intertwined for RA sufferers that it is difficult to distinguish separate effects. Within headache research the association of depression and pain seems to be assumed rather than proven, in part because antidepressant drugs can alleviate both symptoms. However, evidence for an association between pain and depression is often somewhat anecdotal, and rarely are measures of pain, such as the MPQ, and depression taken together. Indeed, what is more often reported upon is frequency of headache, and depression, and this is taken to imply pain as the factor independently causing depression, (Ziegler et al, 1978; Martin, 1978). In fact, it is quite possible that the impact of headache on activities of daily life is more important than the pain per se in causing depression, (Jenkinson and Fitzpatrick, 1990).

8.2.3. Demographic Variables and Mood State

Demographic variables were not found to be associated with mood state. Notably, neither length of illness nor age were not found to be associated with mental health. There is a great body of published evidence on the link between both age and length of illness, and the association with mental health, but this material is conflicting. For example, Newman et al (1989) found that age was not a very significant factor in explaining psychological state, whilst Cassileth et al (1984) found older sufferers to have lower

rates of psychological disturbance. Length of illness has been cited as a possible influential variable in reactions to chronic illness. Swanson, Maruta and Wolff (1986), for example, found that long term head pain patients exhibited elevated levels of depression, whilst Reid (1984) has claimed length of illness to be associated with better psychological adjustment. However, McFarlane and Brooks (1988) found no association between length of illness and psychological state. Newman (1989) suggests, specifically in relation to RA, that length of illness may not necessarily be associated with mental health improvement in RA as the longer individuals have an illness the more serious it is likely to become. Thus, increasing demands are made upon sufferers, and they are thus not simply adapting over time to a relatively static set of demands placed upon them by their illness. This seems a plausible account in RA, but less convincing for migraine, which follows a varied and unpredictable course. However, the demands of migraine are in large measure caused by its lack of predictability. Its tendency to strike apparently randomly may, therefore, mean that it is not an illness that lends itself to patients learning to cope with it over time, and hence poor mental health scores remain elevated.

8.2.4. Coping and Mood State

This study has not found evidence for an association of psychological state with coping strategies. This has been demonstrated by analysis involving zero order correlations between individual coping items, and also multivariate analysis.

This study has attempted to address the issue of coping with chronic pain on two distinct groups of chronic pain sufferers. The items used are similar to those suggested by Brown and Nicassio (1987) (re: the Vanderbilt Pain Management Inventory), although the questionnaire deliberately did not include items which were regarded for the purposes of this study as outcome measures (e.g. Brown and Nicassio include statements such as 'Thinking one cannot do anything to cope with the pain', as a coping item, whereas, in the study reported here, such an item would be regarded more as a manifestation of unsuccessful coping, and therefore not adaptive).

The results reported in this study would not provide evidence for the use of coping strategies as a method of adapting to the demands of the painful chronic illnesses studied here. Coping behaviours were not found to be associated with psychological state or the extent of pain reported. The results of this study indicate that migraine

sufferers adopt more passive strategies of coping than do RA patients, but that there is very little evidence to support the claim that there are pain coping strategies that are associated with positive mood state. Further, the hypothesis that anticipatory strategies exist that permit individuals to cope with the demands of their illness by preparation for RA flare-ups or migraine attacks gains no support here. The results are similar to those of Rosenstiel and Keefe (1983) and Turner and Clancy (1986), who found no evidence for an association between pain coping strategies and positive psychological adjustment. This is not to say that coping strategies do not exist. For example, it is possible that the strategies selected for study here were not the ones adopted by sufferers. In part the choice of behaviours is limited by the nature and extent of the disease whilst in part such behaviours must be a reflection of expectations. An individual who has lived an active life may engage in different strategies of adaptation than one whose life has been generally more passive. The evidence presented here suggests that a number of coping strategies are adopted, but that these are not associated with scores of psychological well being.

Other research shows that there are maladaptive coping strategies, (Rosenstiel and Keefe, 1983). Rosenstiel and Keefe found association an between some negative coping statements and mental health, but this thesis has argued

that such statements are more accurately measures of outcome than coping, and have hence been omitted in this research.

Evidence for the claim there pain coping strategies exist was reviewed by Tan (1980) who found that instructed coping strategies were superior to strategies generated spontaneously by subjects in control groups when laboratory induced pains are used. Likewise, Fernandez and Turk (1989) found that cognitive coping strategies are associated with reduced pain reports. However, their review was based largely upon results gained from subjects in acute pain that had been induced in laboratory conditions. Neither Tan nor Fernandez and Turk address the issue of coping with chronic pain. It is suggested here that the experience of long term pain as a function of illness is a very different phenomenon to that of acute pain, especially acute pain that has been experimentally induced.

Clinically, there is substantial interest in teaching people to cope with pain. Melzack writes,

'Everyone, beginning at an early age, learns to cope with pain by using various strategies. The most common strategy is distraction of attention. For example, while sitting in the dental chair or waiting for an injection in the doctor's office, we often force ourselves to think about something else...In recent years, psychologists have devised a large number of ingenious

methods that utilize different kinds of strategies or coping mechanisms.' (Melzack, 1988, p251)

Within clinical psychology a number of psychological intervention techniques of which one approach is to modify coping strategies. However, there is only inconclusive evidence for their success in utilization of chronic pain coping strategies, and relatively little research undertaken upon the coping strategies used by individuals suffering long term chronic pain. The evidence presented here certainly provides no support for an association between pain coping strategies and positive psychological state. The evidence available so far seems to indicate that clinicians dealing with chronic pain patients should directly address mal-adaptive strategies as outlined in research by Rosensteil and Keefe (1983) and Turner and Clancy (1986), and attempt to reduce patients' use of them, rather than teach coping strategies per se.

8.2.5. Locus of Control and Mood State

No evidence was found for an association between mood state and locus of control. Social class and education were found to be significantly related to locus of control beliefs. Similar findings have been reported elsewhere (Wallston and Wallston, 1981). Much research on control of pain has suggested that subjects' perception of control can lead to lower pain self reports, higher pain tolerance and better psychological state (Averill, 1973). Perceptions of control

have been found to be associated with lower reports of head pain (Courey et al, 1982). However the results of the migraine/RA study reported in this thesis find no evidence for beliefs in control as a possible explanatory variable for reported pain or psychological state.

8.2.6. Health Status and Mood State

The most striking finding of this study is that of the association of mental health with aspects of health status as measured on the Nottingham Health Profile (NHP), (Hunt, McEwen and McKenna, 1986). NHP scores in the domains of sleep, social isolation and energy were found to be significantly correlated with mental health scores for both RA patients, and migraine patients. Patients with elevated scores on energy problems, sleep problems and social isolation scored higher on psychological distress.

The evidence from this study suggests that health status as assessed from the patient's perspective is strongly associated with mood state. Evidence of the importance of other social and psychological variables in mediating the impact of painful chronic illness upon psychological state is conflicting. This research provides little support for the claims that coping and locus of control are important factors affecting psychological state in chronic illness. Further, no zero order correlations were found between pain and mood state. It is suggested here that pain is important

insofar as it affects the daily lives of sufferers. It is interesting to note that both on the Melzack Pain Questionnaire, and the Nottingham Health Profile, sufferers regularly scored on the dimensions of tiredness/exhaustion, and energy respectively. The major finding of this study, therefore, is that patients' assessment of their own health state is the major factor associated with psychological state. This finding is in keeping with that of Frank et al who argue that "Clinicians should recognise that depression is predicted by the patient's appraisal of his or her disease", (Frank, et al, 1988). Certainly it is perceptions of disability that are a significant determinant of patients seeking medical help, (McKenna and Payne, 1989) and such subjective perceptions of circumstances and handicap have been found to influence psychological status among patients with a variety of illnesses, (Counte et al, 1983; Linn and Greenfield, 1982; Westbrook and Viney, 1982). Further it is severity rather than type of disability that is found to be associated most strongly with psychological distress (Viney and Westbrook, 1981).

The use of health status measures in health assessment is a relatively recent phenomena dating back only as far as the mid-seventies with the introduction of instruments such as the Sickness Impact Profile, (SIP), (Bergner et al, 1976). Initially health status measures had been cited as measures of perceived health, or subjective health state. However,

the actual use to which health status measures such as the NHP and SIP have been put has varied considerably. The NHP, for example, initially conceived of as a population survey tool, has been advanced as a useful adjunct to the clinical interview, as an instrument to detect health status changes over time, (Kind and Carr-Hill, 1987), as an instrument to evaluate medical treatments in clinical trials (Hunt, 1988; Parr, et al, 1989), and as an indication of quality of life, (see Walker and Rosser, 1988) as well as a measure of ADL (activities of daily living) (McDowell and Newell, 1987). More recently it has been suggested that the NHP can be statistically reduced to two dimensions (mood state and a pain/mobility dimension) and can be used as a questionnaire to detect psychological disturbance, (McKenna and Payne, 1989). There remains ambiguity as to what the measures are to be used for, and what it is that is actually being measured. Hunt et al (1986) remark that the NHP measures six *distinct* dimensions, and so the decision to reduce the NHP to just two and use it as a measure of mood state is a radical departure from its original purpose. This issue has been raised in relation to other health status measures, by Spiegel et al, (1988), who remark that there is a close relationship between mental health and the scores on self-report health status measures. The results of this study certainly indicate a close relationship between mood state and aspects of health state as measured on the NHP. It is possible, as Spiegel et al suggest, that elevated scores on

health status measures are influenced by mood state. Interpretation of health status scores is, therefore, problematic. However, there is a growing interest in this area, and many authors argue for the potential benefits of health status measures. For example, Callahan, et al (1988) argue that such self report questionnaires¹ have broad utility in the assessment of health state of patients. Fitzpatrick et al (1989) argue that more work is necessary to assess the results of health status instruments with other criteria, both obtained clinically and from the patient. Such research may provide a clearer indication of what is being measured, although it is suggested here that their immediate utility is to provide a profile of health derived from the patient that is an addition to clinical and medical measures.

8.3. CONCLUSION

It is suggested here that the perceived impact of an illness upon daily life is a major determinant of psychological distress, and health status measures go some way in tapping this domain. However, from this study the direction of causality cannot be determined. It is possible that psychological distress causes patients to over-report the impact of illness upon their lives, or that the impact of illness influences mood state. Longitudinal data is required

1. Callahan et al (1988) refer to health status measures as ADL measures. They used a modified version of the Health Assessment Questionnaire (Pincus, et al, 1983).

to provide an answer to this question. The research reported here, however, has attempted to determine the extent to which social and psychological factors are associated with painful chronic illness. The results indicate that a fruitful area for further research is to explore the issue of subjective health status and its relation to mood state. The evidence of this thesis provides little support for any association between a number of other social and psychological variables and mood state, and literature in these areas is often conflicting. For clinical purposes it is suggested health status assessment is a significant area for the understanding of psychological reactions to painful chronic illness.

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APPENDICES

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APPENDIX 1a

THE GENERAL HEALTH QUESTIONNAIRE

GENERAL HEALTH QUESTIONNAIRE

THE FOLLOWING QUESTIONS ASK YOU ABOUT YOUR GENERAL HEALTH OVER THE PAST FEW WEEKS. TRY TO ANSWER ALL OF THE QUESTIONS. AFTER EACH STATEMENT UNDERLINE THE ANSWER ON THE RIGHT THAT SEEMS MOST APPROPRIATE.

HAVE YOU RECENTLY:

1. been able to concentrate on whatever you are doing?

Better than Usual	Same as Usual	Less than Usual	Much less than Usual
----------------------	------------------	--------------------	-------------------------

2. lost much sleep over worry?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

3. been having restless, disturbed nights?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

4. been managing to keep yourself busy & occupied?

More so than Usual	Same as Usual	Rather less than Usual	Much less than Usual
-----------------------	------------------	---------------------------	-------------------------

5. been getting out of the house as much as usual?

More so than Usual	Same as Usual	Rather less than Usual	Much less than Usual
-----------------------	------------------	---------------------------	-------------------------

6. been managing as well as most people would in your shoes?

Better than Most	About the Same	Rather less Well	Much less Well
---------------------	-------------------	---------------------	-------------------

7. felt on the whole you were doing things well?

Better than Usual	About the Same	Less Well than Usual	Much less Well
----------------------	-------------------	-------------------------	-------------------

8. been satisfied with the way you have carried out your tasks?

More Satisfied	About the Same as	Less Satisfied Usual	Much less Satisfied than Usual
----------------	-------------------	----------------------	--------------------------------

9. been able to feel warmth and affection for those near to you?

Better than Usual	About same as Usual	Less Well than Usual	Much less Well
-------------------	---------------------	----------------------	----------------

10. been finding it easy to easy to get along with other people?

Better than Usual	About same as Usual	Less Well than Usual	Much less Well
-------------------	---------------------	----------------------	----------------

11. spent much time chatting to people?

More time than Usual	About the Same as Usual	Less than Usual	Much Less than Usual
----------------------	-------------------------	-----------------	----------------------

12. felt that you are playing a useful part in things?

More so than Usual	Same as Usual	Less so than Usual	Much Less than Usual
--------------------	---------------	--------------------	----------------------

13. felt capable of making decisions about things?

More so than Usual	Same as Usual	Less so than Usual	Much Less Capable
--------------------	---------------	--------------------	-------------------

14. felt constantly under strain?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	--------------------	------------------------	----------------------

15. felt you couldn't overcome your difficulties?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	--------------------	------------------------	----------------------

16. been finding life a struggle all the time?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

17. been able to enjoy your day-to-day activities?

More so than Usual	Same as Usual	Less so than Usual	Much less than Usual
-----------------------	------------------	-----------------------	-------------------------

18. been taking things hard?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

19. been getting scared or panicky for no good reason?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

20. been able to face up to your problems?

More so than Usual	Same as Usual	Less able than Usual	Much Less able
-----------------------	------------------	-------------------------	-------------------

21. found everything getting on top of you?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

22. been feeling unhappy and depressed?*

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

23. been losing confidence in yourself?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

24. been thinking of yourself as a worthless person?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

25. felt that life is entirely hopeless?

Not at all	No more than Usual	Rather more than Usual	Much more than Usual
------------	-----------------------	---------------------------	-------------------------

26. been feeling hopeful about your own future?

More so than usual	About same as usual	Less so than usual	Much less hopeful
-----------------------	------------------------	-----------------------	----------------------

27. been feeling reasonably happy, all things considered?

More so than usual	About same as usual	Less so than usual	Much less than usual
-----------------------	------------------------	-----------------------	-------------------------

28. been feeling nervous and strung up all the time?

Not at all	No more than usual	Rather more than usual	Much more than usual
------------	-----------------------	---------------------------	-------------------------

29. felt that life isn't worth living?

Not at all	No more than usual	Rather more than usual	Much more than usual
------------	-----------------------	---------------------------	-------------------------

30. found at times you couldn't do anything because
your nerves were so bad?

Not at all	No more than usual	Rather more than usual	Much more than usual
------------	-----------------------	---------------------------	-------------------------

APPENDIX 1b

THE MCGILL PAIN QUESTIONNAIRE

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McGill-Melzack
PAIN QUESTIONNAIRE

CIRCLE THE WORDS BELOW THAT BEST DESCRIBE YOUR PAIN.
ONLY ONE WORD PER GROUP SHOULD BE CHOSEN. LEAVE OUT ANY
GROUP WHERE ALL THE WORDS SEEM INAPPROPRIATE.

- | | | | |
|---|---|--|---|
| 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 |

HOW DOES YOUR PAIN CHANGE WITH TIME?

Which of these groups of words best describes the pattern of your pain. Circle no more than one list.

- | | | |
|-------------------------------------|---|------------------------------------|
| 1. Continuous
Steady
Constant | 2. Rhythmic
Periodic
Intermittant | 3. Brief
Momentary
Transient |
|-------------------------------------|---|------------------------------------|

PTO

HOW STRONG IS YOUR PAIN?

Circle one word for each question.

1. Which word describes your pain right now?

1	2	3	4	5
Mild	Discomforting	Distressing	Horrible	Excruciating

2. Which word best describes the pain at it's worst?

1	2	3	4	5
Mild	Discomforting	Distressing	Horrible	Excruciating

3. Which word best describes the pain at its least?

1	2	3	4	5
Mild	Discomforting	Distressing	Horrible	Excruciating

4. Which word best describes the worst toothache you have ever had?

1	2	3	4	5
Mild	Discomforting	Distressing	Horrible	Excruciating

5. Which word best describes the worst stomach ache you have ever had?

1	2	3	4	5
Mild	Discomforting	Distressing	Horrible	Excruciating

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APPENDIX 1c

THE NOTTINGHAM HEALTH PROFILE

THE NOTTINGHAM HEALTH PROFILE

Listed below are some problems people may have in their daily life.

Look down the list and ring YES for any problem you have at the moment. Ring NO for any problem you do not have.

Please answer every question. If you are not sure whether to say yes or no, ring whichever answer you think is more true at the moment.

I'm tired all the time	YES	NO
I have pain at night	YES	NO
Things are getting me down	YES	NO
I have unbearable pain	YES	NO
I take tablets to help me sleep	YES	NO
I've forgotten what it's like to enjoy myself	YES	NO
I'm feeling on edge	YES	NO
I find it painful to change position	YES	NO
I feel lonely	YES	NO
I can only walk about indoors	YES	NO
I find it hard to bend	YES	NO
everything is an effort	YES	NO
I'm waking up in the early hours of the morning	YES	NO
I'm unable to walk at all	YES	NO
I'm finding it hard to make contact with people	YES	NO

The days seem to drag	YES	NO
I have trouble getting up and down stairs and steps	YES	NO
I find it hard to reach for things	YES	NO
I'm in pain when I walk	YES	NO
I lose my temper easily these days	YES	NO
I feel there is nobody I am close to	YES	NO
I lie awake for most of the night	YES	NO
I feel as if I am losing control	YES	NO
I'm in pain when I'm standing	YES	NO
I find it hard to dress myself	YES	NO
I soon run out of energy	YES	NO
I find it hard to stand for long (e.g. at the kitchen sink, waiting for a bus)	YES	NO
I'm in constant pain	YES	NO
It takes me a long time to get to sleep	YES	NO
I feel I am a burden to people	YES	NO
Worry is keeping me awake at night	YES	NO
I feel that life is not worth living	YES	NO
I sleep badly at night	YES	NO
I'm finding it hard to get on with people	YES	NO
I need help to walk about outside (e.g. a walking aid or someone to support me)	YES	NO
I'm in pain going up and down stairs and steps	YES	NO

I wake up feeling depressed	YES	NO
I'm in pain when I'm sitting	YES	NO

APPENDIX 1d

THE MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL

THE MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL

Circle the response that is most in keeping with your attitude to each of the following eighteen statements.

1. If I get sick it is my own behaviour which determines how soon I get well again.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

2. No matter what I do, if I am going to become ill, I am going to become ill.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

3. Having regular contact with my doctor is the best way for me to avoid illness.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

4. Most things that affect my illness happen to me by accident.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

5. Whenever I don't feel well I should consult a medically trained professional.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

6. I am in control of my health.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

7. My family has a lot to do with my becoming sick or staying healthy.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

8. When I get sick I am to blame.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

9. Luck plays a big part in determining how soon I will recover from an illness.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

10. Health professionals control my health.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

11. My good health is largely a matter of good fortune.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

12. The main thing which affects my health is what I myself do.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

13. If I take care of myself, I can avoid illness.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

14. When I recover from an illness, it is usually because other people (e.g. doctors, nurses, family, friends) have been taking care of me.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

15. No matter what I do I'm likely to become ill.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

16. If it's meant to be, I will stay healthy.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

17. If I take the right actions, I can stay healthy.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
-------------------	-------	-------------------	----------------------	----------	----------------------

18. Regarding my health, I can only do what my doctor
tells me to do.

STRONGLY AGREE	AGREE	SLIGHTLY AGREE	SLIGHTLY DISAGREE	DISAGREE	STRONGLY DISAGREE
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APPENDIX 1e

ILLNESS QUESTIONNAIRE DESIGNED FOR THIS RESEARCH

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ILLNESS QUESTIONNAIRE

Enquiries concerning this research should be directed to:

Crispin Jenkinson
Nuffield College, New Road, Oxford, OX1 1NF.
Telephone Oxford (0865) 278500.

This Research is funded by the Economic and Social Research Council, and the research is registered with the Department of Experimental Psychology in the University of Oxford.

(E.S.R.C. Grant No. A00428624033)

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ILLNESS QUESTIONNAIRE

This questionnaire asks questions about you and your illness. The questionnaire is divided into a number of sections. These different sections deal with different aspects of your life, and of the impact that Rheumatoid Arthritis/Headache Suffering has had upon it.

As the title of the questionnaire suggests the main area of concern is 'Pain'. The questionnaire has a number of questions relating to the extent of the pain in your illness, and how it is you attempt to cope with it.

The data collected from the questionnaire will be entered on a computer. The data will be entered in a numeric form, and your name will not be placed on the computer. The data will not be used for any other purpose than this study, and any publications relevant to it. It will be broken down statistically and individuals will not be named. The data will be handled with the utmost confidentiality.

Obviously we would like you to answer all of the questions. However, you are under no obligation to answer any of the questions. Should you not wish to answer certain questions, for whatever reasons, simply ask the individual administering the questionnaire to go on to the next question.

The responses you give will not be reported back to the Doctors treating you, nor will they be used in your treatment.

Crispin Jenkinson
Nuffield College

Section 1 (Demographic Variables)

GENERAL

Name..... Sex.....
Age..... Hospital.....

MARITAL STATUS

Single Married Cohabiting Divorced Separated Widowed
Do you have Children?.....Age Range.....
Do children live at home Yes No

YOUR ILLNESS

Complaint.....
Other Illnesses

OCCUPATION

(Enter retired or unemployed if this is the case)

Occupation at Present.....
Occupation of Spouse at Present.....

If the answers to either or both of the above questions
was currently retired or unemployed then indicate below
the nature of the last employment held by yourself or
spouse.

IF CURRENTLY UNEMPLOYED OR RETIRED

Your last job.....
Your spouses last job.....

WHERE YOU LIVE

Do you live in

- 1.....Your Own House
- 2.....Rented Accommodation
- 3.....Council House
- 4..... House of Relatives or Friends
- 5.....A Home

How many years have you lived in this place.....

Where did you live previously

- 1.....Your Own House
- 2.....Rented Accommodation
- 3.....Council House
- 4..... House of Relatives or Friends
- 5.....A Home

Did you live in another part of the country
before moving to your current address?.....

Where.....

When did you move
to this part of the country.....

EDUCATIONAL QUALIFICATIONS

What Age did you leave School.....

What qualifications do you have, if any?

- 1.....None at All
- 2.....CSE
- 3.....O Levels
- 4.....Higher School Cert
- 5.....A Levels
- 6.....HND/OND
- 7...Degree/Professional Qualification

THE PLACE WHERE YOU LIVE

Is your home damp?.....

What sort of heating does your house have?.....

Do you find that the heating is good enough throughout
the year or can your house be very cold inside
in the winter?

Yes No

Does your home have a phone you can use?.....

Do you have a garden big enough to sit in?.....

If you had the chance
would you move somewhere else?.....

If you would like to move,
what are your reasons?.....

Do you have a Current Driving Licence?.....

Do you have a Car?.....

If you do not drive or have
a car is this due to your illness?.....

Can you depend on a close friend
or relative to give you lifts often?.....

.

Religious Beliefs

What religion do you subscribe to?.....

Do you go to church regularly?.....

If not, is it your illness that prevents you going?.....

Now go straight on to Section 2.

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Section 2 (Questions relating to your general health)

When do you think your illness began?.....

Did you know what it was immediately?.....

If not, what did you think it was?.....

Who told you what your illness was?.....
(e.g. A Doctor, Parent, Friend etc)

Did your parents or
any relatives suffer this illness?.....

Are you generally a fit person?.....

Have you been an in-patient
in hospital in the last twelve months?.....

If so, for what illness?.....

How long were you in hospital?.....

Have you ever sought health advice for RA/Migraine
outside of the Medical Profession? Yes No

If so, to whome did you go?

Osteopath
Homeopath
Acupuncturist
Astrologer
Faith Healer
Other

Section 3 (Explanation for the illness)

Which of the following reasons, if any, do you think may be cause(s) of your suffering from RA/Migraine.

- 3a. Heredity/Genetics (e.g. Parents had it/family history))

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

- 3b. Fate (One of those things)

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

- 3c. Due to your personality (i.e. do you think people with your sort of personality are more likely to contract this ailment)

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

- 3d. Some form of punishment for past behaviour (e.g. from God, the fates etc)

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not			.	So	So

Do you think you may have contracted your illness (cont);

- 3e. Due to the demands of your job, or jobs you may previously have held (e.g. the requirement to be indoors or outdoors for a large part of the day, or the noise of the office etc)

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

- 3f. Due to the demands of modern living

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

Section 4 (Social Relationships)

- 4a. How many people do you talk to on an average day? You may not know these people well, or even by name, but you can stop for a brief chat with them regardless.

None 1 2-3 4-5 6-9 10 & Over

- 4b. Do you know any people you feel happy to confide in and tell them about things that concern you. If so how many? (Number should inc relatives/spouse).

None	1	2-3	4-5	6-9	10 & Over
------	---	-----	-----	-----	-----------

- 4c. Can you see any of these people with ease. That is, can you just call in on them, or do they drop in on you. If so how many?

None	1	2-3	4-5	6-9	10 & Over
------	---	-----	-----	-----	-----------

- 4d. How many of these people have you seen over the last four weeks?

None	1	2-3	4-5	6-9	10 & Over
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- 4e. How often do you go out (e.g. a meal, a drink down the pub, or to see friends etc.)

Never	1 yr	1 month	Every few Months	1 week	Often in week
-------	------	---------	---------------------	--------	------------------

- 4f. Does your illness stop you from going out more?

Yes No

- 4g. Would you like to go out more often?

Yes No

4h. If you would like to go out more often why don't you?

1. Due to the pain
2. Fearful of a flareup
3. Can't walk
4. No one to go with (husband won't go etc)
5. No transport
6. Other

4i. Do you think other people in general really understand the amount of distress caused to you by your illness?

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

4j. Do you think the Doctors and Nurses who have treated you over the past 6 months for RA/Migraine really understand the amount of distress caused to you by your illness?

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

4k. Do you think other family members really understand the amount of distress caused to you by your illness?

1	2	3	4	5	6	7
Def	Prob	Unlikely	Unsure	Possibly	Prob	Def
Not	Not				So	So

4l. Do you live with anyone? (Yes (.....) No)
If you do does the person you live with help you with day to day chores that are problematic with for a person with your illness?

1	2	3	4	5	6	7
Never	Very	Some-	Quite	Very	Almost	Always
	Rarely	times	Often	Often	Always	

Section 5 (The Pain of your Illness)

The Scale Below is an indicator of your Pain.

If the Value '1' were taken to indicate no pain at all, and '7' the greatest pain you recall experiencing, how much pain are you in now?

1-----2-----3-----4-----5-----6-----7

No Pain at All

Greatest
Pain you
have
Experienced

.

THE IMPACT OF THE ILLNESS AND PAIN ASSOCIATED WITH IT
UPON YOUR DAILY LIFE

I would now like to ask you some questions about the impact of the illness and the pain associated with it upon your daily life.

I will begin by asking you questions relating to your illness per se. The questions relate to the last six months.

In the last six months has the illness:

5a. Effected your work? (e.g. slow you down, made you have days off etc).

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5b. Caused problems to your domestic relationships?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5c. Caused problems to your friendships outside of the home?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5d. Effected any pastimes or hobbies you have?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

Does/Did the illness

5e. Caused you to worry about what other people think of you? (e.g. that they may think you are too ill for your job, or putting the symptoms on etc)

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5f. Made you feel that you have no power over your life?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5g. Made you feel that only the Medical Profession could help you?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5h. Made you feel that the Medical Profession is powerless to help you?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5i. Made you worry that you might be bothersome to close friends and relatives?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5j. Made you worry that you might be bothersome to people in general?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5k. Caused you pain? (i.e. how frequent is the pain?)

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

IN RELATION TO THE PAIN OVER THE LAST SIX (6) MONTHS
Does the Pain

5l. Ever become so unbearable, that you are unable to do anything but think about it?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5m. Ever become so bad that all you can do is go to bed and lie still?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5n. Ever keep you awake at Nights (so that falling asleep is not possible)?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5o. Ever wake you up at night?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5p. Make you wish that you had never been born.

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

Does/Did the pain

5q. Make you wish that you could pass away or end it all?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5r. Cause you to cry?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5s. Cause you to lose your temper with those around you?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5t. Cause you to become frustrated and angry with yourself?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

Now I would like to ask you some questions about stiffness that may be associated with your illness.

5s. Do you suffer stiffness with attacks of Migraine/RA?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5t. If you do feel stiff do you try to remain active?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

5u. Does the stiffness make the pain worse?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

Now go straight on to Section 6

Section 6 (Efficacy)

The following questions ask you about your response to a flareup of your illness.

6a. Do you know when you are about to have a flareup (i.e. do you have a feeling (nausea, sickness etc) that indicates you are about to experience great pain due to Migraine/RA.

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6b Do you take anything to prevent the flare up?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6c. How often do such drugs work.

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

In the last six months, when a flareup has occurred;

6d. Is it painful?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6e. Do you take anything to reduce the pain?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6f. Do you seek out company?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6g. Do you try to avoid company?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6h. Do you try to stay active?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6i. Do you try to engage in some activity you usually enjoy to take your mind of the pain

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6j. Do you become frustrated or angry?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6k. Do you think to yourself that there are worse things that could befall you than the pain?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6l. Do you watch TV (Tick here if no TV....)

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6m. Do you listen to the radio?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6n. Do you try to read?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6o. Do you try to think about something else?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6p. Do you try to avoid the pain by simply ignoring it?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

LONG TERM PLANNING

The following questions relate to the coping strategies you might undertake in order to deal with your illness.

6q. As you are no doubt well aware your illness can be unpredictable. Do you store up food and domestic goods deliberately for those days when you might fall ill and be unable to go for such goods yourself?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6r. Do you try to avoid certain foods that you feel might bring on bouts of the illness?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6s. Do you read medical books about the illness and possible ways of dealing with it?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6t. Do you avoid people because of your illness and not wishing to be a burden to them?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6u. Do you pray for your condition to improve?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

LONG TERM ATTITUDES

I would like to ask you some questions in relations to your long term attitudes to your illness.

6v. Do you compare your self to others and think how unfortunate you have been with your health?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6w. Do you ever think of yourself as a fortunate person?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6x. Do you ever think of yourself as the sort of person who likes to discuss the problems of the illness with others?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6y. Do you think of yourself as the type of person who suffers without telling others about your problems?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

6z. Do you try to portray a positive attitude about your illness to others?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

Section 7 (Knowledge of the illness)

7a. Do you make a positive effort after you have been treated to ask the Doctors for information about your illness?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

7b. Do you think the information given to you by the Doctors is generally sufficient?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

Could you now answer these more factual questions.

7c. Do you take drugs for your illness? Yes No

7d. Have these drugs been recommended to you by Doctors?

	Yes	No
1. Valium		
2. Miltex		
3. Librium		
4. Serenol		
5. Miltex		
6. Miltex		
7. Miltex		
8. Miltex		
9. Miltex		
10. Miltex		
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100. Miltex		

7e. How long have you been taking drugs for your illness?

7f. Do you know what drugs are being used to treat your illness at the moment?

No

Yes (Name some of them.....
.....
.....)

7g. What is the purpose of taking these drugs?

Pain Killers	Yes	No
Long term Cure	Yes	No
Anti-inflammatory	Yes	No
Short term Cure	Yes	No
(ie Slows development of illness)		
Other		

7h. How often do you think the medication prescribed for your illness works?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

7i. How often do you deviate from the routine of pill taking recommended by your doctors and take extra medication?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

7j. How often do you deviate from the routine of pill taking recommended by your Doctors and go without taking the medication?

1	2	3	4	5	6	7
Never	Very Rarely	Some- times	Quite Often	Very Often	Almost Always	Always

If you exceed the medication

7k. Do you do so because they prevent inflammation/
prevent the headaches?

Yes No

7l. Do you do so to reduce the pain you are in?

Yes No

If you do not take the medication

7n. Do you not take the pills because they do not
cure (or prevent inflammation of) the migraines/RA.

Yes No

7o. Do you not take the pills because they do not ease
the pain?

Yes No

That is the end of the questionnaire.

Your responses will be kept confidential and will not be reported back to the Doctors treating you.

Thank you for your assistance

Enquiries concerning the research should be made to
Crispin Jenkinson, Nuffield College, Oxford.

GUIDE SHEET

ANSWER THE QUESTIONS WITH ONE OF THE FOLLOWING RESPONSES.

- 1...NEVER
- 2...VERY RARELY
- 3...SOMETIMES/OCCASIONALLY
- 4...QUITE OFTEN
- 5...VERY OFTEN
- 6...ALMOST ALWAYS
- 7...ALWAYS

APPENDIX 1f

THE BECK DEPRESSION INVENTORY

THE BECK INVENTORY

The following questionnaire asks you questions about how you have felt over the last week or so. Ring one statement per group that you feel applies to you at the moment. There are 21 groups each with four statements.

1. I do not feel sad.
I feel sad.
I am sad all of the time and can't snap out of it.
I am so sad or unhappy that I can't stand it.
2. I am not particularly discouraged about the future.
I feel discouraged about the future.
I feel I have nothing to look forward to.
I feel that the future is hopeless and that things cannot improve.
3. I do not feel like a failure.
I feel I have failed more than the average person.
As I look back on my life, all I can see is a lot of failures.
I feel I am a complete failure as a person.
4. I get as much satisfaction out of things as I used to.
I don't enjoy things the way I used to.
I don't get real satisfaction out of anything anymore.
I am dissatisfied or bored with everything.
5. I don't feel particularly guilty.
I feel guilty a good part of the time.
I feel quite guilty most of the time.
I feel guilty all the time.
6. I don't feel I am being punished.
I feel I may be punished.
I expect to be punished.
I feel I am being punished.
7. I don't feel disappointed in myself.
I am disappointed in myself.
I am disgusted with myself.
I hate myself.
8. I don't feel I am any worse than anybody else.
I am critical of myself for my weaknesses and mistakes.
I blame myself all the time for my faults.
I blame myself for everything bad that happens.

9. I don't have any thoughts of killing myself.
I have thoughts of killing myself but I would not carry them out.
I would like to kill myself.
I would kill myself if I had the chance.
10. I don't cry any more than usual.
I cry more now than I used to.
I cry all the time now.
I used to be able to cry, but now I can't cry even though I want to.
11. I am no more irritated than I am normally.
I get annoyed or irritated more easily than I used to.
I feel irritated all the time now.
I don't get irritated at all by the things that used to irritate me.
12. I have not lost interest in other people.
I am less interested in other people than I used to be.
I have lost most of my interest in other people.
I have lost all of my interest in other people.
13. I make decisions as well as I ever could.
I put off making decisions more than I used to.
I have greater difficulty in making decisions than I used to.
I can't make decisions any more.
14. I don't feel I look any worse than I used to.
I am worried that I am looking old or unattractive.
I feel there are permanent changes in my appearance that make me look unattractive.
I believe I look ugly.
15. I can work about as well as before.
It takes an extra effort to get started at something.
I have to push myself very hard to do anything.
I can't do any work at all.
16. I can sleep as well as usual.
I don't sleep as well as I used to.
I wake up one to two hours earlier than usual, and find it hard to get back to sleep.
I wake up several hours earlier than I used to, and cannot go back to sleep.
17. I don't get more tired than usual.
I get tired more easily than I used to.
I get tired from doing almost anything.
I am too tired to do anything.

18. My appetite is not worse than usual.
My appetite is not as good as it used to be.
My appetite is much worse now.
I have no appetite at all anymore.
19. I haven't lost much weight recently.
I have lost more than 5 lbs.
I have lost more than 10 lbs.
I have lost more than 15 lbs.
20. I am no more worried about my health than usual.
I am worried about physical problems such as aches
and pains, or upset stomach, or constipation.
I am very worried about physical problems, and it's
hard to think of much else.
I am so worried about my physical problems that I
cannot think about anything else.
21. I have not noticed any recent change in my interest
in sex.
I am less interested in sex than I used to be.
I am much less interested in sex now.
I have lost interest in sex completely.

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