# Living with rheumatoid arthritis : the coping, control and knowledge.

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# 'Living with Rheumatoid Arthritis: The Role of Coping, Control and Knowledge'.

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# Abstract

This study was designed to investigate psychological factors involved in the adjustment to Rheumatoid Arthritis (RA). In particular, the study examined perceptions of control over daily symptoms, knowledge of RA and the use of coping strategies, and looked at how these factors related to emotional adjustment, clinical disease activity and subjective physical functioning in RA outpatients. The study also aimed to determine aspects of RA which patients perceived as most stressful.

The main study was cross-sectional and designed in two parts. The first part was a quantitative design in which 50 participants completed questionnaires to assess perceptions of RA stressors; health locus of control beliefs over RA symptoms; levels of RA-related knowledge; coping strategies used; emotional adjustment and physical functioning. An objective measure of disease activity was also taken. The second part was a qualitative design consisting of semi-structured interviews with 14 participants, exploring perceptions of stress, control, knowledge, coping and adjustment.

Quantitative data were statistically analysed and compared with previous research findings. Qualitative data were transcribed into predefined themes and compared with the quantitative data.

Results showed that participants consistently rated fatigue and disability as the most stressful aspects of RA. Participants reported more symptoms of anxiety than depression and used a wide range of coping strategies. Quantitative data suggested that participants perceived high levels of chance control over their daily RA symptoms, however, qualitative findings did not support this view. Participants knew most about RA-related issues that were directly relevant to them.

Significant associations were found between coping strategies and psychological outcome, particularly for positive affect. Associations were also found between maladaptive coping and positive physical adjustment and between adaptive coping and negative physical adjustment. Adaptive coping strategies were associated with 'internal' and 'doctor' locus of control and increased knowledge. Few associations were found between outcome and either control or knowledge. Regression analyses found coping strategies to account for some of the variance in outcome variables, particularly positive affect.

The implications for clinical practice were considered. Methodological limitations of the study and implications for future research were also discussed.

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# ‘Living with Rheumatoid Arthritis: The Role of Coping, Control and Knowledge’

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## 1.0 Introduction

> 'It is the rare rheumatologist who has not sat face to face with a crying, inconsolable patient with rheumatoid arthritis whose dreams and life have been overwhelmed by illness, or has not dealt with the deformed and disabled patient who, in spite of illness, proceeds happily ahead.'
>
> (Hawley & Wolfe, 1988, p.932)

The above extract highlights the poor correlation that exists between disease activity and adjustment in people with chronic illness such as rheumatoid arthritis (RA). Consequently, there has been a great deal of interest in the factors that mediate this indirect relationship.

RA is a chronic, systemic inflammatory disorder characterised by joint pain, swelling and stiffness and accompanied by progressive destruction and deformity of the joints. RA affects approximately one per cent of the adult population, a rate that increases with age (Schumacher, 1988). Since the proportion of older people in the population is rising (LaFontaine, 1995), an increasing number of individuals will be learning to live with this painful and disabling condition.

As with many other chronic illnesses, RA has no known aetiology and consequently there is an absence of medical 'cures'. The goal of medical intervention is limited to maximising patient functioning through the management of pain and inflammation and attempting to modify the disease process. Effective management of RA requires individuals to undertake a prolonged regimen of self-care strategies. Patients must learn behaviours and adopt significant lifestyle changes, such as taking medications and performing exercise daily to maintain joint mobility and strength. They must learn how to accommodate exercise, energy conservation strategies and pain relief techniques to the fluctuations of their disease. Therefore attention has shifted to the issue of 'coping' with the illness. Here, psychological factors are likely to be crucial to compliance to a treatment regimen and to the maintenance of a patient's emotional well being and physical functioning (Anderson et al., 1985). Research investigating the role of psychological factors in RA is essential to identify potentially modifiable predictors of adjustment difficulties and to develop interventions that maximise functioning and reduce distress (Smith & Christenson, 1996).

Motivated by the clinical relevance of this issue for an increasing population of people, this research attempts to investigate the relationship between psychological responses to RA and the relationship between such factors and the emotional and physical well-being of those with RA.

In this introduction, there will be a review of the literature on coping, on control, and on knowledge, with reference to theoretical models, studies of chronic illness in general and RA in particular.

## 1.1 The Impact of RA

### *1.1.1 Physical impact of RA*

The joint disease of RA is usually accompanied by signs of swelling, warmth and tenderness of the affected joints. As the disease progresses destruction of the cartilage takes place and joint function is compromised. End stage RA results in subluxion (dislocation) of joints with occasional ankloses (fusion). The cardinal symptoms of RA are persistent pain, stiffness and swelling in joints. In a national survey, 31 per cent of RA patients reported varying degrees of limitation with activities of daily living and almost 60 per cent had to discontinue employment within ten years of disease onset (Felts & Yelin, 1989).

### *1.1.2 Psychological impact of RA*

A number of clinical studies has identified RA patients as a medical population at risk for lowered psychological well-being. Depression has received most attention in the rheumatology literature, though estimates of prevalence vary widely. Cassileth et al. (1984) found no differences in depression among 82 people with RA and four other major diagnostic categories of chronic physical illness, or the general population. But, using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), Chandarana et al. (1987) identified 22 per cent of 86 RA patients with 'anxiety' and 19 per cent with 'depression' scores, while Frank et al. (1988) found that 42 per cent of 137 RA outpatients met DSM-III criteria for either major depressive or dysthymic disorders.

There are, however, conceptual and methodological problems in interpreting the rheumatology literature on depression. For example, prevalence studies are plagued by the contamination of depression measures with such physical manifestations of RA as sleep disturbance and fatigue which can overestimate the prevalence of depression (Blalock et al., 1989; Pincus et al., 1986). Using depressive symptom scales, most studies interpret depressive symptomatology as depressive disorders, but depressive symptom scales were never intended as diagnostic instruments and are not adequate for diagnosing depressive disorders (Rodin et al., 1991).

Despite these problems, the majority of studies suggest there is a greater prevalence of depressive symptoms and disorders among clinical samples of people with RA than among people without serious, chronic diseases. This level of psychological disturbance, however, is comparable to that found among clinical samples of people with other chronic diseases (DeVellis, 1993).

As anxiety and depression symptoms have been found to commonly coexist (Breier et al., 1985), RA patients may suffer from anxiety. In support of this, Hawley & Wolfe (1988) found that anxiety was common in 400 RA patients and anxiety scores were found to be higher than depression scores. However, the literature has focused on depression and tended to overlook the prevalence and impact of anxiety on RA patients.

Although physical outcomes such as pain and impaired functional status might be expected to be positively related to depression in RA populations, the presence and magnitude of this association is unclear (Peck et al., 1989). For example, a number of studies has found depressed RA patients to be significantly more disabled (Pincus et al., 1986; Hawley & Wolfe, 1988). However, Holm et al. (1998) found only a weak correlation between disability and depression. Similarly, Hawley & Wolfe (1988) found no significant relationships between increases in depression and any of the measures of disease activity and disability.

These inconsistent findings may result from the use of invalid measures of functional status and emotional adjustment. As well as the difficulties of assessing depression in RA outlined above, many self-report disability assessments are susceptible to confounding effects of mood on behaviour (Peck et al. 1989).

## 1.2 Coping

The psychological approach to the study of stress conceptualises it in terms of the dynamic interaction between the person and the environment. Stress is thought to arise when a person perceives that he/she cannot adequately cope with the demands being made on him/her or with threats to his/her well being (Lazarus, 1966).

Coping is defined by Lazarus & Folkman (1984) as 'cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (p.141) and they distinguish between two types of coping efforts. 'Problem-focused' coping is aimed at problem solving or doing something to alter the source of the stress. 'Emotion-focused' coping is aimed at reducing or managing the emotional distress associated with the situation.

The distinction between problem and emotion-focused coping strategies has been influential in the research literature, however, other differences between coping styles have been proposed. For example, Miller (1979) distinguished between 'blunters' who use cognitive avoidance and denial strategies and 'monitors' who use information-seeking strategies in relation to stressful situations. However, Carver et al. (1989) claim that when diverse coping strategies are reduced to a smaller number of coping styles it becomes impossible to examine whether the individual strategies bear differential relations to various adaptive outcomes. They therefore criticised the distinctions such as emotion-focused and problem-focused coping as too simple.

Lazarus & Folkman chose to emphasise the consideration of coping style in its own right independently of outcome, however, there is considerable evidence from studies of chronic illness that coping strategies may be related to physical and psychological health outcomes and certain consistencies have appeared in the research. Passive and suppressive strategies such as self-blame, emotional ventilation and cognitive and behavioural avoidance have generally been related to poorer psychological adjustment, slower recovery and increased distress in a number of illness groups (Carver et al., 1992; Felton et al., 1984; Moss-Morris et al., 1996). Coping strategies demonstrating positive effects across illness groups include positive reinterpretation, acceptance of illness, planning and utilising social support and humour (Carver et al., 1992; Dunkel-Schetter et al., 1992; Felton et al., 1984; Moss-Morris et al., 1996).

### *1.2.1 Coping and RA*

There is a considerable amount of literature investigating the relationships between coping and levels of disability and psychological well-being in people with RA. It is important to determine the way people cope with RA as this may impact on their psychological and physical well-being. Furthermore, the self-management aspect of care in RA requires the adoption of specific 'coping' strategies.

Two broad areas of research on coping with RA exist: one group has taken a general focus using the stress-and-coping paradigm to investigate coping strategies used to deal with RA; the other group has taken a more specific focus using conceptual models of pain to examine RA patients' efforts to cope with pain (Melzack & Wall, 1965).

Many of the studies taking a general focus have used the general Ways of Coping Questionnaire (Folkman & Lazarus, 1980) with RA patients. From these studies, cognitive restructuring has been consistently associated with better psychological functioning and wishful thinking with poorer well-being (Felton et al., 1984; Parker et al., 1989). Some studies have found information-seeking to be associated with improved outcome (Felton & Revenson 1984) although others have failed to find this association (Parker et al., 1988).

Cross-sectional studies do not indicate a cause and effect relationship between coping and adjustment. Revenson & Felton (1989) addressed this problem in a six-month longitudinal study. They found a significant result observed only on changes in positive affect (not mastery, self-esteem or acceptance). Increases in positive affect were associated with information seeking and decreases were associated with wish-fulfilling fantasy, self-blame and emotional expression.

Regarding the studies taking a more specific focus by investigating pain coping strategies, a tendency to respond to 'flare-ups' of RA by engaging in passive pain-management strategies (for example, depending on others for pain control, restricting one's functioning due to pain) or with cognitive distortions has been consistently associated with high levels of depressive symptoms and functional impairment. Brown & Nicassio (1987) found passive coping predicted greater pain, depression, helplessness and less self-efficacy. In a six-month longitudinal study, Keefe et al. (1987) found that patients initially reporting catastrophising had greater levels of pain, disability and depression six months on.

The evidence for active coping responses (for example, efforts to function in spite of the pain) related to adjustment is weak and inconsistent. Beckham et al. (1991) and Keefe et al. (1987) found that active coping led to less depression, greater self-efficacy, lower levels of pain and less physical disability. However, Parker et al. (1989) did not find the effects to be significant.

In summary, studies in both general and pain-specific areas of research have suggested that negative or avoidant cognitive strategies are associated with poor outcomes and attempts to restructure thoughts are associated with positive outcomes. Studies are less consistent regarding the role of behavioural coping strategies. In some studies active strategies such as information seeking and 'active coping' have been associated with a better outcome while in other studies the effects are not significant. Thus, while research supports the general contention that there is a relationship between coping and outcome, many of the findings appear contradictory.

These contradictions reflect four problems within the rheumatology coping literature. First, there is a problem in comparing studies of RA patients, since researchers taking either a general focus or a specific focus (on pain) use questionnaires measuring different forms of coping, that is, problem and emotion-focused coping as opposed to active and passive coping.

Second, specific pain coping inventories do not assess how patients deal with multiple other problems. For example, Blalock et al. (1993) found that RA patients were less likely to use behavioural coping strategies in response to problems involving interpersonal relationships than to problems involving daily activities.

Third, it has wrongly been assumed that a realistic and direct confrontation with the stressor leads to an adaptive outcome (Newman et al., 1990). Thus, coping responses such as self-distraction are seen as failures to cope because they are not 'reality bound'. This view is particularly contestable in relation to RA, as strategies that involve avoidance and cognitive distortions of the situation may constitute an adaptive approach. For example, self-distraction may be an effective coping strategy when dealing with high levels of pain. Thus, the effectiveness of any given strategy depends upon its appropriateness for the particular stress faced.

Finally, problems with item inapplicability exist when using generic coping questionnaires such as the Ways of Coping questionnaire with a specific stress such as RA. Recent attempts have been made to design coping strategies specific to RA, for example, the 'Coping with Arthritis Questionnaire' (Newman et al., 1990). However, the reliability and validity of such measures are frequently not examined in any detail and therefore are of questionable use.

### 1.3 Control

According to the stress-and-coping model, coping attempts are primarily determined by appraisals of a potential stressor. Thus, events are not inherently stressful and the impact of potential stressful situations depends on how they are interpreted. Control is defined as the individual's perception that he or she can execute (or has the potential to execute) some action that changes an aversive stimulus (Miller et al., 1979).

'Locus of control' (LOC) is a construct termed by Rotter (1966) to differentiate between individuals who believe that control over valued items is either internal (dependent on an individual's own characteristics or behaviour) or external (dependent on the actions of other people or a matter of fate, luck or chance). Wallston (1992) modified Rotter's (1966) concept of 'locus of control' and applied it to a person's beliefs regarding where control over health lies ('health locus of control') (HLC). If people believe that their own behaviour influences their health status, they possess an internal locus of control orientation. Conversely, if they believe that their health status is influenced by the actions of other people or is due to fate, luck or chance, they have an external health locus of control orientation. Wallston (1992) found that it was possible for people to hold both internal and external beliefs about health status.

Wallston proposed that a person's health locus of control orientation is one of several factors which determine the health-related behaviours a person will perform; and these health-related behaviours in turn partially determine a person's health status. Results from studies in medical illness suggest that beliefs concerning internal versus external control are linked in meaningful ways to health-related behaviours. For example, some findings suggest that persons with stronger beliefs in personal control and weaker beliefs in chance control adhere to medical advice and carry out self-care programmes more regularly than people with weaker beliefs in personal control and stronger beliefs in chance control (Stenstrom et al., 1998; Strickland, 1978). Harkapaa et al. (1996) found that a stronger belief in chance control was associated with less adaptive strategies such as catastrophising in back pain patients.

Brown & Nicassio (1987) found that patients using active coping had stronger beliefs in internal health locus of control, less depression, pain and functional impairment. Passive coping was related to stronger beliefs in chance and powerful others and overall poorer adjustment. Similarly, Carver et al. (1989) found that if individuals believed the stressful situation was amenable to change, they tended to use active coping, planning and positive reinterpretation. These coping strategies were positively associated with optimism and inversely associated with anxiety. However, if patients believed the situation was uncontrollable, they tended to use denial, venting and behavioural disengagement. These strategies were positively correlated with anxiety and negatively correlated with optimism and self-esteem.

However, for a variety of medical conditions, results of studies investigating locus of control have not been consistent. For example, Harkapaa et al. (1996) found that stronger beliefs in powerful others' control were associated with active behavioural coping. Evans & Hughes (1987) found adjustment and metabolic control was worse in diabetic patients with a more internal control orientation. Such contradictions have led investigators to suggest the need for more specific locus of control scales so as to be able to predict beliefs regarding control in particular contexts such as RA.

### *1.3.1 Control and RA*

In the context of the unpredictable disease course in RA and the self-management approach necessary to managing the illness, a psychological construct likely to be an important moderator of the affective and functional impact of the disease is that of health locus of control (Smith et al., 1988).

Persons with RA have been found generally to perceive less control over their illness than people with other types of chronic illness. For example, Felton & Revenson (1984) found that RA patients were as likely as cancer patients to believe they had little control over their illness and both of these groups held stronger beliefs in external control than patients with diabetes or hypertension.

A few studies have investigated the role that RA patients' control appraisals play in determining psychological status, pain or extent of functional limitations. A common finding in chronic illness populations is that outcomes are more positive in persons who have strong beliefs in internal control over their illness (Wallston, 1982). Some degree of control can be achieved over specific aspects of RA, such as managing pain and stiffness and their impact on daily functioning and activities (Young, 1993). There is a presumption that patients' actively participating in treatment decisions and self-management recommendations perceive some degree of personal control over their care. Even under conditions of severe and disabling RA, better adjustment has been associated with perceived personal control over the daily aspects of disease management (Affleck et al., 1987). RA patients who have greater confidence in their own ability to control their illness were found to be less depressed and anxious and exhibited less pain and impairment in daily living (Nicassio et al., 1985; Wallston et al., 1994).

However, Affleck et al. (1987) found that perceived control over the course of RA was associated with negative mood in patients with severe RA. This supports the notion that in the case of a chronic illness, such as RA, a belief in external control may be adaptive, whereas, maintaining belief in personal control in the face of repeated failures to gain control could lead to coping difficulties (Burish et al., 1984). However, these findings are based on illness perceptions of personal efforts to alter significantly the course of a disease, which in RA are apt to fail. When investigating perceptions of control over RA, it is therefore vital that researchers distinguish between beliefs about disease course control and beliefs about personal control over daily symptoms. The failure to do so is likely to result in conflicting findings.

Research focusing on internal and external control has been criticised for being over simplistic. Wallston (1993) reported externality to consist of at least two distinct dimensions, control by powerful others (for example, family, friends, health care professionals) and control by chance (fate, luck or other impersonal determined forces). Taking this perspective, internality can no longer be equated with perceived control and externality with a lack of control. Wallston suggests that it is not the locus of control per se which is important, but it is the perception that health status could be controlled (regardless of the locus) that might contribute to psychological well-being in patients.

For example, believing that other people's actions play a significant role in whether you become ill or get well does not necessarily imply a loss of control, especially if individuals believe they can influence these powerful others to act in their own best interests.

Furthermore, Wallston argued that when considering specific health-related conditions, such as RA, individuals differentiate between the potential influences of medically trained personnel, and that of other people, in a manner that they do not when considering their general health. Wallston et al. (1994) found beliefs in 'doctor' control to be significantly associated with less pain, whereas beliefs in control from 'other people' were significantly associated with more depression. However, not all studies have confirmed this finding. For example, in a study by Affleck et al (1987), negative mood was associated with the belief that providers have greater control over the patients' daily symptoms. More studies are needed to investigate the multidimensional concept of external control with health behaviours and outcome, as these beliefs are potentially conducive to forming an effective alliance between the patient and health professionals.

## 1.4 Knowledge

Individuals differ in the extent to which they seek out information related to threatening events. Some people are vigilant, finding out as much as possible about the nature and consequences of events, while others avoid information and divert their attention away from threatening knowledge.

A common pattern that emerges from research is that avoidant strategies lead to less distress than information-seeking strategies in acute clinical settings. For example, information leads to more distress during investigative medical procedures than does avoidance (Phipps & Zinn, 1986). In the short-term, therefore, information leads to unnecessary worry and heightened attention to symptoms. However, in the longer term, for example, in chronic illness, information seeking may be more adaptive since increased attention may uncover information that facilitates long-term adaptation, such as engaging in appropriate behaviours and self-care (Mullen & Suls, 1982). Felton & Revenson (1984) found that information-seeking was associated with more positive moods than was avoidant coping in patients with mixed chronic illness. However, some research has shown that denial may be adaptive even in the long term. For example, the benefits of denial among breast cancer patients has been observed by Greer et al. (1979).

Perceptions of control have also been proposed to interact with information-seeking behaviour. Using the terms 'monitoring' and 'blunting', Miller (1981) suggested that when an aversive event is perceived as controllable, high monitoring and low blunting are the main responses and information is preferred. In support of this, Wallston (1993) proposes that knowing in advance what is likely to occur in the future is often less distressing than being uncertain about outcomes, even if they are distressing. It has been suggested that having no information about illness inevitably means a lack of control and leads to feelings of helplessness and negative outcomes (Steptoe, 1983). Furthermore, Zindler-Wernet (1984) found that an internal locus of control was associated with increased motivation in seeking information and individuals with an internal orientation have been found to know more about their illness than patients with an external orientation (Seeman & Evans, 1962).

When an aversive event is perceived as uncontrollable, high blunting and low monitoring become the main response modes, since an individual without controlling actions can most effectively reduce stress by avoiding the negative aspects of the event (Miller, 1981). It has been suggested that the strategy of avoiding information is useful in uncontrollable situations as it minimises distress and thereby facilitates coping (Cohen & Lazarus, 1973).

### *1.4.1 Knowledge and RA*

Patient knowledge of RA is regarded as important because the majority of the treatment for RA must be undertaken in the home environment and patients cannot participate effectively in their own care without the knowledge necessary to monitor and manage their symptoms (Davis et al., 1994).

Research has indicated that many RA patients have incomplete knowledge about disease symptoms, aetiology and drug therapy (Hill et al., 1991). Kaye & Punchak (1988) found that all patients in their study wanted more information about the disease and most of them believed that knowing more would allow them to cope better with the disease. This supports the view that, with sufficient information, people may be able to use coping strategies effectively because they know what they are preparing for (Johnson, 1975).

From the above discussion, it could be assumed that RA individuals with internal orientation of control would be more knowledgeable about their illness. Individuals adhering to beliefs in medical control may also be more knowledgeable, as they are more likely to have listened and read the information given to them by health professionals. However, there is a paucity of studies investigating the effects of information on knowledge in RA patients and chronic disease patients in general. Furthermore, studies evaluating RA educational programmes have shown that little evidence exists to support the notion that providing educational information by itself is sufficient to change behaviour (Lindroth et al., 1997).

### 1.5 Problems with existing research

A number of difficulties are apparent within the existing research. First, studies assume that the 'stress' of RA includes only physical aspects such as pain and immobility. However, patients have to deal with different problems at different times in the course of the illness. When the disease is active, the immediate concern of pain, stiffness and new restrictions on activities may be paramount (Newman et al, 1990). In periods of stability, dealing with other consequences of RA may be most important. RA can lead to major changes in family and marital functioning and social activities; sexual problems; financial problems due to work disability and problems with adherence to medical treatment and lifestyle recommendations (Anderson et al., 1985; Cornelissen et al., 1988; Liang, 1984). Within the rheumatology literature, very little attention has been paid to the stressors of the disease as perceived by patients. As a result, the focus of the coping process remains unclear.

Two studies have found that feeling dependent, disability and pain were rated by RA patients as the three most important health-related problems (Taal et al., 1993; Van Lankfield et al., 1993). In other studies, pain was also rated as a less important problem than disability and feeling dependent (Cornelisson et al., 1988). This is in contrast to findings in other studies where pain has been reported as the most important problem for RA patients (Brown et al., 1987).

A second problem is that conceptual models guiding research into the adjustment of chronic illness reflect a predominant focus on the assessment of negative emotions (Smith & Christenson, 1996). Consequently, they reveal little information about RA patients' adaptive responses or positive characteristics. Researchers have demonstrated that positive affective states are not simply the opposite of negative states and have suggested a bi-dimensional approach to the measurement of mood (Felton et al., 1984; Smith & Christenson, 1996).

Third, studies have confused the use of objective measures of disease activity with measures of self-reported physical function, which may be considered to be subjective measures. For example, many studies include grip strength as a measure of objective disease activity; however, an individual's grip strength may depend on subjective perceptions of level of functional disability.

Fourth, there is still no consensus as to whether it is more useful to focus on broad tendencies which may represent general coping styles or to study a wide range of very specific coping strategies (Ingledew et al., 1996). The problems outlined above regarding the RA coping literature suggest that measuring both general coping strategies and coping strategies specific to the self-management aspect of RA may be advantageous. In support of this, Ingledew et al. (1996) modified the COPE inventory (Carver et al., 1989) which measures several aspects of problem-focused, emotion-focused coping and coping responses that may interfere with active coping by adding specific health behaviours.

Fifth, the consequence of engaging in a number of coping strategies can either be adaptive or maladaptive. Seeking emotional support can provide reassurance, but, sources of sympathy can be used more as outlets for the ventilation for one's feelings (Billings & Moos, 1984). Similarly, self-distraction can sometimes be a highly adaptive response (Klinger, 1975); but at other times it can impede adaptive coping (Aldwin & Revenson, 1987). Finally, although turning to religion has been suggested as a coping tactic that might be important to aid positive reframing, it might also serve as a source of emotional support which might impede active coping (McCrae & Costa, 1986).

Sixth, many of the measures have not been developed for a RA patient population but rather for the general population of chronic illnesses, therefore the use of RA specific measures in research is needed.

Seventh, although the provision of medically-related information has been extensively addressed in relation to control, coping and outcome in preparation for surgical procedures, no studies have addressed the association of illness-related knowledge in a chronic illness population, despite the potentially clinically relevant implications of the use of self-management strategies for outcome.

Eighth, the majority of research has used quantitative measures, to the virtual exclusion of qualitative data. However, some research into other chronic illnesses has suggested that qualitative data may provide valuable additional insights to validate and supplement quantitative findings (Jue, 1994). Moreover, no standardised quantitative measure to ascertain RA stress exists in the literature and has been suggested that inconsistent findings have resulted from the different phrasing of questions across studies (Taal et al., 1993). Comparison of quantitative and qualitative methods of collecting data on perceived RA stresses might clarify this issue.

Ninth, most research has adopted a limited approach, possibly due to the complexity of the variables, for example, exploring the relationship between coping and psychological well-being or coping and physical health. No studies have sought to simultaneously measure the relationships between coping, appraisals of control and knowledge on the one hand and objective disease activity, subjective physical and psychological well-being on the other.

## 1.6 The present study

Using measures that are appropriate for a RA population, the present study will investigate perceptions of control, knowledge, coping and psychological and physical outcome and compare them with previous findings. Qualitative methodology will also be used and will be compared with quantitative findings. Measures of positive affect will be included, and the study will distinguish between subjective and objective measures of physical outcome.

General coping strategies used in response to RA, as well as more specific RA-related management strategies will be investigated. Coping strategies will be examined individually and associations between coping and outcome will be investigated. 'Adaptive' coping strategies to be examined will include active coping, acceptance, planning, humour, positive reframing and self-management behaviours. 'Maladaptive' coping strategies will include alcohol/drug use, behavioural disengagement, denial and venting. Although denial has been associated with both positive and negative outcome, in the context of a long-term illness such as RA, it will be regarded as maladaptive. Coping strategies having no predicted relationships with outcome on the basis of theory or previous research will also be examined.

Perceptions of internal control and a multidimensional concept of external control will be explored using a disease-specific scale. Perceptions of 'internal' and 'doctor' locus of control will be assumed to reflect perceptions of personal control over daily symptoms, and beliefs in 'chance' and control of 'other people' to reflect a lack of control. Associations between control with coping strategies and outcome will be investigated. Levels of knowledge of RA will be examined as well as its associations with perceptions of control and coping strategies. Finally, to expand on the limited findings regarding the consequences of RA that patients perceive as stressful, a questionnaire will be developed and administered.

## 1.7 Aims and hypotheses

Hypotheses have only been included where a clear prediction can be made from previous theory and research. The hypothesised relationships between the main variables in the present study are presented in Figure 1.

AIM 1: To investigate the physical and psychosocial consequences of RA that patients perceive as stressful.

Hypothesis 1: Pain and loss of physical mobility will be perceived as the most stressful consequences of RA.

AIM 2: To investigate perceptions of control over daily symptoms, knowledge of RA, coping strategies used and psychological and physical outcome and compare these findings with previous research.

AIM 3: To investigate, using qualitative means, patients' perceptions of the stressful consequences of RA; control over symptoms; knowledge of RA, coping strategies and the psychological and physical impact of RA. To relate this qualitative information to the quantitative data.

AIM 4: To investigate relationships between physical functioning and psychological outcome.

Hypothesis 2: Negative affect will be associated with increased depression and anxiety and lower positive affect; positive affect will be associated with decreased depression, anxiety and lower negative affect

Hypothesis 3: Negative physical outcome will be associated with negative psychological outcome. Positive physical outcome will be associated with positive psychological outcome.

AIM 5: To investigate relationships between physical and psychological outcome and perceived control over RA, knowledge of RA and coping strategies.

Hypothesis 4: Negative psychological outcome and negative physical outcome will be associated with increased beliefs in 'chance' and 'other people' locus of control; less knowledge; increased maladaptive coping and decreased adaptive coping

Hypothesis 5: Positive affect will be associated with increased beliefs in 'internal' and 'doctor' locus of control; increased knowledge; increased adaptive and decreased maladaptive coping strategies.

AIM 6: To investigate relationships between control, knowledge and coping strategies.

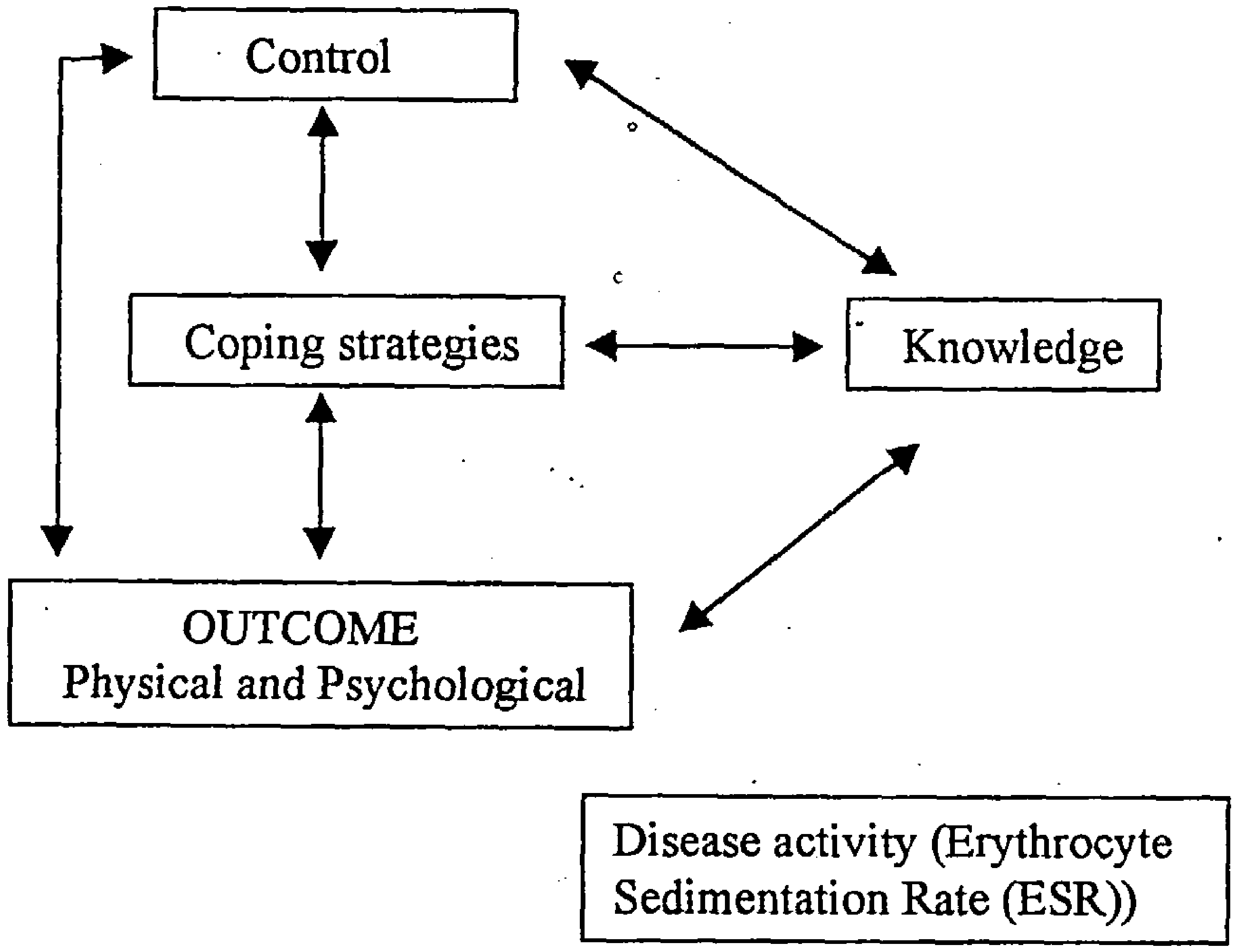
Hypothesis 6: Increased beliefs in 'internal' and 'doctor' locus of control will be associated with increased knowledge; increased adaptive coping and decreased maladaptive coping.

Hypothesis 7: Increased knowledge will be associated with increased adaptive coping and decreased maladaptive coping

AIM 7: To investigate the associations shown by those coping strategies having no predicted relationships with control, knowledge and outcome on the basis of theory or previous research (self-distraction, emotional support and religion)

AIM 8: To predict which variables are associated with outcome.

Figure 1. Hypothesised relationships between main variables in the present study



1.8 Pilot Study

The aims and hypotheses to be explored in the current study were developed as a result of a pilot study (Appendix 1). The pilot study was conducted with nine participants, to identify whether it was possible to cover the breadth of areas that were originally considered for investigation. The pilot study aimed to reduce the number of original hypotheses and psychometric tests and to assess the acceptability of the type of questionnaires to participants. The pilot study also aimed to develop a questionnaire to assess perceptions of RA-related stresses for use in the present study.

# 2.0 Method

## 2.1 Ethical Approval

Ethical approval was obtained for the pilot study from the Local Health Authority Research Ethics Committee in June 1998 (Appendix 2). The proposal for the main study was resubmitted and agreed by the Ethics Committee in August 1998 (Appendix 3).

## 2.2 Design

The design was cross sectional and divided into two components:

- Quantitative design: A correlational survey design requiring structured questionnaire completion by all of the participants.
- Qualitative design: Semi-structured interviews administered to a sample of the participants.

## 2.3 Participants

Data were obtained from adults with rheumatoid arthritis (RA) attending an outpatient clinic in a single district. Criteria for inclusion into the research included:

- Diagnosis of definite or classic RA by a rheumatologist using criteria from the American College of Rheumatology (Arnett et al., 1988).
- Age 18 years old and over
- Not diagnosed as having any other serious illness
- No obvious intellectual impairment
- No recent experience of a major life event
- Completion of an informed consent form

Fifty-six RA patients were asked to participate in the questionnaire component of the study and 50 people agreed. Patients who declined to participate cited difficulty with travelling to the hospital and the length of time to complete the questionnaires as reasons for their decision. All 50 participants were asked to take part in a further semi-structured interview and seven participants refused. From the 43 participants who agreed to take part, 20 were given an appointment and 14 attended for a semi-structured interview.

**Table 1.** Information on participants in the present study

| **Participants** | **N** | **Age range** | **Mean age (SD)** | **% Males : Females** |
|---|---|---|---|---|
| **Main study** | 50 | 30 - 82 | 55.98 (12.92) | 30 : 70 |
| **Semi-structured interview** | 14 | 30 - 70 | 55.00 (12.95) | 21 : 79 |

Table 1 summarises the descriptive details of the 50 participants that took part in the main study and the 14 participants that went on to take part in the semi-structured interview. The higher ratio of females to males found in both groups of participants is typical of a RA population (Anderson et al., 1985).

2.4 Measures

*Demographic information* (Appendix 4).

For the purpose of the study a detailed demographic information schedule was designed. Demographic information included participant age, sex, marital status, occupation (previous occupation if retired, disabled or unemployed), years of education, dependants and ethnic origin.

Information related to RA included the length of time since RA symptoms started, length of time since RA was diagnosed by a rheumatologist, type of joints affected by RA and current medication.

*Form C of the Multidimensional Health Locus of Control Scale (MHLC)* (Wallston et al., 1994) (Appendix 5).

The MHLC is an 18 item condition-specific locus of control scale that can be adapted for use for any medical condition. It establishes beliefs about the extent to which health behaviour is controlled by internal factors, chance factors, doctors and other (powerful) people. The internal and chance sub-scales comprise six items each and the doctors and other (powerful) people sub-scales include three items each.

For each item, participants rate the extent of their agreement or disagreement using a six-point Likert scale. Separate scores are obtained for each of the four sub-scales by adding the respondent's scores on the items in each sub-scale. Since the scores on each item range from one (strongly disagree) to six (strongly agree), the scoring range for internal and chance sub-scales are from six to 36, and for doctor and powerful others sub-scales from three to 18.

Wallston et al. (1994) used data from 273 RA patients and 111 chronic pain patients and established that the sub-scales were sufficiently internally consistent to be used in research. The sub-scales were found to be moderately stable three years later (in a sample of persons with RA who had not received systematic interventions designed to alter their beliefs). Comparison with previous versions of the MHLC and Levenson's Locus of Control measure (Levenson, 1973) provided considerable evidence for the concurrent validity of the sub-scales (Wallston et al., 1994).

*Patient Knowledge Questionnaire (PKQ)* (Hill et al., 1991) (Appendix 6).

This is a British questionnaire developed for use by Hill et al. (1991) to assess patients' knowledge of RA and its various treatments. The questionnaire consists of multiple-choice questions covering four major topics: general knowledge (including aetiology, symptoms and tests); drugs and how to take them; exercise regimes; and joint protection, pacing and priorities.

The PKQ consists of sixteen multiple-choice questions with a choice of 80 possible answers, 30 of them correct. Answers are recorded by circling a number and one point is given for each correct answer. A 'don't know' option is provided.

The PKQ has been evaluated for reliability and Hill et al. (1991) concluded that the PKQ was internally consistent (r = 0.72). A four week test re-test produced a value of r = 0.81 which was judged as acceptable. No measure of validity has been published.

*The Hospital Anxiety and Depression Scale (HADS)* (Zigmond & Snaith, 1983). (Appendix 7).

This is a 14-item questionnaire providing a brief state measure of anxiety and depression as 'normal', 'mild', 'moderate' and 'severe'. It is designed for use in medical outpatient clinics to detect anxiety and depression without contamination of scores by reports of physical symptomatology. It therefore contains items that are unlikely to be influenced by the physical symptoms of RA (such as fatigue). Each item is scored from zero to three and the total scores range from zero to 21 for both the anxiety and depression sub-scales. Higher scores indicate greater anxiety or depression.

Moorey et al. (1991) examined the internal consistency of the two subscales and showed acceptable Cronbach's alpha levels of 0.93 for anxiety and 0.90 for depression. Concurrent validity was established by Zigmond & Snaith (1983) who found that the HADS sub-scales correlated significantly with 5-point psychiatric rating scales of anxiety and depression for 100 medical outpatients (anxiety, r = 0.54; depression, r = 0.79). Hermann (1997) reviewed the validation data and clinical results of the HAD for over 200 studies and concluded that the scale has good test re-test reliability and cross-cultural validity.

*Positive and Negative Affect Schedule (PANAS)* (Watson et al., 1988) (Appendix 8).
The PANAS was developed as a brief measure of both negative and positive affect dimensions. The schedule consists of 20 adjectives used to describe different feelings and emotions (10 positive and 10 negative). Respondents rate their feelings by indicating the extent to which the word describes their feelings on a five-point scale from 'very slightly or not at all' to 'extremely'.

Both sub-scales have shown high internal consistency by exceeding alpha = 0.84 and the PANAS has demonstrated concurrent validity (Watson et al., 1988).

*Health Assessment Questionnaire (HAQ)* (Fries et al., 1980) (Appendix 9).
The HAQ assesses the extent of functional disability. It requires respondents to assess their degree of difficulty in performing activities of daily living in eight general categories: dressing and grooming, arising, eating, walking, hygiene, reach, grip and outside activity.

The HAQ contains 20 items that are rated on a four-point Likert scale, from 'I am able to do this without any difficulty' to 'I am unable to do this'. Daily function scores range from 0 to 24 and these are then converted into a summary mean measure of disability with a range of 0 to 3. Higher scores denote greater disability in performing daily activities.

This measure has been found to have adequate internal consistency (Peck et al., 1989). Construct validity of the HAQ has been demonstrated through correlations with physical indexes such as joint count and morning stiffness (Fries et al., 1982). The American College of Rheumatology (ACR) recommends that the HAQ be used by RA patients to assess their physical function (Felson et al., 1993).

*Pain Visual Analogue Scale (VAS)* (Appendix 10).

Participants rated their average level of pain intensity experienced in the past week using a visual analogue scale (VAS). The VAS consists of a 10cm horizontal line anchored by two extremes of pain: ‘no pain’ and ‘pain as bad as it could be’. Participants were asked to make a mark on the line which represented their perceived level of pain intensity, and the scale was scored by measuring the distance from the ‘no pain’ end to the patients mark. The VAS is scored from zero to 100, the higher the value indicating higher levels of pain.

The VAS is frequently used with persons experiencing chronic pain and it is the recommended method for RA patient’s to assess their level of pain (Felson et al., 1993). In a comparison with five other measures of pain intensity, Jensen et al. (1986) concluded that the VAS demonstrated construct and predictive validity.

*Erythrocyte sedimentation rate (ESR)*

The ESR is a widely used laboratory blood measure that generally parallels the levels of arthritis activity, particularly inflammation. The ESR is the rate (millimetres per hour) at which red blood cells, when mixed with an anticoagulant, separate from plasma and settle to the bottom of the test tube. Fluctuations in ESR consistently have indicated fluctuations in disease activity in RA (Kelley et al., 1985).

A measure of ESR was collected from blood taken at the end of the interview or from a recent blood sample recorded at a recent assessment appointment. In the latter case ESR was obtained in the period from one week before the interview until one week after, since ESR may vary with disease activity. A high score represents more severe disease activity in patients with RA.

*RA Stresses Questionnaire* (Appendix 11)

This questionnaire was developed for the purpose of the study. It initially included 11 items (Appendix 33), and was amended as a consequence of the pilot study to include a further ten items. Participants were asked to indicate on a five-point Likert-type scale the extent to which they had experienced 21 aspects of RA as distressing or bothersome over the previous week (from 'never' to always'). Participants were then required to name the three most problematic consequences of RA they experienced over the past week.

*Brief COPE* (Carver et al., 1989) (Appendix 12).

This is a modified version of the COPE (Carver et al., 1989). This scale consists of 22 items and measures 11 coping strategies. These include self-distraction, active coping, denial, alcohol/drug use, use of emotional support, behavioural disengagement, venting, positive re-framing, planning, use of humour, acceptance and religion.

A four-point Likert scale ranging from 'I usually don't do this at all' to 'I usually do this a lot' measured how frequently participants used each way of coping in response to the stresses associated with having RA over the past week. Separate scores for each of the scales were computed by adding the scores on the two items, the scores for each scale range from two to eight. The validity of the Brief COPE was investigated on a British sample of one hundred orofacial cancer patients (Humphris et al., 1995). Humphris et al. (1995) found evidence of concurrent validity between these sub-scales and the Mental Adjustment to Cancer sub-scales (Watson et al., 1988). This measure was used as it assesses a wide range of coping responses and is not limited to measuring pain coping strategies.

As a result of the pilot study (Appendix 40), eight items were included at the end of the Brief COPE to represent four RA self-management behaviours (two items for each strategy). These four strategies included energy conservation, adapting activities, physical strategies and knowing limitations. Two items were also included to represent the use of alternative therapies (for example, acupuncture).

*Semi-structured Interview* (Appendix 13).

A semi-structured interview was designed to obtain qualitative data from participants on the issues covered by questionnaires. This was to enable comparisons to be made between qualitative information and quantitative data obtained from the questionnaires.

The format of the semi-structured interview evolved by transforming the five general areas covered by the quantitative part of the study into twelve open-ended questions (Table 2). All interviews were audiotaped and responses were transcribed with the participant's permission.

**Table 2.** Questions asked in each general area covered by the semi-structured interview

| General area | Questions |
|---|---|
| **Current physical and psychological functioning** | 1. Currently to what extent is the effect of your arthritis influencing what you are able and not able to do?<br>2. Currently to what extent is the effect of your arthritis influencing your mood (how you feel)?<br>3. How would you rate the current intensity of your pain on a scale of zero to ten (with zero being no pain and ten being pain as bad as it could be)? |
| **RA stresses** | 4. What aspects of RA do you find most stressful/bothersome at the present time? |
| **Control over RA symptoms** | 5. To what extent do you believe you yourself can control (influence) the severity of your arthritic symptoms?<br>6. To what extent do you believe that others (i.e. doctors/significant others) can control (influence) the severity of your arthritic symptoms?<br>7. To what extent do you believe that the severity of your symptoms are controlled by 'fate/chance' i.e. that no-one has any control over them? |
| **Coping with RA** | 8. What do you do or tell yourself to manage (cope with) the consequences of having arthritis? |
| **Knowledge of RA** | 9. Can you describe what causes your arthritic symptoms? In what way do you think that having arthritis changes how your body works in order to produce the arthritic symptoms that you experience?<br>10. What medication are you currently taking for your arthritis? What is does this medication do? What are the potential side-effects of this medication?<br>10. What would you say are the best strategies to reduce the symptoms of arthritis when you have a flare-up?<br>11. Have you found out about arthritis i.e. books, videos/TV, internet, radio? |

## 2.5 Procedure

The research took place in the outpatient clinic of a General Hospital. Patients meeting the inclusion criteria were asked by a specialist rheumatology nurse at their assessment appointment whether they would be willing to take part in the research. The nurse gave a brief explanation about the research and patients were given an information sheet (Appendix 14). All patients who agreed to participate were given an appointment to be seen individually by the researcher in the outpatients department from two to four weeks later. When the researcher saw the participant a brief summary of the research was given and they were asked if they had read and understood the information sheet.

It was emphasised to participants before consent was sought that they might be asked to go for a blood test and an explanation of ESR was given. If participants had weekly blood tests then they were asked permission for a measure of their ESR to be included in their next blood test. If they did not have regular blood tests, they were asked to go to the pathology department for a blood test after the interview.

Opportunity was given for participants to ask questions and raise any concerns about the research. Participants were informed that they could withdraw from the study at any time. Assurance was given that the information they gave was confidential and anonymous and that it would not affect other aspects of their medical treatment. Informed written consent was then gained from those who agreed to participate (Appendix 15).

The researcher verbally asked participants for demographic and RA-related information. Participants were then asked to complete the following measures in the order shown below:

- Stresses Questionnaire
- Brief COPE
- Form C of the MHLC scale
- PKQ
- HADS
- PANAS
- HAQ
- VAS

If participants had any physical impairments that prevented them from completing the questionnaires independently (for example, poor vision or inability to write), the researcher helped them to fill in the questionnaires. This applied to ten of the participants due to restricted joint movement and/or high levels of pain in their hands or wrists.

All 50 participants were then asked whether they would be willing to come back and talk in more depth about their experiences of having RA, specifically the areas covered by the questionnaires. Participants who agreed to come back were informed that they would receive an appointment card within two weeks if they were to attend. It was emphasised to participants that the decision to ask them to return was based on a random process. They were asked to inform the rheumatology department if they either changed their mind or did not wish to attend again, or if the date was not suitable. At the end of the first meeting, a further opportunity to ask questions was given and participants were thanked for their co-operation.

The time taken for participants to complete the quantitative component of the study varied between 25 minutes and one hour.

### *2.5.1 Procedure for semi-structured interviews*

From the 43 participants who agreed to be interviewed, 20 were randomly selected as the target number. This stage of the procedure was carried out from four to twelve weeks following the questionnaire stage.

Participants were thanked for agreeing to come back and talk in more depth about their experiences. They were informed that the researcher would be asking open-ended questions covering the same areas as the questionnaires, but that more time was available to discuss issues. Verbal consent for the interview was again obtained and they were given the opportunity to withdraw from this stage of the study. Participants were asked permission to audiotape the meeting. It was emphasised to participants that the information they gave would be confidential and anonymous, that the researcher was the only person with access to the tapes, and that these would be kept in a locked filing cabinet and deleted after analysis.

An opportunity to ask questions about the nature of the interview was given before the interview commenced. The questions were simply phrased and open ended and these were rephrased and probes were used where necessary. The ordering of the questions varied according to the flow of conversation.

Interviews lasted from 45 minutes to one and a half-hours, after which participants were asked if they had any further comments or questions and were again thanked for their co-operation in the study.

# 3.0 Results

Descriptive results are presented first, followed by the results which relate to testing of the hypotheses. Quantitative data are supplemented by qualitative findings where appropriate.

## 3.1 Quantitative analysis

As parametric tests were to be carried out on the quantitative data, the skewness and kurtosis of variables were analysed. These analyses showed that skewness and kurtosis were in the acceptable range for 18 variables (between +2 and –2) (Appendix 16), but out of the acceptable range for 14 variables (above +2 and below –2). These variables were transformed (using a square root transformation, a log transformation or an inverse transformation depending on the nature and severity of the deviation). The kurtosis and skewness of the transformed variables were re-analysed to check that they had satisfied the normal distribution requirements (Appendix 17).

## 3.2 Qualitative analysis

The fourteen interviews were transcribed verbatim under each domain of questioning (adjustment, stress, control, coping and knowledge). The decision to transcribe the data into these predefined areas was made for two reasons. First, the aim of the qualitative information was to integrate it and make comparisons with quantitative findings; it would not form a separate part of the study. Second, participants' responses could readily be assigned into each area of questioning as they had generally kept to these areas during the interview.

## 3.3 Participant Characteristics

A total of 50 participants completed the questionnaires and 14 participants were interviewed using the semi-structured interview format, forming the qualitative component of the study. Table 3 shows that the majority of participants were married or living with a partner (78%), white (96%) and had left education at school-leaving age (78%). A small number of participants were currently employed (12%) with most being retired or registered disabled (74%). The majority of participants had previously worked full or part-time (92%). 28 per cent of participants had dependants.

RA most commonly affected participants' hands (94%) and high percentages of participants reported other joints being affected by RA. Regarding treatment, nearly all participants were on second line disease modifying drugs (94%) with a smaller percentage on steroids. Twenty-four per cent of participants reported having one or more joint replacements. As expected, the length of time since RA diagnosis was less than the number of years participants had RA (Table 4). The duration that participants reported having RA varied from nine months to 37 years, with the highest number of participants having RA between 11 and 20 years.

**Table 3.** Percentage distribution of participants characteristics

| **Participants characteristics** | | **%** | **Participants characteristics** | | **%** |
|---|---|---|---|---|---|
| **Marital status** | Married/living as | 78 | **Previous occupation** | Full-time employment | 90 |
| | Divorced/separated/ widowed | 14 | | Part-time employment | 2 |
| | Never married | 8 | | Housewife | 8 |
| **Ethnic origin** | White | 96 | **Joints affected by RA:** | Hand | 94 |
| | Asian | 4 | | Knee | 88 |
| **Education** | Left school-age | 78 | | Ankle/toes | 84 |
| | Higher education | 22 | | Elbow | 74 |
| | | | | Hip | 74 |
| **Present occupation** | Full-time employment | 8 | **Medication** | Second-line disease modifying drugs | 94% |
| | Part-time employment | 4 | | Steroids<br>70% | |
| | Retired | 44 | | | |
| | Disabled | 30 | | | |
| | Housewife | 10 | | | |
| | Unemployed | 2 | | | |
| | Student | 2 | | | |

**Table 4.** Means (SD), ranges and percentage distribution of disease duration and time since diagnosis (years)

| | **Disease duration (years)** | **Time since RA diagnosis (years)** |
|---|---|---|
| **Mean (SD)** | 13.58 (8.98) | 11.99 (8.58) |
| **Range** | 0.75 – 37 | 0.5 – 36 |
| **<6 years** | 24% | 30% |
| **6 – 10 years** | 20% | 20% |
| **11 – 20 years** | 40% | 36% |
| **21 – 30 years** | 10% | 10% |
| **>30 years** | 6% | 4% |

### 3.4 Stresses

Table 5 summarises the quantitative and qualitative findings regarding those aspects of RA that participants perceived as stressful. Using the RA Stresses Questionnaire, participants rated fatigue as the most stressful consequence of having RA (Table 6). Pain and mobility were the next two highest rated stresses. Hypothesis 1 is not supported as pain and immobility were not the most frequently rated consequences of RA.

**Table 5.** Items reported as stressful consequences of RA from the RA Stresses Questionnaire and during the semi-structured interview.

| Stresses questionnaire | | Semi-structured interview | |
|---|---|---|---|
| **Stresses** | **Mean (SD)** | **Stresses** | **Number of participants** |
| Fatigue | 3.78 (1.39) | Tiredness (fatigue) | 6 |
| Pain | 3.62 (1.28) | Pain | 1 |
| Mobility | 3.60 (1.23) | Mobility | 8 |
| Unpredictability | 3.36 (1.51) | Cannot plan | 2 |
| Feeling of loss | 3.22 (1.45) | | |
| Not feeling useful | 3.02 (1.32) | | |
| Fear of the future | 2.98 (1.62) | Worry about the future | 1 |
| Misunderstood by others | 2.98 (1.61) | Other people not understanding | 2 |
| Dependent | 2.88 (1.49) | Dependence on others | 1 |
| Low mood | 2.74 (1.23) | Effect on mood | 4 |
| Planning ahead | 2.72 (1.53) | Extra planning | 2 |
| Fear of children getting RA | 2.66 (1.6) | Worried pass RA on | 1 |
| Body image | 2.62 (1.61) | Body image | 6 |
| Effect on family/relationships | 2.56 (1.55) | Effect on family and relationships | 1 |
| Losing social contact | 2.34 (1.44) | Loss of social life | 3 |
| Side-effects of medication | 2.56 (1.55) | Side-effects of medication | 6 |
| Loss of dignity | 2.08 (1.31) | | |
| Hard to accept | 1.96 (1.31) | Wishing you didn't have it | 1 |
| Loss of earnings | 1.94 (1.45) | | |
| Taking medication | 1.72 (1.14) | Having to go for weekly blood tests | 1 |
| Sexual difficulties | 1.64 (1.08) | | |
| | | Frustration | 4 |
| | | Given up activities | 5 |
| | | Loss of job | 5 |
| | | Social embarrassment | 3 |

However, the most frequently cited item included in participants' 'top three' stresses was immobility and then fatigue (Table 6). Pain was rated only once. Hypothesis 1 is therefore partially supported, but only for immobility and not for pain.

**Table 6.** Percentage distribution of items included by participants in their 'top three' stressors

| Rank order | Stressor | % |
|---|---|---|
| 1 | Mobility | 43% |
| 2 | Pain | 41% |
| 3 | Fatigue<br>Fear of the future | 27% |
| 5 | Dependant<br>Effect on mood | 20% |
| 7 | Unpredictability<br>Not feeling useful | 18% |
| 9 | Fear of children getting RA | 14% |
| 10 | Loss of earnings | 12% |
| 11 | Body image | 10% |
| 12 | Loss of dignity<br>Having to plan ahead | 8% |
| 14 | Side-effects of medication<br>Effect on family/relationships | 6% |
| 16 | Sexual<br>Losing social contact<br>Hard to accept<br>Feeling of loss<br>Misunderstood by others | 4% |

Loss of mobility and tiredness were frequently cited in the semi-structured interview which supports the quantitative findings (Table 5), for example, 'not being able to physically do simple things ... everything is so much more effort and takes longer'. However, a number of differences exist between the two types of data.

First, pain was reported less frequently in the semi-structured interview. Second, a number of stresses were cited more frequently in the semi-structured interview, such as, the effects of taking medication. This was linked with not being able to drink alcohol and the subsequent decrease in social life. One participant even refused to go on a second-line medication as they felt their one night out a week with their friends kept them sane and they refused to give this up. The effect of RA body image was also frequently mentioned, for example, 'I never feel dressed up and can't wear nice shoes so I have to wear 'geriatric' shoes'. The frequent occurrence of loss of employment was regarded as stressful, not for financial reasons, but because of no longer feeling useful, 'I feel useless ... who would employ me with the unpredictability of flare-ups and number of hospital appointments I have?'

Third, additional stresses emerged in the semi-structured interview, in particular, the consequences of the physical effects of RA. These included feelings of frustration, for example, 'my body is letting my brain down ...mentally I want to do things, but physically I can't' and having to give up enjoyable activities such as martial arts, swimming, amateur dramatics, dancing and knitting. Participants felt these contributed to feeling depressed, irritable and lacking in motivation. 'Planning' was mentioned in two ways: not being able to plan future events, such as holidays, due to the unpredictability of RA; and the need for extra planning for everyday tasks, for example, 'everything is so much more effort'. 'Social embarrassment' was frequently cited, for example, 'people looking at your hands and watching you fumbling around with money', 'having to justify yourself and feeling like a fraud because you can't always see RA'.

## 3.5 Psychological Outcome

Scores from the HADS indicated higher levels of anxiety symptoms than depressive symptoms (Table 7). Eighteen per cent of participants' scores indicated borderline depressive symptoms (8 – 10) and 32 per cent borderline anxiety symptoms. A score of over 11 indicating more definite symptoms of depression was found for eight per cent of participants for depressive symptoms and 22 per cent for anxiety symptoms.

Depression scores from the present study are lower than those reported in a RA population by Murphy et al. (1999), where 17 per cent had a score greater than ten. However, results are consistent with Chanadarana et al.'s (1987) findings that anxiety symptoms were reported more than depressive symptoms.

Scores from the PANAS showed that participants reported higher positive affect than negative affect (Table 8). This supports other research findings from RA and non-RA adult populations (Smith & Christensen, 1996; Watson et al., 1988). Only slight differences in positive affect were found in the present study compared with a previous

RA study and adult population scores. Higher negative affect was found compared with previous RA and adult population.

**Table 7.** Means, standard deviations, median and range values for HADS scores in the present study and in previous research

| **Subscale** | **Possible range** | **Present study N = 50** | | |
|---|---|---|---|---|
| | | **Mean (SD)** | **Median** | **Range** |
| **Depression** | 0 - 21 | 5.22 (3.47) | 5 | 0 - 14 |
| **Anxiety** | 0 - 21 | 8.02 (4.3) | 8 | 1 - 19 |

**Table 8.** Descriptive statistics for the PANAS for the present study and previous research

| **Sub scale** | **Possible range** | **Present study n = 47** | | | **Smith & Christensen (1996) RA N=72** | | **Watson (1988) Adult population N = 1002** |
|---|---|---|---|---|---|---|---|
| | | **Mean (SD)** | **Median** | **Range** | **Mean (SD)** | **Range** | **Mean (SD)** |
| **PA** | 10 - 50 | 31.98 (7.81) | 31 | 14 - 45 | 29.6 (7.4) | 17 – 49 | 33. 3 (7.2) |
| **NA** | 10 - 50 | 19.26 (8.53) | 16 | 10 - 45 | 15.3 (5.8) | 9 – 34 | 17.4 (6.2) |

In the semi-structured interview eight participants described feelings associated with a general negative mood. Six participants described feelings associated with depressive symptoms, for example, feeling 'miserable', 'low', 'down' as well as a lack of motivation 'everything is forced… you have to force yourself to do everything'. One participant reported negative thoughts associated with low mood, 'when you're very low you think what on earth am I living for … I'm not contributing to life'. Six participants reported feelings of bad temper, for example, feeling 'frustrated', 'annoyed' and 'grumpy'. Compared with the quantitative data, feelings of depression were reported more than anxiety. At the time of the interview five participants described a positive mood, such as, 'I feel very bright rather than down in the dumps' and 'I feel better in myself, my mood has lifted'.

### 3.6 Self-Report and Clinical Measures of Physical Status

Descriptive statistics for the data on self-report measures of pain and disability and the medical status variable are displayed in Table 9. VAS scores indicated that participants ranged from feeling 'no pain' to experiencing 'pain being as bad as it could be'. The mean VAS score of 50.6 (29.32) represents a moderate level of pain. The HAQ scores also showed a range disability from no disability to severe functional limitations. The mean HAQ score was in the upper part of the 'some difficulty' category indicating a moderate level of disability. The VAS and HAQ scores reflect typical levels of pain disability in RA populations (Peck et al., 1989; Murphy et al, 1999).

A measure of clinical status (ESR) was collected from fewer participants than the self-reported measures. The mean ESR level obtained was 21.49mm/hr (16.84), with a range of four to 65.

**Table 9.** Descriptive statistics for VAS (pain), HAQ and ESR scores.

| Physical measures | N | Possible range | Mean (SD) | Median | Range |
|---|---|---|---|---|---|
| **VAS (pain)** | 49 | 0 - 100 | 50.6 (29.32) | 50 | 0 - 100 |
| **HAQ** | 50 | 0 – 3.0 | 1.68 (0.7) | 1.7 | 0 – 2.8 |
| **ESR** | 37 | 2 - 140 | 21.49 (16.84) | 17 | 4 - 65 |

When participants were asked about their current physical state in the semi-structured interview, they mentioned the same aspects as those covered by the quantitative measures. Participants talked about their level of pain and how this affected what they could do. Seven participants described difficulties or an inability to carry out activities relating to social life, work, domestic activities and self-care. They cited having a flare-up and consequently, high levels of pain, tiredness and stiff joints as reasons for these problems. Three participants described their current status as stable and did not describe any difficulty in carrying out activities, for example, 'not so bad ... I've had it so long, I'm used to the pain'. Four participants described an improvement in their physical state due to medical treatment and consequently less pain and an increased activity level: 'Gold made a big difference .. less pain ... everything has been easier'; ' ...since the injections in my ankle I can do a lot more .. I've found a big difference'.

### 3.7 Coping Strategies

The scores for each coping strategy from the Brief COPE range from two to eight. Table 10 shows that the most frequently used coping strategy reported by participants was acceptance. Four of the coping strategies added to the Brief COPE were the next most frequently used. These included knowing limitations, physical management strategies, adapting to activities, and energy conservation. Alcohol use (participants did not report using drugs other than prescribed medication), behavioural disengagement and denial were the least reported strategies.

Information from the semi-structured interview regarding coping was coded into 24 categories (Appendix 18). The number of participants using each strategy is shown in Table 10. In contrast to the Brief COPE scores, the most frequently reported coping strategies included self-distraction, planning and a positive attitude. Emotional support was also frequently cited. Information relating to additional coping strategies was generated by the semi-structured interview with a popular strategy being to keep up general interests and hobbies. As with the Brief COPE, participants frequently mentioned knowing limitations, physical management strategies and adapting to activities as helping them cope.

**Table 10.** Mean and standard deviations of coping strategies used from the Brief COPE scale and frequency of coping strategies reported by participants in the semi-structured interview.

| **Brief COPE N= 50** | | **Semi-structured interview N = 14** | |
|---|---|---|---|
| **Coping strategy** | **Mean (SD)** | **Coping strategy** | **Number of participants** |
| Acceptance | 7.42 (1.2) | Acceptance | 3 |
| Knowing limitations | 7.00 (1.34) | Knowing limitations | 6 |
| Physical management strategies | 6.84 (1.33) | Physical exercise (to cope with joint stiffness)<br>Wearing splints<br>Keeping warm/heat treatments<br>Increase medication<br>TENS machine | 6<br>3<br>4<br>2<br>2 |
| Adapting to activities | 6.76 (1.59) | Adapting activities | 6 |
| Energy conservation | 6.7 (1.43) | Pacing (balancing activity and rest)<br>Rest | 4<br>4 |
| Self-distraction | 5.94 (1.9) | Self-distraction (keeping busy, to take mind off stress) | 8 |
| Emotional support | 5.82 (2.04) | Emotional support | 6 |
| Active coping | 5.48 (2.03) | | |
| Use of humour | 5.04 (2.29) | Humour | 2 |
| Planning | 4.92 (2.03) | Planning ahead/breaking tasks down | 7 |
| Positive re-framing | 4.66 (2.00) | Thinking ‘someone always worse off than you’<br>Positive attitude | 5<br>7 |
| Religion | 4.24 (2.6) | Religion | 1 |
| Venting | 4.06 (2.13) | | |
| Alternative therapies | 2.98 (1.71) | Alternative | 3 |
| Denial | 2.7 (1.09) | Carrying on as normal | 3 |
| Alcohol/drug use | 2.5 (1.33) | Alcohol | 2 |
| Behavioural disengagement | 2.46 (0.84) | Give up ‘just want to vegetate’ | 1 |
| | | Keeping active (general interests) | 5 |
| | | Doing something to feel useful | 2 |
| | | Advice from other RA patients | 2 |

### 3.8 Control

Table 11 summarises how strongly participants believed in each dimension of control over their RA symptoms using the MHLC (Form C) (the higher the score the stronger the belief). Chance beliefs were rated higher than internal control beliefs. Participants also had higher beliefs in doctor control than other people control. Compared with Wallston et al.'s (1994) findings, participants in the present study showed higher beliefs in chance, doctor and other people control and lower beliefs in internal control.

**Table 11.** Descriptive statistics for MHLC (Form C) subscales for the present study and Wallston's et al (1994) study

| Subscale | Possible range | Present study n = 50 | | | Wallston et al (1994) study RA population n= 273 |
|---|---|---|---|---|---|
| | | Mean (SD) | Median | Range | Mean (SD) |
| **Internal** | 6- 36 | 16.92 (5.98) | 16 | 6 - 30 | 17.50 (5.89) |
| **Chance** | 6- 36 | 21.06 (6.26) | 22 | 8 - 31 | 16.60 (6.10) |
| **Doctor** | 3 - 18 | 15.20 (2.95) | 16.5 | 9 - 18 | 13.43 (3.28) |
| **Other people** | 3 - 18 | 10.34 (4.43) | 10 | 3 - 18 | 7.48 (3.27) |

In contrast to MHLC (Form C) scores, qualitative findings suggest high internal control (Table 12). Participants reported being able to take responsibility for the physical side of RA, such as: knowing their limitations ('facing what you can and cannot do and not exceeding those'); balancing rest and activity ('if you try and do too much, paying for it afterwards'); taking medications regularly; lifting things certain ways and keeping moving. Control over psychological aspects was also reported by having a positive attitude and thinking 'you can't give in to it'. Qualitative findings also show low beliefs in chance control, this was attributed to beliefs in high internal control, for example, 'no, it's not down to chance because I felt better on medication'.

As with the MHLC (Form C) scores, qualitative findings suggest strong beliefs in medical control, for example, 'I believe without their help I'd be in a wheelchair'. Participants reported the benefit of medication in suppressing and controlling physical symptoms, for example, 'medication helps because if I forget to take it then I soon know about it'. The information and emotional support provided by the medical profession also benefited participants, 'if I need to speak to a nurse or doctor they are always there....psychologically they are my walking stick'; 'doctors here are excellent, not just medication, but the support they provide as well, I feel this back-up is very important'. In addition, participants acknowledged the importance of joint collaboration between doctors and themselves. For example, 'they influence only to a certain extent because you have to take the medication...you have to work together and listen to them'; 'you need treatment, but you need to do exactly what you are told to do'.

As with the MHLC beliefs, beliefs in significant others influencing symptoms were lower than doctors' control, but still quite high. The negative emotional impact of a significant other was reported as making physical symptoms worse through stress, for example, 'my husband causes all the stress because he is so irritable... if all this was removed I wonder if my symptoms would be reduced'. Positive emotional support was also reported to improve physical symptoms, for example, 'my daughter seems to understand which helps me stop feeling so depressed and therefore so bad physically'. Practical support from significant others was reported as helping physical symptoms 'he has a lot of influence as he does all of the housework, it would be very difficult without him, I could do it, but it would be a lot harder and more painful'

**Table 12.** Number of participants agreeing or disagreeing with each aspect of control in the semi-structured interview

| **Subscale** | **Yes** | **No** | **Don't know** |
|---|---|---|---|
| **Internal** | 11 | 1 | 2 |
| **Chance** | 1 | 10 | 3 |
| **Doctor** | 13 | 0 | 1 |
| **Other people** | 9 | 5 | 0 |

### 3.9 Knowledge

Scores from the RA Patient Knowledge Questionnaire show the level of knowledge in the present study to be similar to findings from Hill et al. (1991) (Table 13).

**Table 13.** Means, standard deviations, medians and range values for RA Patient Knowledge Questionnaire scores for the present study and Hill et al.'s (1991) study

| Sample | Possible range | Mean (SD) N = 47 | Median | Range |
|---|---|---|---|---|
| **Present study** | **0 - 30** | 15.98 (4.56) | 16 | 6 - 25 |
| **Hill et al (1991)** | **0 – 30** | 16.00 (5.3) | 16 | 3 - 28 |

In the semi-structured interview, participants showed limited knowledge regarding the causes of their symptoms and four participants stated that they did not know anything at all. Although nine participants correctly mentioned the involvement of joints, only three reported the involvement of the fluid between joints. Others provided wrong explanations, such as 'infected joints' or 'uric acid in the blood'. The involvement of the immune system was appropriately mentioned by only five participants but in no detail, for example, 'disease of the immune system'. A number of participants reported that this information had been explained by a doctor but that they could not remember. Participants were more knowledgeable regarding their medication. Thirteen knew the name(s) of medication and nine knew what their medications were for. Ten participants correctly named the side effects for the medications they took.

All the strategies suggested to help cope with a flare-up were appropriate except for one participant's recommendation of alcohol (Appendix 19). Ten participants suggested rest; five mentioned using heat from various sources; four emphasised the importance of keeping going physically (to prevent stiffness) and three said to do things slowly. Few participants sought information regarding RA (Appendix 19). Five participants said that they no longer sought information and four gained information from the hospital (specialist nurses, doctor and leaflets given by the hospital).

## 3.10 Relationships between Variables

The strength and direction of linear relationships between variables were investigated by computing Pearson's product-moment correlations (r), two-tailed test (Appendix 20 - 24). Results were taken to be significant at a level of $p < 0.05$ and highly significant at a level of $p < 0.01$.

Five variables were found to be still out of range in terms of skewness and kurtosis after the data had been transformed (denial, alcohol/drug use, behavioural disengagement, acceptance and alternative therapies) (Appendix 17). These variables were put through both a Pearson correlation and a non-parametric test, Spearman's rank correlation (Appendix 25 - 29). The same pattern of significant associations was produced by each test and therefore they are reported as parametric correlations .

### *3.10.1 Relationships between physical and psychological outcome*

Hypothesis 2 predicted that negative affect would be associated with increased depression and anxiety and lower positive affect, and that positive affect would be associated with decreased depression, anxiety and lower negative affect

Table 14 summarises associations between physical and psychological outcome variables. Hypothesis 2 is supported as highly significant relationships were found between the four psychological variables. Depression was positively correlated with anxiety and negative affect (NA) ($n=50$, $r=0.63$, $p<0.01$; $n=47$, $r=0.56$, $p<0.01$); anxiety and NA are also positively correlated ($n=47$, $r=0.74$, $p<0.01$). Positive affect (PA) was negatively correlated with depression ($n=47$, $r=-0.59$, $p<0.01$); anxiety ($n=47$, $r=-0.40$, $p<0.01$) and NA ($n=47$, $r=-0.50$, $p<0.01$).

As expected, no significant associations were found between subjective physical functioning measures (pain and disability) and objective physical measure of disease activity (ESR) (Table 14).

Hypothesis 3 predicted that negative physical outcome would be associated with negative psychological outcome and positive physical outcome would be associated with positive psychological outcome. Hypothesis 3 was not supported by quantitative data as no significant relationships were demonstrated between negative physical outcome and negative psychological outcome or positive physical outcome and positive psychological outcome (Table 14).

Qualitative findings support Hypothesis 3 as participants linked psychological and physical outcomes together. All participants reporting poor physical functioning also reported low mood, for example, 'it's very depressing when you can't do the jobs in the house that you want to because of the pain'. Participants found that high levels of pain directly affected their mood, for example, 'you're just aching all over, it's like toothache and you can't get rid of it... you can't sleep and you feel depressed, grumpy and snappy'. Participants reporting an improvement in physical functioning also reported a positive mood. 'I feel so much better in myself because I'm able to do more and less pain is involved'.

**Table 14.** A matrix of correlations between physical and psychological outcome

| Subscale | Depr | Anx | PA | NA | HAQ | VAS | ESR |
|---|---|---|---|---|---|---|---|
| Depression | - | | | | | | |
| Anxiety | .633** | - | | | | | |
| PA | -.596** | -.401** | - | | | | |
| NA | .561** | .744** | -.500* | - | | | |
| HAQ | .163 | .104 | .025 | .065 | - | | |
| VAS | .045 | .140 | -.053 | .096 | .320* | - | |
| ESR | -.231 | -.159 | -.053 | .023 | .257 | .027 | - |

*p<.005; **p<0.01

*Note:* Depr = depression; Anx = anxiety PA = positive affect; NA = negative affect; HAQ = health assessment questionnaire; VAS = pain visual analogue scale; ESR = erythrocyte sedimentation rate

### *3.10.2 Relationships between negative outcome and control, knowledge and coping*

Hypothesis 4 predicted that negative psychological outcome and negative physical outcome would be associated with increased beliefs in 'chance' and 'other people' locus of control; less knowledge; increased maladaptive coping and decreased adaptive coping

No significant relationships were found between negative outcomes and beliefs in chance, other people control or lower knowledge (see Appendix 23). Therefore these aspects of hypothesis 4 were not supported. However a significant association found between lower anxiety and increased internal control (n=50; r= -0.30; p<0.05) partially supports hypothesis 4.

The predicted relationships between negative psychological outcome and coping stated in hypothesis 4 were partially supported. Highly significant associations were found between increased anxiety symptoms and increased alcohol and drug use (n=50;

r= 0.41; p<0.01). Increased depressive symptoms and higher NA were also significantly associated with increased alcohol and drug use (n=50; r= 0.31; p<0.05), (n=50; r= 0.37; p<0.05). A highly significant correlation was also found between increased use of humour and less depressive symptoms (n=50; -0.39; p<0.01).

However, the relationships found between negative physical outcome and coping were opposite to those predicted by hypothesis 4. Increased pain was significantly associated with more energy conservation (n=49; r=0.36; p<0.05) and less disability was significantly correlated with increased alcohol and drug use (n=50; r=-0.29; p<0.05).

### *3.10.3 Relationships between positive affect and control, knowledge and coping*

Hypothesis 5 predicted that positive affect would be associated with increased beliefs in 'internal' and 'doctor' locus of control; increased knowledge; increased adaptive and decreased maladaptive coping strategies.

No associations were found between positive affect and either internal or doctor control. The positive correlation found between positive affect and knowledge (n=46; r= 0.32; p<0.05) partially supports hypothesis 5. Also in support of hypothesis 5, significant relationships were found between increased positive affect and increased use of positive reframing (n=47; r= 0.41; p<0.01), energy conservation (n=47; r= -0.41; p<0.01); less alcohol use (n=50; r= -0.38; p<0.01) and less behavioural disengagement (n=50; r= -0.35; p<0.05).

### *3.10.4 Relationships between control, knowledge and coping strategies*

Hypothesis 6 predicted that increased beliefs in 'internal' and 'doctor' locus of control would be associated with increased knowledge; increased adaptive coping and decreased maladaptive coping.

Neither increased internal or doctor control were found to be associated with increased knowledge. This does not support hypothesis 6. However, greater internal control was associated with increased use of positive reframing (n=50; r= 0.41; p<0.01) and less alcohol and drug use (n=50; r= -0.37; p<0.01). Greater doctor control was significantly associated with more energy conservation (n=50; r=0.33; p<0.05) and less denial (n=50; r= -0.33; p<0.05). These associations partially support hypothesis 6.

Hypothesis 7 predicted that increased knowledge will be associated with increased adaptive coping and decreased maladaptive coping. A number of relationships support this hypothesis. Highly significant relationships were found between greater knowledge and more active coping (n=47; r=0.374; p<0.01) and less behavioural disengagement (n=47; r= -0.399; p<0.01). Greater knowledge was also significantly associated with more adaptation to activities (n=47; r= 0.294; p<0.05) and less denial (n=47; r= -0.310; p<0.05).

### *3.10.5 Relationships of coping strategies with no predicted hypothesis (emotional support, self-distraction and religion) to outcome, control and knowledge*

With regard to coping and outcome, greater emotional support was significantly correlated with less depressive symptoms (n=50; -0.31; p<0.05) but also highly correlated with increased pain (n=49; r= 0.42; p<0.01). Greater use of self distraction was highly correlated with fewer depressive symptoms (n=50; r= -0.49; p<0.01) and also correlated with more knowledge (n=47; r= 0.32; p<0.05).

## 3.11 Regression Analyses

Regression analyses were performed to analyse the relative contributions of independent variables to the physical and psychological outcome variables in the study. A series of multiple regression analyses was performed with the dependent variables of anxiety, depression, PA, NA, disability and pain. Criteria for entry included a significant correlation of an independent variable with an outcome variable using Pearson's product-moment correlation. For all analyses, variables were entered stepwise after participant's length of disease (years RA) had been controlled for (p (entry) <0.05 and p (exit) >0.1). Scatterplots for each regression equation were produced (Appendix 30 - 32).

### *3.11.1 Factors associated with psychological outcome*

Greater anxiety was associated with increased alcohol and drug use. Alcohol and drug use accounted for 14 per cent of the variance in anxiety controlling for years RA (Table 15). Variables associated with increased depression were less self-distraction and greater alcohol and drug use (Table 16). Self-distraction and alcohol and drug use accounted for 28.5 per cent of the variance in depression. Years of RA did not have any association with depression.

**Table 15.** Dependent variable: Anxiety

| Independent variable | adjusted R squared | Beta | T | Sig T |
|---|---|---|---|---|
| Years RA | -0.013 | 0.073 | 0.513 | 0.610 |
| Alcohol and drug use | 0.14 | 0.439 | -3.097 | 0.003 |

NB: variable not in final equation: internal LOC

**Table 16.** Dependent variable: Depression

| Independent variable | adjusted R squared | Beta | T | Sig T |
|---|---|---|---|---|
| Years RA | 0.043 | 0.103 | 0.735 | 0.466 |
| Self distraction | 0.202 | -0.510 | -3.891 | 0.000 |
| Alcohol and drug use | 0.285 | 0.331 | -2.536 | 0.015 |

NB: variables not in final equation: emotional support and humour

Greater negative affect was associated with increased alcohol and drug use. Alcohol and drug use accounted for 11.4 per cent of the variance in negative affect, controlling for years RA (Table 17).

**Table 17.** Dependent variable: Negative affect

| Independent variable | adjusted R squared | Beta | T | Sig T |
|---|---|---|---|---|
| Years RA | -0.022 | 0.156 | 1.046 | 0.301 |
| Alcohol and drug use | 0.114 | 0.420 | -2.810 | 0.070 |

**Table 18.** Dependent variable: Positive affect

| Variable | adjusted R squared | Beta | T | Sig T |
|---|---|---|---|---|
| Years RA | 0.060 | 0.349 | 3.101 | 0.003 |
| Positive reframing | 0.283 | 0.334 | 2.874 | 0.006 |
| Energy conservation | 0.413 | 0.421 | -3.674 | 0.001 |
| Behavioural disengagement | 0.512 | -0.323 | 2.874 | 0.006 |

NB: variables not in final equation: alcohol and drug use, knowledge

Years of RA were found to have a significant association with positive affect (Table 18), accounting for six per cent of the variance in positive affect scores. Other variables associated with increased PA were greater positive reframing and energy conservation and less behavioural disengagement. Years of RA, positive reframing, energy conservation and behavioural disengagement accounted for 51.2 per cent of the variance in positive affect.

### *3.11.2 Factors associated with physical outcome*

Years of RA did not have any association with pain (Table 19). Independent variables associated with increased pain were greater emotional support and greater energy conservation. They accounted for 22.5 per cent of the variance in pain scores.

**Table 19.** Dependent variable: Pain

| Variable | (adjusted R square) | Beta | T | Sig T |
|---|---|---|---|---|
| Years RA | 0.009 | 0.115 | 0.915 | 0.365 |
| Emotional support | 0.165 | 0.401 | 3.212 | 0.002 |
| Energy conservation | 0.225 | 0.323 | 2.568 | 0.014 |

# 4.0 Discussion

A summary of the quantitative and qualitative findings of the present study will be given and the interpretation of these results will be discussed with reference to the main aims and hypotheses. The clinical implications of the study will be considered and methodological limitations of the present study and implications for future research will be discussed.

## 4.1 Summary of Aims

Using quantitative and qualitative methodology, the study investigated the physical and psychosocial consequences of RA that patients perceived as stressful. The study examined perceptions of control over daily symptoms, level of RA knowledge and coping strategies employed, as well as psychological and physical outcome in a RA population. Quantitative findings were compared with previous research and the qualitative data.

The associations of control, coping and knowledge to psychological and physical outcome were analysed and regression analyses were employed to determine whether any aspects of control, coping and knowledge predicted outcome. Other associations investigated in the study were those between physical functioning and psychological outcome and those between control, knowledge and coping strategies.

## 4.2 Stress

Aim one of the present study was to determine the most stressful aspects of RA as perceived by patients. Quantitative and qualitative results from the present study indicate that disability and fatigue were consistently rated by participants as the most stressful consequences of RA. However, although pain was rated highly by the RA Stresses Questionnaire, it was not reported as a stressful consequence of RA in the semi-structured interviews. Hypothesis one, which predicted that pain and loss of physical mobility would be perceived as the most stressful consequence of RA was therefore supported for disability but not for pain. The inconsistent findings regarding pain support the suggestion that responses vary with phrasing of questions (Taal et al., 1993). When patients are asked explicitly whether pain is a problem, the majority state that it is. However, for many patients the pain itself is not their main concern, but the restrictions in daily functioning and fatigue, possibly due to the pain.

In contrast to previous findings, fatigue was found to be a major stress of RA. Fatigue is a secondary symptom of RA, and has been found to have strong associations with pain, disability and depression (Belza, 1995; Wolfe et al., 1996). Unlike pain and disability, fatigue is not commonly associated with RA in the public eye and patients may perceive it as stressful because it is an unexpected symptom. Patients may not relate it to part of the rheumatic disease and therefore worry that something else is wrong with them.

However, findings showed RA patients have to cope with a wide variety of disease-related stressors, not just pain, disability and fatigue. Thus, problems arise in other areas of RA patients' lives such as family and marital functioning, social, financial and emotional, as a result of the biological effects of the disease. In some phases of the disease, one or other of these other problems may become temporarily more important than the three main stresses.

A marked similarity existed between the items included in the RA Stresses Questionnaire and the stressors mentioned by participants in the semi-structured interview. This supports the relevance of the items included in the questionnaire to a RA population. However, it is clear from the qualitative information that the number of times a stressor is cited should not determine its 'importance' alone. For example, only one participant in the semi-structured interview cited the effect of RA on family and relationships as a stressor. However, further discussion revealed that this participant's husband had left her, claiming that he could not cope with the possibility that she might be disabled in years to come and telling her 'you might as well shoot yourself'. Thus the impact of a stressor on the individual needs to be considered.

The semi-structured interview highlighted the association that exists between physical and psychological stressors. Participants described these stressors as a series of vicious cycles that are difficult to separate. For example, during a flare-up, the inability to carry out an activity because of a high level of pain or stiffness would lead to feelings of frustration. This frustration would then lead to worrying about household chores not getting done, and these would generalise to feelings of loss and worthlessness, which would then worsen feelings of pain and frustration, and so on. Thus, it may not always be possible to separate out the different stressor elements.

### 4.3 Outcome

#### 4.3.1 *Psychological Outcome*

In the present study, the HADS scores indicated a higher presence of anxiety symptoms compared with depressive symptoms. A lower level of depression was found compared with a study of RA patients by Murphy et al. (1999) and symptoms of anxiety were higher than those reported by Chandarana (1987). This refutes the assumption that depression is the most common psychological disturbance associated with RA and supports findings that anxiety plays a crucial role in RA (Hawley & Wolfe, 1988). Because the HADS was developed for use with patients with physical disorders and excludes somatically-related items (Pincus et al., 1986), these findings support the possibility that levels of depression have been overestimated in previous studies through 'criterion contamination' of measures (somatic symptoms interpreted as depressive symptoms).

From the range of RA stressors reported by participants, the presence of both anxiety and depressive symptoms in a RA population is not difficult to explain. For example, demographic factors, disability, social isolation and economic deprivation were all found to make significant contributions to the explanation of depressed mood (Newman et al., 1989).

The present findings also show that the majority of people with RA do adjust satisfactorily to the disease and its consequences and do not experience symptoms of anxiety or depression. Consistent with previous findings, higher levels of positive affect were found compared with negative affect (Smith & Christensen, 1996; Watson et al., 1988). This supports an expanded concept of emotional adjustment to include positive affective states.

Anxiety, depression and negative affect were found to be positively correlated with each other and negatively correlated with positive affect. This supports hypothesis two, which predicted that negative affect would be associated with increased depression, anxiety and lower positive affect; and that positive affect would be associated with decreased depression, anxiety and negative affect. The finding that positive and negative affect form separate aspects of emotional quality of life supports a two dimensional model of mood in this population (Smith & Christensen, 1996).

### 4.3.2 *Psychological and Physical Outcome*

The present study failed to find any association between physical outcome (pain and disability) and psychological outcome. Hypothesis three, which predicted that negative physical outcome would be associated with negative psychological outcome, and that positive physical outcome would be associated with positive psychological outcome was therefore not supported. This indicates that most RA patients who were emotionally distressed were not necessarily disabled or experiencing high levels of pain. However, all participants linked their mood and physical state in the semi-structured interviews. Factors other than disability and pain that contribute to depressed mood may explain the differences in qualitative and quantitative findings. For example, Katz & Yelin (1995) found it was the loss of ability to perform valued activities, rather than the functional impairment, which led to the development of depressive symptoms in RA patients. Previous studies may also have exaggerated the depression-disability linkage by using depression instruments with somatic content and self-report measures of functional status which were emotionally coloured. The present study used instruments with a known sensitivity to the somatic aspects of RA (the HADS) and assessed aspects of disability least likely to be influenced by psychological factors (Peck et al., 1989).

The importance of psychosocial factors in determining adjustment to RA was confirmed by the lack of association between objective disease activity (ESR) and subjective physical outcome (pain or disability).

### 4.4 Coping

It is clear from the quantitative and qualitative data generated by the present study that participants used a wide range of coping mechanisms in response to their RA. This supports the finding that a high proportion of individuals with RA tend to use a large range of coping strategies to a moderate extent (Newman et al., 1990).

The pattern of use of the various coping strategies from the Brief COPE and semi-structured interviews in the present study is very similar to previous findings in which participants reported greater use of adaptive that maladaptive strategies (Carver et al., 1989; Kennedy et al., 1995). Scores from the Brief COPE indicated that acceptance was the most frequently used coping strategy. This implies that the majority of participants accepted the reality of the consequences of RA. This findings fits with Carver et al.'s (1989) prediction that acceptance might be expected to be important in circumstances in which the stressor is something that must be accommodated to, as opposed to circumstances that can be easily changed. The high scores obtained for the self-management strategies suggests that participants frequently used a range of RA-specific coping strategies. This highlights the importance of including these illness-specific strategies within a generic questionnaire. The low use of maladaptive coping strategies suggests that either these RA patients were coping extremely well or that they did not want to admit using these strategies, particularly alcohol and drugs.

The fact that many of the coping strategies cited in the semi-structured interview were included in the Brief COPE implied that the use of this measure together with supplementary self-management strategies was appropriate. However, on closer inspection, a number of differences between these two sets of data emerge. For example, scores from the Brief COPE imply a low level of 'active coping', yet it is clear that many participants frequently engaged in a range of active self-management strategies. The Brief COPE also implies a low level of self-distraction, yet the qualitative findings suggest that this is a frequently used way of coping. This suggests that these items were misinterpreted by participants as they were not specific enough to RA.

### *4.4.1 Coping and Outcome*

Using the quantitative findings, it is not possible to infer coping function from coping style. However, the qualitative data provide information as to why a particular strategy was employed by an individual.

In support of hypothesis five, which predicted that adaptive coping strategies would be related to positive affect; positive reframing, humour, energy conservation and less behavioural disengagement were found to be associated with positive affect. As with previous research cognitive restructuring strategies were associated with positive psychological outcome (Carver et al., 1989; Felton & Revenson, 1989). Positive reframing was associated with increased positive affect and humour with decreased depression.

From the qualitative findings it appears that positive reframing was aimed at managing psychological well-being in a number of ways. Participants described reviewing the situation with the intention of coming to terms with the worst and 'thinking positively' or an optimistic attitude, for example 'I give myself positive thoughts each night to wake up to the day after'. Second, they described a 'fighting spirit', for example 'I don't feel that I'm ready to let it win, so I fight it ... you need determination'. This supports findings that fighting spirit was associated with better psychological adjustment in women with breast cancer (Filipp, 1990). The importance of a sense of determination or fighting spirit is supported by the finding that less behavioural disengagement was associated with positive psychological outcome. This implies that not reducing one's efforts to deal with the stressor or not giving up the attempt to attain goals with which the stressor is interfering is adaptive. Participants derived comfort in thoughts such as 'other people are worse off than me' and recognising that the problems they were experiencing were less serious that those experienced by other people. Using information about other people to assess one's own health status has been termed by the literature as the 'social comparison process' (Festinger, 1954). Research suggests that individuals with RA do predominantly tend to make comparisons to those in a worse state (downward comparisons) and that downward comparisons were associated with better psychological well-being (Blalock et al., 1993).

The present study has found that some coping efforts have little association with reduced negative states and instead are associated with increased positive affect. This has important implications for coping theory as coping strategies are employed, by definition, to reduce vulnerability to negative feeling states. Zautra et al. (1995) questioned whether coping strategies can be called effective coping strategies if they do not serve to reduce negative states, but instead, help the person retain a more positive outlook by enhancing his or her positive emotions. The association between coping strategies and increased positive affect is one of the most pertinent findings in the present study. Effective functioning is not only a question of stress reduction but it might be vital for people to maintain the positive aspects of their life. Many of the coping strategies reported in the semi-structured interview support this assertion, for example, not giving up previously enjoyed activities or finding alternative hobbies to replace those that can no longer be physically carried out.

In partial support of hypothesis four, which predicted that maladaptive coping strategies would be associated with negative psychological outcome, alcohol use was found to be correlated with increased anxiety, depression and negative affect. Qualitative findings suggested that alcohol was used as a short-term strategy to reduce the pain, however, it was also aimed at ameliorating the emotional impact of aversive events, for example, 'helping me think about having the illness less'. This supports previous findings that strategies of diverting attention from the realities of the problem are linked with poor psychological adjustment (Felton & Revenson, 1984).

In contrast to coping and psychological outcome, the relationships between coping and physical outcome were opposite to those predicted in hypothesis four. For example, energy conservation was associated with more pain and disability. Rather than interpreting energy conservation as a maladaptive strategy however, it could be that it is an adaptive strategy when the physical consequences of RA are at their worst. Alcohol use was found to be associated with less disability. Alcohol use may be utilised by individuals at the earlier stage of the disease who were having difficulty coming to terms with the illness. These individuals would be less disabled as their RA had not progressed enough to affect their mobility. This association supports longer-term findings that not focusing on a problem may allow it to become more serious, thereby making more difficult the coping that eventually must occur (Carver, et al., 1989).

A number of coping strategies were examined which had no predicted outcome, since previous findings had associated them with both positive and negative adjustment (Carver et al., 1992). Emotional support was associated with both decreased depression and increased pain and thus maintaining its reputation as a 'double edged sword'. These findings suggest that getting moral support, sympathy or understanding regulates emotional responses. However, they also suggest that focusing on distress may distract people from adaptive coping efforts and movement beyond that distress (Carver, et al., 1989). Alternatively, however, people may be seeking emotional support in response to a flare-up or more emotional support might be provided if a person is in obvious pain.

Rather than exerting a negative influence on levels of pain, emotional support may therefore be utilised in response to pain.

Self-distraction was associated with less depression. Qualitative information indicated that self-distraction was used to distract participants from their worries and concerns rather than from their pain. This supports Brown et al.'s (1989) finding that active coping strategies (e.g. staying busy or active) are associated with less depression than patients who use passive strategies (e.g. dependence on others).

Many of the predicted associations between coping strategies and outcome were not found. This may be because they did not exist or alternatively may be due to the misinterpretation of some of the Brief COPE items. That is, participants may not have rated using some coping strategies as they did not perceive them as applicable to their ways of coping. For example, as previously discussed, participants might not have rated 'active coping', despite using a wide range of self-management strategies. Nevertheless, the overall patterns of findings found between coping strategies and outcome support previous studies. Cognitive strategies, such as, positive reframing, were consistently associated with positive psychological adjustment but not associated with positive physical adjustment. Inconsistent findings were also found in relation to behavioural coping strategies, such as alcohol use and energy conservation, as they were associated with different psychological and physical outcomes. These findings indicate that behavioural coping strategies may operate in different ways in their relation to psychological and physical adjustment, and it is therefore unproductive to subsume them into the same adaptive and maladaptive categories for both psychological and physical adjustment.

### 4.5 Control

The stronger beliefs in chance than internal control found by the MHLC scale supports previous findings that RA patients believe they have little control over their illness (Felton & Revenson, 1984; Wallston et al., 1994). However, the large discrepancy found between these findings and the high internal and low chance beliefs from the qualitative information questions the accuracy of this result. Despite participants being asked about their beliefs regarding control over their 'daily symptoms' of RA, it seems that that they misinterpreted the chance items on the MHLC as asking for their beliefs over the controllability over the ‘course’ of their illness. Thus, results indicate that participants perceive no control over the course of the illness, that is, they cannot control whether they are going to have a flare-up. However, they do perceive control over the severity of these symptoms once they are present.

This distinction between control over RA course and daily symptoms was apparent in the qualitative findings. For example, a participant believed that chance controlled the course of their illness, ‘no, no matter what you do, you have no influence over your symptoms’ as well as believing that they could exert control over their symptoms ‘if I’d been stupid enough to do things yesterday when I was bad, then I wouldn’t have been here today’. The conflicting findings support the importance of distinguishing between beliefs about disease course control and beliefs about personal control over daily symptoms when investigating perceptions of control over RA.

In support of previous findings, the present study showed that participants believed in more than one health locus of control (Wallston, 1992). Qualitative information provided an insight regarding how these aspects of control influenced symptoms of RA. As predicted, ‘internal’ and ‘doctor’ implies a sense of control over symptoms. Participants described personal control over physical symptoms, such as balancing rest and activity, as well as adopting a positive attitude to gain control over the psychological consequences of RA.

The differences found between beliefs in chance, other people and doctor control support a multi-dimensional concept of external health locus of control. Findings support Wallston et al.’s (1994) contention that when considering their health-related conditions, individuals differentiate between the potential influences of medically trained personnel, such as doctors, and of other people. As predicted, the findings suggest that participants believe health professionals to have control over their symptoms. Moreover, they perceive that health professionals to influence their symptoms not only through the provision of medical ‘treatment’ but also through the emotional support and information that they offer. It is important, however, not to generalise these findings to all RA patients. These findings are based on a population that has access to a rheumatology service that offers good psychological support including specialist nurses. Perceptions could therefore differ depending on the service that is offered to patients.

The prediction that a strong belief in control by chance is fairly indicative of perceived non-control or lack of control (Wallston, 1992) was supported. However, contrary to expectation, 'other people' were perceived by participants to influence the symptoms of RA patients in both a positive and negative way. Overall, these findings suggest that it is not the locus of control per se which is important, but the perceptions that health status can be controlled, regardless of the locus.

### *4.5.1 Control and Coping*

Associations between control and coping were examined to test hypothesis six which predicted that increased beliefs in internal and doctor control would be associated with adaptive coping strategies. Hypothesis six was partially supported as increased adaptive strategies and decreased maladaptive strategies were associated with internal control (increased positive reframing and less alcohol and drug use) and doctor control (increased energy conservation and less denial). This supports Carver et al.'s (1989) findings that if individuals see the situation as amenable to change, they engage in more positive reinterpretation and active coping, and less denial.

The association between internal control and positive reframing supports Rothbaum et al.'s (1982) suggestion that control can be associated with cognitive factors, for example, accepting the situation by ascribing it to a meaning or purpose ('interpretative control') and thinking about the situation differently, as in construing benefits or gains ('cognitive control'). The coping strategies associated with beliefs in doctor control support the influence that health professionals exert. One of the consultants in the rheumatology service strongly encourages patients to conserve energy and rest when it is necessary. This could explain the association with energy conservation. Less denial also suggests that patients have a more realistic approach to RA, perhaps gained from information provided by health professionals.

The results do not confirm earlier findings which suggest that people with stronger beliefs in personal control adhere to medical advice and carry out self-care behaviours more regularly than those do with weaker beliefs in personal control. However, findings do suggest that control gained from health professionals encourage the adoption of self-management skills (for example, energy conservation).

### *4.5.2 Control and outcome*

To determine whether negative outcome was associated with increased chance and other people locus of control beliefs (hypothesis four), and whether positive affect was associated with internal and doctor locus of control beliefs (hypothesis five), associations between control and outcome were investigated. No associations were found to exist between negative outcome and beliefs in chance or other people locus of control, therefore previous findings that chance and other people control are associated with poorer adjustment were not supported (Wallston et al., 1994).

However, hypothesis four was partially supported as an association was found between internal control and decreased anxiety. This partially supports the commonly held view that perceptions of control over illness are likely to have the greatest significance for psychological adaptation (Anderson et al., 1985). Findings do not, however, support the alternative view that surrendering control to powerful others is adaptive in situations where few opportunities for personal control are available and that maintaining a belief in personal control would lead to coping difficulties (Burish et al., 1984). Thus the issue of control and outcome remains unclear.

The lack of predicted and converse associations between control and either outcome or coping strategies suggests that either the test scales are not sensitive, there is no relationship, or there is a more complex relationship. Problems with participants misinterpreting items on the MHLC have previously been suggested and might well have influenced the lack of associations found. However, it is probable that the locus of control concept is only one of a number of complex factors that converge to form 'perceived control'. In particular, it has been suggested that locus of control and self-efficacy work together to determine health consequences. 'Self-efficacy' refers to a person's belief that he or she can engage in a specific behaviour (Bandura, 1977). Thus, self-efficacy is concerned with control over behaviour and locus of control is in reference to outcome. People may hold different beliefs with regard to these two concepts and this may account for the lack of associations found using the locus of control concept. For example, people may have an internal locus of control; however, if they have low self-efficacy, then they do not necessarily believe that they can perform the behaviours necessary to achieve valued reinforcements.

## 4.6 Knowledge

Scores from the PKQ indicated that participants had average levels of knowledge regarding the aetiology, medication and management of RA. However, when these areas were examined individually in the semi-structured interview, participants displayed low levels of knowledge regarding aetiology and did not tend to seek RA-related information. It appears that the participants were most knowledgeable about issues relevant to them, that is, medication and use of self-management strategies.

### *4.6.1 Knowledge and Outcome*

The only relationship found between increased knowledge and outcome was that with greater positive affect. This finding supports hypothesis five, which stated that positive affect would be associated with increased knowledge. This finding is congruent with more experimental research in which preparatory information is associated with increased psychological adjustment to medical procedures (for example, Kendall et al., 1979). The finding supports the suggestion that knowledge about disease, symptoms, prognosis and treatment exerts a positive influence, perhaps by enhancing predictability and a sense of cognitive control. Alternatively, however, this finding could be attributed to a third variable, as the regression analysis revealed that increased positive affect was associated with increasing number of years that participants had RA.

### *4.6.2 Knowledge and Control*

No associations were found between knowledge and beliefs in control. Hypothesis six, which stated that increased beliefs in internal and doctor locus of control would be associated with increased knowledge was therefore not supported. This supports studies which found providing information alone does not increase perceived control (Lorig et al., 1987). The lack of association may be because the relationship does not exist or again due to the problems discussed above relating to use of locus of control alone and the validity of the MHLC questionnaire.

### *4.6.3 Knowledge and Coping*

Associations were found between increased knowledge and more adaptation to activities and active coping and less behavioural disengagement and denial. These findings support hypothesis seven, which stated that increased knowledge would be associated with, increased adaptive coping and decreased maladaptive coping. This suggests that people with more accurate and extensive knowledge may engage in more appropriate coping strategies (Felton & Revenson, 1984). However, a lack of association with other coping strategies, particularly those associated with health practices, implies that knowledge alone is not sufficient to predict health behaviours. This supports the lack of correlations reported between changes in health knowledge and health behaviour (Lorig et al., 1987).

As with the locus of control construct, the lack of associations found in relation to knowledge may be due to the confounding effects of self-efficacy. Research has shown that the positive effects of educational programmes (use of health behaviours and positive outcomes) may be gained not so much through knowledge alone, but through the enhancement of self-efficacy in the skills used to cope with the variability of RA (Lorig et al., 1987).

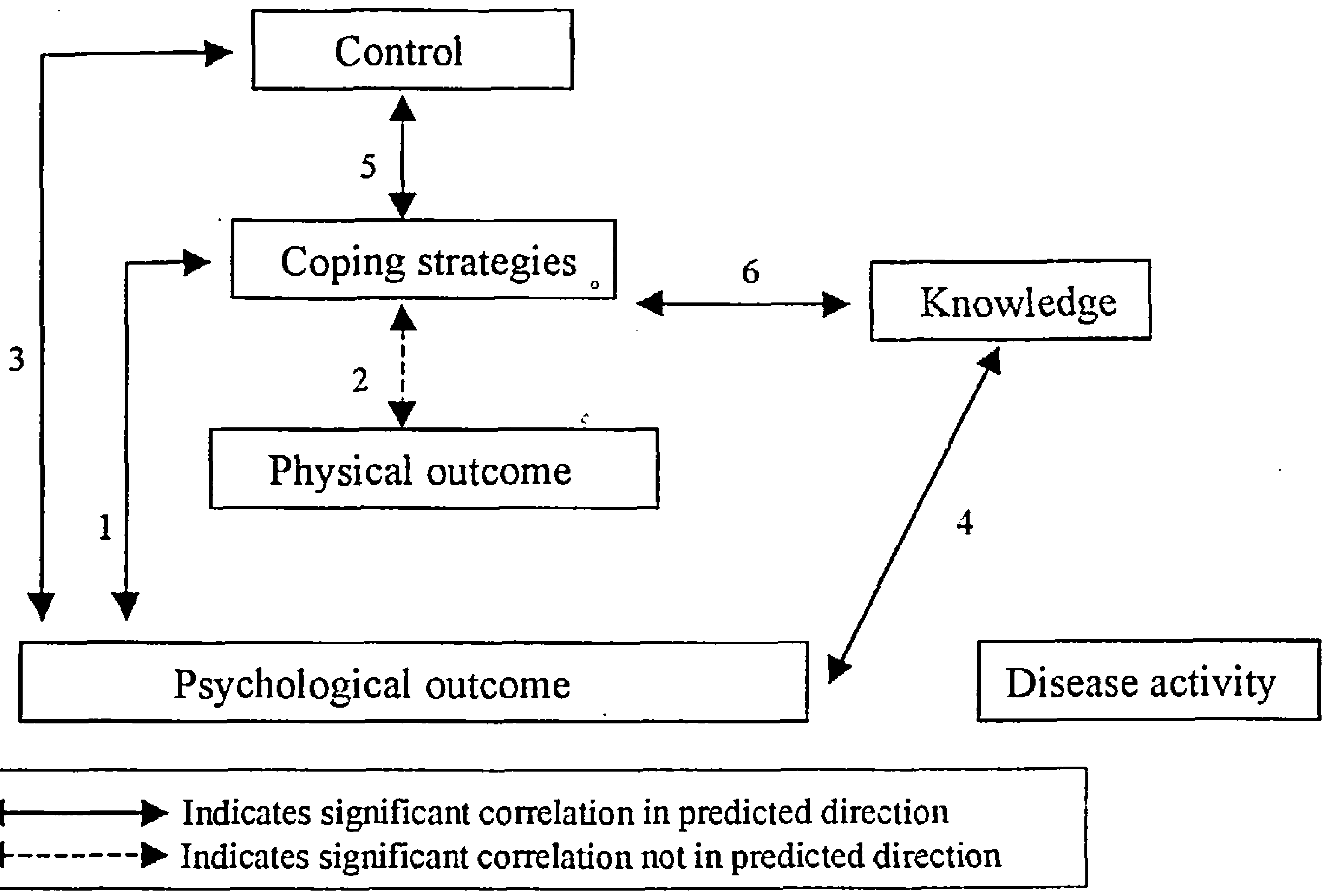
### 4.7 Regression Analysis

Multiple regression analyses confirmed that the concept of coping was important to current models of stress and coping in RA patients. Specifically, a number of coping strategies emerged as significant predictors of negative psychological outcome (alcohol use and self-distraction) and pain (increased emotional support and energy conservation), despite controlling for years RA which was likely to affect outcome. Perceptions of control and knowledge did not emerge as significant predictors of any outcome measure. This implies that cognitive and behavioural coping styles are important when considering the role of negative psychological factors and pain in the adjustment process. However, the relatively small amount of the variance coping strategies accounted for suggests that other factors are involved in adjusting to RA.

Increased use of positive reframing and energy conservation; decreased use of behavioural disengagement and the number of years that participants had suffered from RA accounted for over 50 per cent of the variance in positive affect. This supports the contention that time may lead to a higher level of psychological adaptation, as individuals learn to adjust to the disease (Newman & Revenson, 1993). The higher amount of variance accounted for in positive affect, compared with negative psychological outcomes, together with different coping strategies found to predict positive affect and negative psychological outcomes, suggests that negative affect and positive affect are separate dimensions, rather than functioning on a continuum.

A summary of the relationships between variables produced in the present study is presented in Figure 2.

Figure 2. Actual relationships between variables in the present study



| |
|---|
| 1. Relationships between coping and psychological outcome:<br>Increased humour, self-distraction, emotional support associated with less depression.<br>Increased positive reframing, energy conservation; less alcohol use, less behavioural disengagement associated with increased PA.<br>Increased alcohol use associated with increased depression, anxiety and NA |
| 2. Relationships between coping and physical outcome:<br>Increased emotional support and energy conservation associated with increased pain.<br>Increased alcohol use associated with less disability. |
| 3. Relationships between control and psychological outcome:<br>Higher internal control associated with less anxiety. |
| 4. Relationships between knowledge and psychological outcome:<br>More knowledge associated with increased PA |
| 5. Relationships between control and coping:<br>Increased internal control associated with increased positive reframing and less alcohol use<br>Increased doctor control associated with increased energy conservation and less denial |
| 6. Relationships between knowledge and coping:<br>Increased knowledge associated with increased active coping, adapting to activities, self-distraction; less denial and behavioural disengagement. |

## 4.8 Implications for Clinical Practice

The aim of a study of this nature is to provide a framework to indicate the different points at which interventions might be made in order to help a person better adjust. From the interpretations of the results from the present study a number of implications can be made for health professionals working with patients with RA.

Health professionals should be aware that RA patients experience a wide range of stresses as a consequence of RA and that these vary from one individual to the next. They need to listen and address these needs rather than assuming pain and disability are always the main problems. In particular, health professionals should address fatigue with patients and reassure them that these are characteristic symptoms of RA. They might address anxieties concerning unpredictability and fear of the future by encouraging patients to engage in a day-to-day approach and accept that they are not totally able to control the course of the illness.

Depressed and anxious medical patients frequently do not report emotional symptoms to their physician unless the physician enquires about them specifically (Rodin et al., 1991). Health professionals should be particularly alert for symptoms of anxiety in their patients. The lack of association found between psychological and physical outcome implies that health professionals must guard against mistakenly attributing the additive effects of anxiety and depressive symptoms to worsening primary illness. A brief screening instrument such as the HADS could be used to help their clinical judgement.

The practical aim of research into coping and adjustment is to identify some successful coping strategies that could be taught to RA patients. Findings suggest that the study of the coping processes used by patients with RA should not be limited to the study of coping with pain and disability; and coping needs to be considered in the context of the perceived stress.

A central finding from the present study is that what patients do in response to their RA does influence the psychological impact the disease has on them. Health professionals need to focus more on patients' coping strategies and promote strategies associated with positive outcome. Discussions about coping strategies may be encouraged to take place in the routine consultation with health professionals. However, given the physicians' busy routine, an alternative may involve seeing a health professional who is familiar with studies of coping and can help plan the ways in which the individual may adapt to the problems of RA. When evaluating the effectiveness of specific coping efforts, both the physical and psychological domains need to be explored. Some strategies may not promote adherence, but may make the patient feel less depressed. Others may allow the individual to lead a more active life but not deal with issues of loss of physical function. Use of ineffective coping strategies, for example alcohol, may be identified through screening and appropriate clinical interventions.

Findings from the present study suggest that psychological adaptation to RA is best achieved if individuals use strategies which promote cognitive restructuring. A patient may be helped to manage his/her emotional experience by trying to elicit information regarding how they perceive the problem situation and helping them change those dysfunctional aspects of cognition which help generate it. For example, helping patients achieve a realistic and functional view of the current problem situation and how it can be handled; suggesting other coping options available; encouraging patients to make downward comparisons; encouraging a sense of determination and 'fighting spirit' by looking at previous successes and coping from day-to-day rather than in the future. Patients might also be informed and encouraged to use a range of self-management strategies to help manage their physical symptoms. For instance, energy conservation should be promoted by encouraging patients to adopt a flexible approach with regard to rest and activity and learning to 'pace' activities, especially when experiencing high levels of pain. Although patients could be encouraged to seek emotional support during flare-ups, health practitioners should recommend that they use active self-management strategies as well.

Health professionals need to be aware that patients hold differing health locus of control beliefs as these may have implications for the way that professionals approach consultations. For example, weak beliefs of internal control over symptoms suggest that the goal of most clinical management should be to help patients see that there are things they can do to manage their illness and that the illness need not be as hopeless and overwhelming as it might first appear. Health professionals need to be aware of and, if necessary, address the influence of a patient's social support network on symptoms and assess whether significant others are exerting a positive or negative influence. The finding that medical personnel exert powerful influence over patients is especially conducive to forming an alliance between the patient and the rheumatology team that could be the basis for effective management of the disease (Wallston, 1993). For example, a patient may be more likely to comply with medication even if the beneficial results are not immediately apparent.

The present study supports findings from the RA patient education literature that the transfer of knowledge is not sufficient to bring about desirable health behaviours and outcomes. However, the transfer of information should not be dismissed because it is fundamental to all patient education (Daltroy & Liang, 1991). Health professionals need to concentrate on providing information relating to symptoms, medication and self-management strategies. This is the information that is retained by patients and is most relevant to their self-care efforts. Although this cannot guarantee adherence to treatment, clients cannot participant in their own self-care without the relevant knowledge. Unless the patient requests otherwise, it is not necessary to provide a great deal of information relating to the aetiology of RA as this information tends not to be remembered.

### 4.9 Limitations of Present Study and Implications for Future Research

The study was cross-sectional in design and it is therefore impossible to make causal statements about the relationships found among the variables. For example, the study assumes that coping determines outcome. However, coping may also be a consequence of a physical or psychological state, that is, disability and emotional distress resulting from the illness could determine the coping responses. This was especially apparent for coping strategies associated with physical outcome. For example, energy conservation would be expected to be employed as a consequence of increased disability and pain, rather than as a cause of increased disability and pain. Furthermore, findings involving variables that remained outside of the acceptable range of skewness and kurtosis after transformation should be regarded as tentative.

As was suggested in the above discussion relating to correlations involving locus of control, simple correlations between coping and psychological adjustment may overlook a key 'third' variable in the design. The present study only considers determinants of coping that arise from the stressful situation rather than those arising from other aspects of the environment (Alwin & Revenson, 1987). For example, the actions of a patient's spouse have been found to either enhance or interfere with coping strategies adopted (Manne & Zautra, 1989).

One important direction for future research is to use longitudinal studies to determine the causal relationships of associations found in this study, particularly those between coping and outcome. In addition to providing an insight into causal order, longitudinal studies would reveal important transitions in the coping strategies which RA patients use over time. Few studies have attempted to evaluate how coping changes over time as the course of the illness becomes apparent to the patient and she/he learns through experience of the success and failure of various coping strategies. Longitudinal studies are likely to reveal important transitions in the coping strategies of RA patients. Longitudinal studies are also needed to investigate the effects of patients' knowledge of different aspects of RA with coping strategies and outcome.

The self-report methods used in the present study are susceptible to response bias from participants. It is difficult to know the degree to which responses are coloured by the participant's attempt to present himself or herself in a favourable light to the authority responsible for their care. The inclusion of independent data from other sources, for example, spouses and clinicians would further strengthen the validity of the methodology of future research.

Self-report anxiety and depressive symptom scales are useful for identifying people who might be at risk for having an anxiety and/or depressive disorder. However, these findings should be interpreted with caution as scores may be elevated among people who are experiencing very transient distress, but who are generally well-adjusted (Murphy et al., 1999). The reliability and validity of the modified Brief COPE and the RA Stresses Questionnaire were not tested. Further research developing and using such measures would therefore be useful.

Participants were predominantly white, middle class individuals and therefore did not represent other ethnic groups and social classes. Participants only included those who attended one particular outpatient rheumatology clinic and findings cannot be generalised to RA patients who are managed through other services, or do not attend tertiary health care services. Replication is needed on samples of RA patients from more diverse ethnicities and sociodemographic backgrounds as well as those experiencing differing services.

Studies are also needed to clarify patients' perceptions of control over 'daily symptoms' of RA and control over the overall 'course' of RA using a valid measure that distinguishes between these two contexts. Furthermore, future research investigating health locus of control beliefs should assess the extent to which individuals believe that they have the ability to carry out behaviours (self-efficacy) and not just the belief that it will be effective.

The finding that coping strategies influence psychological adjustment suggests that psychological interventions that boost coping effectiveness are warranted in emotionally distressed RA patients. These interventions need to be developed and evaluated. Furthermore, the possibility that people may appraise different types of illness-related problems in systematically different ways and consequently cope with them in different ways, would appear to be a promising avenue for future research in RA populations. If future research finds that the adaptiveness of certain coping strategies are problem-specific, then interventions that link instruction on various coping strategies to particular problems could be developed and tested.

That some RA patients are depressed, anxious or otherwise in need of intervention is not in doubt. However, many do not experience anxiety and depression, and useful information should come from explorations of the means by which most physically ill patients remain psychologically well adjusted. The decrease of negative affect has traditionally been a goal in the medical literature on managing chronic disease and the enhancement of positive affect is a neglected, but clinically relevant area.

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# Appendix 1

## Pilot study

### Introduction

The original focus of the study was to investigate a wide range of cognitive and psychosocial factors theoretically considered to contribute to the process of adaptation to RA. The original focus also aimed to investigate the consequences of RA perceived as stressful by RA patients.

The study intended to examine associations between cognitive and psychosocial factors to psychological well-being (anxiety, depression, negative and positive affect); functional disability (physical activity and grip strength); and disease activity (erythrocyte sedimentation rate (ESR)). The cognitive and psychosocial factors initially considered for investigation were:

- Illness appraisals (illness identity; timeline; consequences; control/cure and cause)
- Controllability of symptoms
- Self-efficacy
- Knowledge of RA
- Coping strategies employed to deal with RA
- Extent and quality of social support

The relevance of perceptions of control, knowledge of illness and use of coping strategies to RA have been discussed in the introduction to the present study. The remaining cognitive and psychosocial factors will only be discussed briefly as they were removed from the main study as a result of the pilot study findings.

The fundamental premise of the stress and coping theory of Lazarus and Folkman (1984) is that how one copes with a disease is an important determinant of adjustment. Given this premise, it is important to identify factors that promote particular coping styles. Coping attempts are primarily determined by appraisals of the disease and Leventhal et al. (1984) proposed that patients create their own models or representations of their illness in order to make sense and respond to problems caused by the onset of illness. The 'self-regulation model' of Leventhal et al. (1984) proposes that patients' illness representations are based around distinct components. Patients will have their own ideas about the identity, cause, time-line, cure, controllability and consequences of their illness. The 'identity' component is concerned with patients' ideas about the label of their condition and the associated symptoms. The 'causal' component reflects the patients' ideas about the likely cause(s) of the illness and the 'time-line' component indicates their perceptions of the likely duration of their health problems as acute, chronic or cyclical. The 'consequences' component comprises individuals' beliefs about illness severity and likely impact on physical, social and psychological functioning. The 'cure' component indicates the extent to which patients believe their condition is amenable to cure or control. Leventhal et al. (1984) proposed that these representations determine coping and, via this, other outcomes such as mood and disability. Moss-Morris et al. (1996) supported this contention by finding associations between illness perceptions and coping in patients with chronic fatigue syndrome (CFS). Weinman et al. (1996) found these illness representations to be correlated with levels of distress and disability in diabetes, RA. CFS and chronic pain patients.

Another appraisal associated with coping and adjustment is self-efficacy. Self-efficacy refers to a person's beliefs in his or her ability to respond to and control environmental demands and challenges (Bandura, 1977). In the case of chronic illness, the concept of self-efficacy has been used to contend that people's beliefs concerning their ability to initiate coping behaviours predicts their accomplishment of those coping behaviours. For example, Schiaffino & Revenson (1992) demonstrated that self-efficacy beliefs are related to greater problem-focused coping in RA patients. Self-efficacy beliefs represent a changeable psychological state which can be altered by educational interventions (Lorig et al., 1987), not a permanent personality trait. Strong beliefs in self-efficacy have also been closely linked to improvements in health status (Lorig et al., 1987).

Coping with RA involves stresses associated with coming to terms with the meaning of the illness to one's life and issues of coping with pain, stiffness and physical activity restrictions. It has been asserted that to cope with many of these challenges, RA patients need an available and satisfying network of interpersonal relations on which they can rely for emotional support and more practical help during periods of pain and disability (Revenson, 1993). Although appraisal is frequently posited to be the primary influence on coping, external resources, such as social support, have been shown to play a role in shaping coping behaviour (Newman & Revenson, 1993). The perceived availability of social support has also been associated with psychological well-being and improved physical health in individuals with RA (Smith & Wallston, 1992). At the same time, however, the illness may have a detrimental effect on the patient's family and friends, which in turn, may affect the patient's adjustment (Manne & Zautra, 1990).

Social support is proposed to operate in a number of ways. For example, social support may enable RA patients to use effective coping strategies by helping them come to a better understanding of the problem faced and increase motivation to take instrumental action (Thoits, 1986). Social support may also reduce emotional stress which may encourage the performance of positive health behaviours (Wallston et al., 1993).

The range of cognitive and psychosocial factors included in the original focus of the study produced a high number of provisional hypotheses:

Provisional hypotheses

(1) Negative affect will be associated with increased depression and anxiety and lower positive affect; positive affect will be associated with decreased depression, anxiety and negative affect.

(2) Negative physical outcome will be associated with negative psychological outcome and positive physical outcome and positive psychological outcome will be associated.

(3) Appraisals of strong illness identity; chronic timeline; severe consequences; lack of control or cure and internal causes will be associated with increased psychological distress, level of disability and pain.

(4) Appraisals of lower self-efficacy will be associated with increased psychological distress, level of disability and pain.

(5) Less knowledge will be related to increased psychological distress, physical disability and pain.

(6) Internal and doctor locus of control will be related to less psychological distress, physical disability and pain.

(7) Chance and other people locus of control will be associated with increased psychological distress, level of disability and pain.

(8) Adaptive coping strategies will be associated with decreased psychological distress, level of disability and pain.

(9) Maladaptive coping strategies will be associated with increased psychological distress, level of disability and pain.

(10) Adaptive coping strategies will be associated with increased self-efficacy; knowledge; internal and doctor control; weak illness identity; acute timeline; less severe consequences; perception of control or cure and external causes.

(11) Maladaptive coping strategies will be associated with decreased self-efficacy and knowledge; chance and other people control; lack control or cure and internal causes.

(12) Internal and doctor control will be associated with increased self-efficacy; knowledge; perception of control or cure and external causes.

(13) Chance and other people control will be associated with decreased self-efficacy and knowledge; strong illness identity; chronic timeline; severe consequences; lack of control or cure and internal causes.

(14) Higher self-efficacy will be associated with higher knowledge.

## Aims of the pilot study

Due to the high number of provisional hypotheses, it seemed unlikely that covering the breadth of areas originally considered would be possible. A pilot study was conducted to test this assertion and to try and condense and contract the original hypotheses and number of psychometric tests into a manageable number. The aim would be to focus on factors which would be most pertinent to RA. The pilot study also aimed to assess the acceptability of the type of questionnaires to participants. A final intention of the pilot study was to aid the development of a questionnaire to assess perceptions of RA-related stresses for use in the main study.

## Method

### *Design*

The design was a cross sectional, correlational survey design requiring questionnaire completion. The pilot involved quantitative measurement and analysis methods.

*Participants*

Criteria for participant inclusion were the same as those described in the main study (See method section)

**Table 20.** Information on participants in the pilot study

| Participants | N | Age range | Mean age (SD) | % Males : Females |
|---|---|---|---|---|
| Pilot study | 9 | 39 - 74 | 58.89 (11.96) | 33 : 67 |

Table 20 shows that nine participants took part in the pilot study. A total of 11 RA patients were initially asked to participate, one patient declined and one did not attend. Pilot participants did not take part in the main study. A higher proportion of female participants to male participants took part in the pilot study.

*Measures*

*RA Stresses Questionnaire* (Appendix 33).

The RA stresses questionnaire was developed for the purpose of the main study. This questionnaire was developed on the basis of commonly recurring themes regarding RA-related stresses. This information was generated through discussions with specialist rheumatology nurses and a review of the literature. Participants were presented with 11 aspects of RA that could be of importance to people with RA. They were asked to indicate on a five-point Likert-type scale the extent to which they had experienced each aspect as distressing or bothersome over the previous week (from 'never' to always').

*Illness Perception Questionnaire* (IPQ) (Weinman et al., 1996) (Appendix 34).

The IPQ was developed to assess cognitive representations of illness, based on the five components of Leventhals's Illness Representation Model (Leventhal et al., 1984). The measure consists of 26 statements on a Likert-type scale, from strongly agree to strongly disagree. These statements are related to the five components that have been found to underlie cognitive representations of illness (Skelton & Croyle, 1991): (1) identity (disease label and symptoms); (2) timeline (whether the illness threat is acute chronic, cyclic); (3) consequences (physical, economic and social); (4) antecedent causes and (5) potential for control and cure.

Weinman et al. (1996) showed evidence of discriminant validity between illness groups including rheumatoid arthritis as well as diabetes, chronic fatigue syndrome and pain. The scale also showed evidence for concurrent and predictive validity. Evidence of internal reliability of the scale was provided by Cronbach's alphas of 0.82 for 'identity'; 0.73 for 'timeline'; 0.82 for 'consequence'; and 0.73 for 'control/cure' (it is not possible to sum all of the items for the 'cause' scale as each item represents a specific causal belief).

*Generalised Self-Efficacy Scale* (GSES) (Schwarzer, 1992) (Appendix 35)

The GSES is a ten-item scale that assesses the strength of an individual's general belief in his or her coping ability across a range of demanding situations. Respondents are required to indicate the extent to which each statement applies to them on a four-point Likert type scale, from 'not at all true' (one) to 'exactly true' (four). The higher the score, the greater the individual's sense of self-efficacy.

Schwarzer (1992) found high internal consistency ratings for five samples, with Cronbach's alphas ranging from 0.82 to 0.93. Concurrent and predictive validity have also been established (Schwarzer, 1992). In a study of 278 adults with arthritis, Barlow, et al (1996) concluded the GSES was reliable and valid for use among community-based samples of people with arthritis.

*COPE* (Carver et al., 1989) (Appendix 36)

COPE is a multidimensional coping inventory in which respondents go through 60 coping statements indicating the extent to which they make use of 15 strategies in response to a specific situation or during a specific time period. These strategies are active coping; planning; seeking instrumental support; seeking emotional support; suppression of competing activities; turning to religion; positive reinterpretation and growth; restraint coping; acceptance; focus on and venting of emotions; denial; mental and behavioural disengagement; alcohol and drug use and humour. Four items made up each scale. Participants rated the extent they engaged in each statement in response to their RA over the previous week on a four point Likert type scale (from 'I don't do this at all' to I do this a lot'). The higher the score for each scale, the more the individual engaged in that type of coping.

The internal consistency (Cronbach's alpha) of the COPE scales exceeded 0.6 with the exception of one scale (mental disengagement) (Carver et al., 1989). An eight-week test retest indicated that the coping tendencies measured by the COPE are reasonably stable. Carver et al. (1989) also demonstrated construct validity of the COPE. The COPE is regarded as the best theoretically based instrument currently available to assess a wide range of coping responses (Weinman et al., 1995).

*Significant Others Scale (SOS)* (Power et al., 1988) (Appendix 37).

The SOS elicits information on ideal and actual levels of emotional and practical social support, for a range of key relationships in an individual's life. Participants select individuals to be rated for two emotional and two practical types of social support functions. Using a seven-point frequency scale, each individual is rated in terms of the level of support received and the ideal level of support (from 'never' to 'always'). The higher the score, the greater the frequency of social support.

Test-retest reliability was calculated for 73 female students over a six-month period and the concurrent and construct validity of the SOS has been established (Power et al., 1988).

*Grip strength*

Grip strength is a recommended measure for RA disease severity (Felson et al., 1993). Grip strength was measured using a mercury column sphygmomanometer with a standard grip bag. Participants were instructed to squeeze the bag with each hand as tightly as possible on three separate trials. The maximum height of the mercury column achieved on each occasion was taken. The mean of the three values (in mm Hg) constituted the grip strength score for each hand. The minimum grip strength score is zero mm Hg and the maximum is 300 mm Hg.

The following measures were also used in the main study and are described in the method section.

- Demographic information (Appendix 4)
- Form C of the Multidimensional Health Locus of Control Scale (MHLC) (Appendix 5)
- Patient Knowledge Questionnaire (PKQ) (Appendix 6)
- The Hospital Anxiety and Depression Scale (HADS) (Appendix 7)
- Positive and Negative Affect Schedule (PANAS) (Appendix 8)
- Health Assessment Questionnaire (HAQ) (Appendix 9)
- Pain Visual Analogue Scale (VAS) (Appendix 10)
- Erythrocyte sedimentation rate (ESR)

### Procedure

The procedure was similar to that employed in the main study (described in the method section), but with the following differences. First, measures of grip strength, ESR, self-reported pain intensity and HAQ scores were taken by specialist nurses at the patient's assessment clinic and the results of these measures were collected by the researcher the same day the participant took part in the pilot study.

Second, participants were asked to complete the following questionnaires (this took between 45 minutes to two hours):

- RA Stresses Questionnaire
- Form C of the MHLC scale
- IPQ
- GSES
- COPE
- PKQ
- SOS
- HADS
- PANAS

(Two participants were helped to fill in the questionnaires by the researcher due to physical impairments that prevented them from completing the questionnaires independently).

Third, after participants had completed the Stresses Questionnaire, they were asked for additional stresses they experienced that were not included in the list. They were also asked whether they perceived any of the items as incomprehensible. Participants were asked at the end of the COPE questionnaire if they responded in any other ways to their arthritis that were not included in the questionnaire.

Fourth, at the end of the session, participants were asked for feedback about the number and nature of the questionnaires as well as for general comments about the procedure.

Finally, participants were not asked at the end of the session whether they would be willing to come back and talk in more depth about their experiences of having RA as the qualitative component of the study was only carried out in the main study.

These differences in the pilot study procedure meant that the information sheet (Appendix 38) and consent form (Appendix 39) given to participants in the pilot study were different from those given in the main study.

Results

- Participants stated that all the items in the stresses questionnaire were relevant, although the meaning of three items were queried by some participants, these included 'loss of physical mobility', 'change of physical appearance', effect on family/relationships'. A large number of additional stresses were generated by participants, for example, feeling tired and fatigued, having to take medication and having to constantly plan ahead (Appendix 40).
- After the COPE had been administered, participants reported a number of additional coping strategies they used (Appendix 40). These mainly focused on self-management behaviours carried out by the individual to alleviate symptoms of RA.
- All the participants in the pilot study felt that there were too many questionnaires. The procedure was extremely time-consuming, taking up to two hours on some occasions.
- The pilot study highlighted that a considerable length of time elapsed from when the measures were taken by the specialist nurse at the assessment clinic and the date of questionnaire completion.
- Participants reported that they felt constrained in their responses to items in some of the questionnaires (particularly in the COPE and the MHLC scale) and they felt that the questionnaires frequently neglected issues that they considered important.

Additionally, the process of completing the questionnaires prompted all the participants to provide information that was not being recorded within the questionnaire format.

## Discussion and Conclusions

In response to the information provided by the pilot study, the following revisions were made for the main study:

- The stresses questionnaire was revised (Appendix 11). All of the items included in the pilot questionnaire remained in the revised version and three of the items were rephrased. These were 'loss of physical mobility (prevented from performing activities at home/work/leisure)'; 'the effect on family and other relationships' and 'change of physical appearance, i.e. how you feel about how you look'. The other stresses generated by participants were summarised into ten items. To provide a summary of perceived stresses, participants were asked to rate their 'top three problematic consequences' of having RA at the end of the revised questionnaire.
- A theme that continually emerged during the pilot study was the importance of self-management in a chronic illness. By addressing the issues felt to be most relevant to self-management, that is, perceptions of control over symptoms, knowledge of RA and coping strategies, it was possible to reduce the hypotheses and measures. The relevance of control, knowledge and coping to RA is covered in the introduction to the main study. Three questionnaires were dropped from use in the main study (IPQ; GSES and SOS). Grip strength was also removed from the main study as it provided a measure of functional disability that was also measured by the HADS. The COPE was replaced by a shorter version (Brief COPE) and ten items were added to the Brief COPE to represent the five types of coping strategies generated by participants. Four of the strategies were RA-specific and these included adapting activities, conserving energy, knowing limitations and specific physical pain management strategies. The remaining strategy that was included was the use of alternative therapies.
- It was decided that in order to obtain all variables at the same time, the VAS and HAQ would be taken by the researcher. If a recent ESR had not been taken, participants would be required to have a blood test. This proposal was resubmitted and agreed by the Ethical Committee in September 1998 (Appendix 3).

- A qualitative component was introduced in the main study to obtain detailed and 'richer' information from participants in the areas under investigation.

Summary of pilot study findings

From the findings of the pilot study it was clear that the original focus of the research was too broad. Perceptions of control, knowledge and coping emerged as the most important factors in relation to adjustment to RA, in particular the self-management aspect. On the basis of these findings, the present study concentrates on perceptions of control, knowledge and coping in relation to RA and the original hypotheses and the number psychometric tests have been reduced to an acceptable number to participants. The pilot study also aided the development of a questionnaire to assess perceptions of RA-related stresses for use in the main study.

## Appendix 2

EAST LANCASHIRE
HEALTH AUTHORITY

NHS
1948 - 1998

610226
[illegible]
[illegible]

AM/AB/6/98

15 June 1998

M.
Whitegate Drive Health Centre
156 Whitegate Drive
BLACKPOOL

Dear M.

**AN INVESTIGATION INTO COGNITIVE AND PSYCHOSOCIAL FACTORS IN ADJUSTMENT TO RHEUMATOID ARTHRITIS**

Thank you for submitting the above application which was reviewed by the Blackburn, Hyndburn and Ribble Valley Local Research Ethics Committee at its meeting on 12 June 1998.

Ethical approval has been granted for the study to be undertaken in the district.

The study has been given approval only in relation to its acceptability from an ethical point of view. If, subsequently, departure from the methodology outlined in your application is contemplated, the Ethics Committee must be advised and the proposed changes approved.

Members are interested in following the progress of research projects and would welcome receipt of a final report when the work has been completed which will be received in confidence.

Yours sincerely

A Myers

**Dr A Myers**
**Chairman**
**Blackburn, Hyndburn & Ribble Valley**
**Local Research Ethics Committee**

## Appendix 3

EAST LANCASHIRE
HEALTH AUTHORITY

610227
Your Ref:
Our Ref: AM/AB/6/98
Direct Dial: (01282)
Facsimile : (01282) 610223

15 August 1998

M
Whitegate Drive Health Centre
156 Whitegate Drive
BLACKPOOL

Dear M

**AN INVESTIGATION INTO COGNITIVE AND PSYCHOSOCIAL FACTORS IN ADJUSTMENT TO RHEUMATOID ARTHRITIS**

Thank you for your letter and enclosures of 7 August 1998 which have now been reviewed by the LREC.

The Committee had no objections to the proposed changes but would assume that an explanation of the meaning of "ESR" would be given at the time that consent was obtained.

Yours sincerely

a. Myers
ab

**Dr A Myers**
**Chairman**
**Blackburn, Hyndburn & Ribble Valley**
**Local Research Ethics Committee**

## Appendix 4

## Background details

1. Age at this time?

2. Male ☐ Female ☐

3. What is your current marital status?

Married ☐ Divorced ☐
Living with partner ☐ Widowed ☐
Separated ☐ Never married ☐

4. What is your occupation? Indicate student, housewife, disabled, retired, unemployed.

5. If you are retired, disabled or unemployed what was you previous occupation?

6. How many years of formal education have you had?

7. Do you have any dependent children living with you? Yes ☐ No ☐

8. Do you have any other dependants living with you? Yes ☐ No ☐

9. Ethnic origin?

10. How many years have you had arthritis?

11. How many years ago was your arthritis diagnosed by a rheumatologist?

12. Which of your following joints are affected by arthritis?

Fingers ☐ Hips ☐
Wrist ☐ Knees ☐
Elbow ☐ Ankles ☐
Shoulder ☐ Toes ☐
Neck ☐ Other ..........
All ☐

13. What medication are you currently on for your arthritis?

## Appendix 5

## Multidimensional Locus of Control Scale

This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale that ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with the statement.

| | |
|---|---|
| 1= Strongly disagree | 4 = Slightly agree |
| 2 = Moderately disagree | 5 = Moderately agree |
| 3 = Slightly disagree | 6= Strongly agree |

| | | | | | | |
|---|---|---|---|---|---|---|
| 1. I am directly responsible for my arthritis getting better or worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. Other people play a big role in whether my arthritis improves, stays the same, or gets worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. Following doctor's orders to the letter is the best way to keep my arthritis from getting worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. Whenever my arthritis worsens, I should consult a medically trained professional | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. As to my arthritis, what will be will be | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. Whatever goes wrong with my arthritis it is my own fault. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. The main thing which affects my arthritis is what I do to myself. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Luck plays a big part in determining how my arthritis improves | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. If my arthritis takes a turn for the worse, it is because I have not been taking proper care of myself | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Whatever improvement occurs with my arthritis is largely a matter of good fortune | 1 | 2 | 3 | 4 | 5 | 6 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 11. I deserve the credit when my arthritis improves and the blame when it gets worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. If I am lucky, my arthritis will get better. | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. The type of help I receive from other people determines how soon my arthritis improves. | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. If my arthritis worsens, it's a matter of fate | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. If my arthritis worsens, it is my own behaviour which determines how soon I feel better again. | 1 | 2 | 3 | 4 | 5 | 6 |
| 16. If I see my doctor regularly, I am less likely to have problems with my arthritis. | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. Most things that affect my arthritis happen to me by chance. | 1 | 2 | 3 | 4 | 5 | 6 |
| 18. In order for my arthritis to improve, it is up to other people to see that the right things happen. | 1 | 2 | 3 | 4 | 5 | 6 |

# Appendix 6

## Patient Knowledge Questionnaire

1. Can you choose **TWO** true statements from the following list?
Rheumatoid Arthritis:
a. is inherited from your parents
b. starts after a joint has been damaged
c. is caused by cold damp weather
d. the cause is not known
e. may be triggered by a bacteria or virus
f. don't know

2. Can you choose **TWO** true statements from the following list?
Rheumatoid Arthritis:
a. affects only the bones of the body
b. occasionally affects the lungs, eyes or other tissues
c. is most common in old age
d. is a long-term disease
e. is curable
f. don't know

3. Can you choose **THREE** symptoms which can be caused by Rheumatoid Arthritis?
a. anaemia
b. nodules
c. overweight
d. hair loss
e. high blood pressure
f. fatigue
g. don't know

4. Can you choose **TWO** blood tests which are used to assess how active your arthritis is?
a. cholesterol level (CL)
b. erythrocyte sedimentation rate (ESR)
c. blood group
d. plasma viscosity (PV)
e. plasma protein
f. don't know

5. Can you choose **TWO** true statements about non-steroidal anti-inflammatory drugs?
a. they stop the disease from progressing
b. they take many weeks to start working
c. they reduce pain, swelling and stiffness
d. they need only to be taken when the pain is bad
e. they should be taken with food
f. don't know

6. Can you choose the **ONE** most common side-effect that non-steroidal anti-inflammatory tablets can cause?
a. itching of the skin
b. indigestion
c. bruising
d. dry mouth
e. loss of taste
f. don't know

7. Can you choose **TWO** 'long-term drugs' which can put the disease into remission?
a. Methotrexate
b. Diclofenac also called Volterol
c. Indomethacin also called Indocid, Indocid 'R', Imbrilon
d. Sulphasalazine also called Salazopyrin, E/C Salozopyrin
e. Ibuprofen also called Brufen, Fenbid, Nurofen
f. Don't know

8. Can you choose **TWO** true statements about pain killing tablets?
Painkillers
a. are not addictive
b. should only be taken when pain is severe
c. should be taken before carrying out an activity which you know causes you pain
d. should be taken when pain starts to build up
e. should always be taken with food
f. don't know

9. Can you choose **TWO** correct answers about exercise and Rheumatoid Arthritis?
a. it is unnecessary to exercise if you are normally active
b. exercise will cure rheumatoid arthritis
c. exercise will weaken damaged joints
d. move your+ joint to the point of pain and then a bit further
e. exercise can reduce the chance of a joint deformity
f. don't know

10. Can you choose the **TWO** most suitable ways for someone with Rheumatoid Arthritis to take regular exercise?
a. muscle tightening exercise
b. gentle jogging
c. walking
d. yoga
e. shopping trips
f. don't know

11. Can you choose **ONE** activity which you should carry out when all your joints are painful and stiff?
a. refrain from all exercise
b. rest in bed for most of the day
c. carry out your usual range of movement exercises
d. exercise quite vigorously
e. don't know

12. Can you choose **TWO** treatments which would be most suitable if your wrists are becoming more than usually painful, swollen and stiff?
a. rest them by putting on wrist splints
b. reduce the stiffness by vigorous exercise
c. use them as much as possible
d. avoid movement by keeping them in one position as much as possible
e. put the joints through a range of movement several times a day
f. don't know

13. Can you choose **TWO** sentences from this list?

The most practical way to protect your joints from strain is to
a. use them quickly
b. use the larger joints rather than the smaller ones where possible
c. slide objects rather than lift them
d. do as little as possible
e. carry on as though you did not have arthritis
f. don't know

14. Can you choose the **ONE** most suitable activity when you have a busy day planned but realise you're feeling tired?
a. take the day off and do more tomorrow
b. do everything you have planned to do
c. take a short rest and then do all the things you had planned
d. do essentials and leave the rest
e. spend the day resting in bed
f. don't know

15. Can you choose **TWO** suitable methods of conserving your energy?
a. sit down whilst ironing
b. plan activities to balance work and rest periods
c. use the strongest and largest muscles possible
d. use both hands to carry objects such as full saucepans
e. don't know

16. Can you choose **TWO** methods of joint protection?
a. grip objects tightly
b. use a dishcloth rather than a sponge
c. use the palm of your hands not your fingers when opening a jar
d. apply heat or ice to the joint
e. having power assisted steering on your car
f. don't know

## Appendix 7

## HADS

Clinicians are aware that emotions play an important part in most illnesses. Read each item and underline the reply which comes closest to how you've been feeling in the past week. Don't take too long over your replies: Your immediate answer will probably be more accurate than a long thought-out response.

**I feel tense or wound up:**
Most of the time
A lot of the time
From time to time, occasionally
Not at all

**I still enjoy the things I used to enjoy:**
Definitely as much
Not quite so much
A little, but it doesn't worry me
Not at all

**I get a sort of frightened feeling as if something awful is about to happen:**
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

**I can laugh and see the funny side of things:**
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

**Worrying thoughts go through my mind:**
A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

**I feel cheerful:**
Not at all
Not often
Sometimes
Most of the time

**I can sit at ease and feel relaxed:**
Definitely
Usually
Not often
Not at all

**I feel as if I am slowed down:**

Nearly all of the time
Very often
Sometimes
Not at all

**I get a sort of frightened feeling like 'butterflies' in the stomach:**

Not at all
Occasionally
Quite often
Very often

**I have lost interest in my appearance:**

Definitely
I don't take as much care as I used to
Definitely less than I used to
Hardly at all

**I feel restless as if I have to be on the move:**

Very much indeed
Quite a lot
Not very much
Not at all

**I look forward with enjoyment to things:**

As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

**I get sudden feelings of panic:**

Very often indeed
Quite often
Not very often
Not at all

**I can enjoy a good book or radio or TV programme:**

Often
Sometimes
Not often
Very seldom

## Appendix 8

## Positive and Negative Affect Schedule

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past week

Use the following scale to record your answers:

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| very slightly or not at all | a little | moderately | quite a bit | extremely |

___________interested

___________distressed

___________excited

___________upset

___________strong

___________guilty

___________scared

___________hostile

___________enthusiastic

___________proud

___________irritable

___________alert

___________ashamed

___________inspired

___________nervous

___________determined

___________attentive

___________jittery

___________active

___________afraid

## Appendix 9

## Health Assessment Questionnaire

In the questionnaire we are interested in learning how your illness affects your ability to function in daily life. Please tick the one answer which best describes your usual abilities over the past week.

| | Without any difficulty | With some difficulty | With much difficulty | Unable to do |
|---|---|---|---|---|
| **Are you able to :**<br>Dress yourself including tying shoelaces and doing buttons? | | | | |
| Wash you hair yourself? | | | | |
| Stand up from a dining chair without armrests? | | | | |
| Get in and out of bed? | | | | |
| Cut your own meat when eating a meal? | | | | |
| Lift a full cup or glass to your mouth? | | | | |
| Open a packet of biscuits or a packet of cereal or a bag of sugar? | | | | |
| Walk outside on flat and even ground? | | | | |
| Climb up five steps? | | | | |
| Wash and dry your entire body? | | | | |
| Take a bath? | | | | |
| Get on and off the toilet? | | | | |
| Reach and get a 2 pound object (such as a bag of sugar) just above your head? | | | | |
| Bend dome to pick clothing from the floor? | | | | |
| Open car doors from the outside of the car? | | | | |
| Open jars that have previously been opened? | | | | |
| Turn taps on and off? | | | | |
| Go on errands and shop? | | | | |
| Get in and out of the car? | | | | |
| Do chores such as vacuuming or housework or light gardening? | | | | |

**Please tick any of the following gadgets that you use:**

_____Walking stick (state on or two)

_____Crutches

_____Zimmer frame

_____Wheelchair

Do you always choose front fastening clothes because you cannot manage back fastening?

Gadgets used for dressing (e.g. button hook, zipper pull)?

_____Built up of special cutlery

_____Raised toilet seat

_____Bath seat

_____Bath rail

_____Long mop for washing self

_____Special or built up chair

_____Raised toilet seat with rails

_____Bath board

_____Helping hand/easireach

_____Bath hoist

If you have a shower, do you always use this because you cannot manage the bath?

______Jar opener (for jars previously opened)

______Tap turners or special lever taps

Others (specify):

# Appendix 10

## Pain Visual Analogue Scale

How much pain have you had because of your arthritis in the **past week**?

No pain Pain as bad as it could be

# Appendix 11

## Stresses Questionnaire

**To what extent have the following aspects of your arthritis caused you distress or bothered you over the past week?**

| | Never | A little | Sometimes | Mostly | Always |
|---|---|---|---|---|---|
| Loss of physical mobility (prevented from performing activities at home/work/leisure) | ☐ | ☐ | ☐ | ☐ | ☐ |
| Fatigue/tiredness | ☐ | ☐ | ☐ | ☐ | ☐ |
| Pain | ☐ | ☐ | ☐ | ☐ | ☐ |
| Side-effects of medication | ☐ | ☐ | ☐ | ☐ | ☐ |
| Loss of earnings | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having to taking medication, have injections etc | ☐ | ☐ | ☐ | ☐ | ☐ |
| The unpredictability of RA | ☐ | ☐ | ☐ | ☐ | ☐ |
| Thinking about the future | ☐ | ☐ | ☐ | ☐ | ☐ |
| The effect on family and other relationships | ☐ | ☐ | ☐ | ☐ | ☐ |
| Change of physical appearance i.e. how you feel about how you look | ☐ | ☐ | ☐ | ☐ | ☐ |
| Fear of children getting arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| Sexual problems resulting from physical problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having to constantly plan ahead | ☐ | ☐ | ☐ | ☐ | ☐ |
| Losing contact with people | ☐ | ☐ | ☐ | ☐ | ☐ |
| Feeling dependent on others | ☐ | ☐ | ☐ | ☐ | ☐ |
| Effects on mood | ☐ | ☐ | ☐ | ☐ | ☐ |
| Feeling misunderstood by others who do not appreciate difficulties | ☐ | ☐ | ☐ | ☐ | ☐ |

| | Never | A little | Sometimes | Mostly | Always |
|---|---|---|---|---|---|
| Feeling a sense of loss (wishes unfulfilled) | ☐ | ☐ | ☐ | ☐ | ☐ |
| Loss of dignity | ☐ | ☐ | ☐ | ☐ | ☐ |
| A sense of not being useful | ☐ | ☐ | ☐ | ☐ | ☐ |
| Finding it hard to accept you have RA | ☐ | ☐ | ☐ | ☐ | ☐ |

**From the above list, what would you rate as the <u>top three problematic consequences</u> of having arthritis?**

1. ..........................................................................................

2. ..........................................................................................

3. ..........................................................................................

## Appendix 12

## BRIEF COPE

The following items deal with ways you've been coping with the stresses associated with having rheumatoid arthritis. There are many different ways to try to deal with problems. These items ask what you've been doing to cope with rheumatoid arthritis. Each item says something about a particular way of coping. I want to know to what extent you do what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not – just whether or not you do it.
Use these response choices:

1 = I usually **don't do this at all**
2 = I usually do this **a little bit**
3 = I usually do this **a medium amount**
4 = I usually do this **a lot**

1. I turn to work or other activities to take my mind off things 1 2 3 4
2. I concentrate my efforts on doing something about the situation I'm in 1 2 3 4
3. I say to myself 'this isn't real' 1 2 3 4
4. I use alcohol or other drugs to make myself feel better 1 2 3 4
5. I get emotional support from others 1 2 3 4
6. I give up trying to deal with it 1 2 3 4
7. I take action to try and make the situation better 1 2 3 4
8. I refuse to believe that it has happened (is happening?) 1 2 3 4
9. I say things to let my unpleasant feelings escape 1 2 3 4
10. I use alcohol or other drugs to help me get through it 1 2 3 4
11. I try to see it in a different light, to make it seem more positive 1 2 3 4
12. I try to come up with a strategy about what to do 1 2 3 4
13. I get comfort and understanding from someone 1 2 3 4
14. I give up the attempt to cope 1 2 3 4
15. I look for something good in what is happening 1 2 3 4
16. I make jokes about it 1 2 3 4

| | | | | |
|---|---|---|---|---|
| 17. I do something to think about it less, such as going to cinema, reading, watching TV, daydreaming, sleeping or shopping. | 1 | 2 | 3 | 4 |
| 18. I accept the reality of the fact that it happened (is happening) | 1 | 2 | 3 | 4 |
| 19. I express my negative feelings | 1 | 2 | 3 | 4 |
| 20. I try to find comfort in my religion or spiritual beliefs | 1 | 2 | 3 | 4 |
| 21. I learn to live with it | 1 | 2 | 3 | 4 |
| 22. I think hard about what steps to take | 1 | 2 | 3 | 4 |
| 23. I pray or meditate | 1 | 2 | 3 | 4 |
| 24. I make fun of the situation | 1 | 2 | 3 | 4 |
| 25. I adjust my activity to how I an physically feeling | 1 | 2 | 3 | 4 |
| 26. I use 'alternative' therapies | 1 | 2 | 3 | 4 |
| 27. I know the limitations to what I can do | 1 | 2 | 3 | 4 |
| 28. I try and conserve my energy as much as possible | 1 | 2 | 3 | 4 |
| 29. I adapt my activities to what I can do | 1 | 2 | 3 | 4 |
| 30. I use practical strategies such as hot/cold packs, splints | 1 | 2 | 3 | 4 |
| 31. I use non-medical treatments | 1 | 2 | 3 | 4 |
| 32. If I cannot achieve something, I'll find another way of doing it | 1 | 2 | 3 | 4 |
| 33. I take medication regularly | 1 | 2 | 3 | 4 |
| 34. I stop and rest when I need to | 1 | 2 | 3 | 4 |

## Appendix 13

### Semi-structured interview

**Adjustment**

1. Currently to what extent is the effect of your arthritis influencing what you are able and not able to do?

2. Currently to what extent is the effect of your arthritis influencing your mood (how you feel)?

3. How would you rate the current intensity of your pain on a scale of zero to ten (with zero being no pain and ten being pain as bad as it could be)?

**Stress**

4. What aspects of arthritis do you find most stressful/bothersome at the present time?

**Control**

5. To what extent do you believe you yourself can control (influence) the severity of your arthritic symptoms?

6. To what extent do you believe that others (i.e. doctors/significant others) can control (influence) the severity of your arthritic symptoms?

7. To what extent do you believe that the severity of your symptoms are controlled by 'fate/chance' i.e. that no one has any control over them?

**Coping**

8. What do you do or tell yourself to manage (cope with) the consequences of having arthritis?

**Knowledge**

9. Can you describe what causes your arthritic symptoms? (physiology – immune system etc). In what way do you think that having arthritis changes how your body works in order to produce the arthritic symptoms that you experience?

10. What medication are you currently taking for your arthritis? What is does this medication do? What are the potential side-effects of this medication?

11. What would you say are the best strategies to reduce the symptoms of arthritis when you have a flare-up?

12. Have you found out about arthritis i.e. books, videos/TV, internet, radio?

Is there anything else that you think is relevant/important that we have not discussed?

## Appendix 14

### Information sheet

I am a Trainee Clinical Psychologist in my final year of a three-year doctorate training course. As part of my training, I am required to carry out some research and I would like to invite you to take part in this research.

The research to be carried out has been approved by the Local Research Ethics Committee appointed by the Health Authority. This does not imply any endorsement.

**What is the research about?**
In this study I am interested in exploring factors involved in coping and managing rheumatoid arthritis. The areas that I am interested in looking at are aspects of arthritis that people find most stressful; how people think about their arthritis; the different coping strategies that people use and how people feel they are currently functioning, both physically and emotionally.

I hope that I what I will learn will contribute to an understanding of how psychological processes are involved in adapting to a chronic illness. This information might then contribute to developing ways of helping individuals to adjust and manage their arthritis.

**What will happen?**
If you agree to take part in the study after you have read this information sheet, an appointment to come and see me will be arranged. When we meet you will have the opportunity to ask questions or express any concerns about the research. I will then ask you to sign a consent form.

You will then be asked to complete a number of short questionnaires related to the topics described above. *At the end of your appointment you may be asked to have a blood sample taken at the pathology laboratory before you leave the hospital. This is so the ESR in your blood can be measured.*

**What will happen to the information that I give?**
All information will be held in the strictest confidence and will not be discussed with your doctor or nurse.

**What if you don't want to take part?**
We understand that some people will not want to take part in a research project and you have every right to decline.
**You are not obliged to participate in the research. If you decide not to participate in the study this will not affect your treatment at the Rheumatology Clinic.**

**What if you change your mind?**
If at any stage you wish to discontinue your participation in this study this decision will be respected immediately.

**Thank-you for your help**

**(Trainee Clinical Psychologist) Telephone: 01253 763232 ex 249**

## Appendix 15

### Research Consent Form

**An Investigation into the Relationship between Cognitive and Psychosocial Factors and Adjustment in Adults with Rheumatoid Arthritis.**

**Please answer the questions below by circling your response:**

| | |
|---|---|
| Have you received and read an information sheet? | **YES/NO** |
| Have you had a chance to ask questions about the study? | **YES/NO** |
| Do you understand that you are free to withdraw of the study any time and without having to give a reason for withdrawing? | **YES/NO** |
| Do you agree to allow a measure of grip strength to be taken? | **YES/NO** |
| Do you agree to give a sample of blood for a measure of your ESR level after this meeting? | **YES/NO** |
| Do you agree to take part in this study? | **YES/NO** |

**Signed**............................................................ **Date**..............................

## Appendix 16

**Values of kurtosis and skewness of variables found to be in the acceptable range.**

| Variable | N | Mean (SD) | Skewness | | Kurtosis | | | |
|---|---|---|---|---|---|---|---|---|
| | | | Statistic | Std Error | Statistic / Std error | Statistic | Std Error | Statistic / Std error |
| **Age** | 50 | 55.98 (12.92) | -0.343 | 0.337 | 1.018 | -0.641 | 0.662 | -0.968 |
| **Self-distraction** | 50 | 5.94 (1.90) | -0.394 | 0.337 | -1.169 | -1.069 | 0.662 | -1.615 |
| **Active coping** | 50 | 5.47 (2.05) | -0.308 | 0.337 | -0.914 | -1.146 | 0.662 | -1.731 |
| **Emotional support** | 50 | 5.82 (2.04) | -0.500 | 0.337 | -1.484 | -1.042 | 0.662 | 1.574 |
| **Venting** | 50 | 4.06 (2.13) | 0.668 | 0.337 | 1.982 | -0.903 | 0.662 | 1.364 |
| **Positive reframing** | 50 | 4.66 (2.00) | 0.268 | 0.337 | 0.795 | -0.982 | 0.662 | 1.483 |
| **Planning** | 50 | 4.92 (2.03) | -0.085 | 0.337 | -0.252 | -1.195 | 0.662 | 1.805 |
| **Energy conservation** | 37 | 6.70 (1.43) | -0.660 | 0.337 | -1.958 | -0.753 | 0.662 | -1.137 |
| **Internal HLC** | 50 | 16.92 (5.98) | 0.045 | 0.337 | 0.134 | -0.528 | 0.662 | -0.798 |
| **Other people HLC** | 50 | 10.34 (4.43) | 0.205 | 0.337 | 0.608 | -0.877 | 0.662 | -1.325 |
| **Chance HLC** | 50 | 21.06 (6.26) | -0.280 | 0.337 | -0.831 | -0.809 | 0.662 | -1.222 |
| **Doctor HLC** | 50 | 15.36 (3.17) | -0.396 | 0.337 | -1.175 | -0.409 | 0.662 | -0.618 |
| **Knowledge** | 47 | 15.98 (4.56) | 0.037 | 0.347 | 0.107 | -0.397 | 0.681 | -0.583 |
| **Depression** | 50 | 5.22 (3.47) | 0.674 | 0.337 | 2.00 | -0.034 | 0.662 | -0.051 |
| **Anxiety** | 50 | 8.02 (4.30) | 0.550 | 0.337 | 1.632 | 0.002 | 0.662 | 0.003 |
| **Positive affect** | 47 | 31.98 (7.81) | -0.141 | 0.347 | -.0406 | -0.341 | 0.681 | -0.501 |
| **HAQ** | 50 | 1.676 (0.701) | -0.500 | 0.337 | -1.484 | -0.496 | 0.662 | -0.749 |
| **VAS (pain)** | 49 | 50.6 (29.32) | 0.010 | 0.340 | 0.029 | -1.187 | 0.668 | -1.777 |

## Appendix 17

### Data transformations used and values of kurtosis and skewness calculated for transformed variables

| Variable | N | Data transformation | Mean (SD) | Skewness |  |  | Kurtosis |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  | Statistic | Std Error | Statistic / Std error | Statistic | Std Error | Statistic / Std error |
| **Acceptance** | 50 | Reflect and inverse | 0.839 (0.295) | -1.374 | 0.337 | -4.077 | 0.047 | 0.662 | 0.071 |
| **Adapting activity** | 50 | Reflect and logarithm | 0.256 (0.280) | 0.541 | 0.337 | 1.605 | -1.185 | 0.662 | 1.790 |
| **Alcohol/drug use** | 50 | Inverse | 0.452 (0.107) | -2.040 | 0.337 | 6.053 | 2.802 | 0.662 | 4.233 |
| **Alternative therapy** | 50 | Inverse | 0.406 (0.134) | -0.956 | 0.337 | -2.837 | -0.693 | 0.662 | -1.047 |
| **Behavioural disengagement** | 50 | Inverse | 0.439 (0.102) | -1.263 | 0.337 | -3.748 | -.056 | 0.662 | -0.085 |
| **Denial** | 50 | Inverse | 0.416 (0.119) | -0.872 | 0.337 | 2.588 | -0.962 | 0.662 | -1.453 |
| **ESR** | 37 | Square root | 4.305 (1.742) | 0.552 | 0.388 | 1.423 | -0.670 | 0.759 | -0.883 |
| **Humour** | 50 | Reflect and square root | 0.499 (0.322) | -0.574 | 0.337 | -1.703 | -1.148 | 0.662 | -1.734 |
| **Knowing limitations** | 50 | Reflect and logarithm | 0.222 (0.255) | 0.614 | 0.337 | 1.822 | -0.997 | 0.662 | 1.506 |
| **Negative affect** | 47 | Logarithm | 1.247 (0.179) | 0.419 | 0.347 | 1.208 | -0.937 | 0.681 | -1.376 |
| **Physical management** | 50 | Reflect and square root | 1.407 (0.430) | 0.596 | 0.337 | 1.769 | -0.510 | 0.662 | -0.770 |
| **Religion** | 50 | Reflect and square root | 2.067 (0.705) | -0.682 | 0.337 | -2.024 | -1.328 | 0.662 | 2.000 |
| **Years RA diagnosed** | 50 | Square root | 3.216 (1.296) | 0.019 | 0.337 | 0.056 | -0.627 | 0.662 | -0.095 |
| **Years RA** | 50 | Square root | 3.469 (1.253) | 0.071 | 0.337 | 0.211 | -0.651 | 0.662 | -0.098 |

# Appendix 18

## Participants responses from the semi-structured interview included in the categories of coping strategies

(The numbers in brackets, from 1 to 14 identifies each individual participant)

**Alcohol**
Alcohol tends to help with the pain (1)
I tend to drink alcohol in the evening to ease the pain, it also gives you a boost (2)

**Self-distraction** (taking mind off RA)
Still go out clubbing, feel better when go out with friends (1)
Working keeps my mind off it (2)
If I'm bad I try to keep busy – go out in the car on a trip, distracting yourself carries you through that part if the day. Find something to do to take your mind off it (4)
Sit and watch TV a lot of the time (4)
Getting out to see my friends at the church (5)
I read a lot (5)
Looking after my grandson takes my mind off it (9)
Looking after my four year old daughter does take my mind off it (10)
If I'm fed up, I'll do something (11)
I'll try and have a walk or go out in the car if I'm having a bad day (13)

**Keeping going**
Will go through the pain barrier if I have to get something done (1)
Just get on with it like I did before (1)
I just keep going because I wouldn't like to lose my independence.. when I couldn't undo tops and I had to ask my husband to do them the dependence was worse than the pain, so I just keep going (9)
I try and carry on as normal ... you've got to ... I don't want to lose my dependence. I try and work through it (the pain) (13)
I force myself to go out every Saturday night. No matter how I feel ... if I didn't I would just sit at home and vegetate (13)

**Adapting**
I can't do what used do in the pantomime ... so I do other tasks (1)
I'm getting a talking PC at work (1)
Brain still working perfectly therefore you can adapt. I'm going to get a computer and write a novel. If I don't do anything to take over what I did before, then I'll just end up sitting passively at home, that the most horrible type of life (2)
You adapt over the years, you have to find other ways of doing things (e.g. to wring a dishcloth place dishcloth over a long spout and twist it round) (3)
There have to be a lot of adaptations e.g. during the school holidays I'll alternate my son going round to his friends and them coming to ours (6)
You've got to have all sorts of gadgets, everything is done differently (7)
It's no good saying 'I can't open that bottle, so I won't bother having it', you've got to find a way around things. You've got to think things through to find the way round it (7).
You just adjust your life to it (11)
Food processor has changed my life ... I don't know how I managed without it before (11)

I think that once you give in to this illness, that it ... there's no way they'll put me in a wheelchair ... I fight it...it gets me down sometimes, but I keep fighting (9)
I never think to the future, in another 10 years they might have a cure (10)
I take a day-to-day approach, why worry about the future when you could get knocked over by a bus tomorrow (10)
What motivates me to keep going and active, despite the pain, is the thought of being in a wheel chair (11)

**Pacing** (balancing activity and rest)
I have to keep sitting down when I'm on a day out...to have a rest (3)
If I'm going for a day out, the next day I would make sure that I'm able to rest (8)
I try and combine rest and activity ... resting all the time is not the right thing because I stiffen (10)

**Planning ahead/breaking tasks down**
With shopping, I'll do half of Bolton one week and the other half the next week (3)
I'll set myself little goals, for example, 'at 1 o'clock you will ...' (6)
I'll do double meals so if I'm having a bad day the next week a meal is prepared (6)
I do things in little bits rather than all at one (e.g. I took two days to put the Christmas tree up; wrapped up Christmas presents up as I bought them) (7)
Give myself more time to do things than I used to (8)
I tend to do the ironing a little every night because I can't handle a full pile and I know if I don't feel well today, I'll have double tomorrow (10)
You spread out what you have to do, you've plenty of time so do a bit each day (11)
Taking each day as it comes and breaking down tasks (12)

**Acceptance**
I've been through denial, the first five years I didn't accept RA, the last two years I've accepted it, I fight it still, but you need to accept that it's going to be there forever (6)
Just accepting it, you can't make it go away (12)
I think that I've accepted it, it won't go away, but it can be controlled (13)

**Humour**
I can laugh about it now (3)
I try not to let it affect me, I laugh and joke and see the funny side of it (10)

**Alternative**
I see a homeopath who helps me (5)
I have aromatherapy oils, for massage (9)
Acupuncture helps quite a lot with my neck pain (12)

**Knowing limitations**
At work, I stop when I've had enough (1)
I know my limitations and accept that I may suffer the next day for doing things (3)
I know the limits to what I can do (4)
I've learnt my limitations... as you get older you do (although it's taken me 29 years) (9)
When I'm having a flare-up, I think to myself 'no, I can't do that today', you know you should do it but you've got to learn to leave it for another day (10)
Knowing my limitations to what I can and cannot do (12)

**Thinking 'someone always worse off than you'**
It's a crippler, but it's not a killer like cancer... I don't know anyone that's died of it ... you're still here ... I could be a lot worse off (3)
You can always find someone worse off than yourself (4)
You see people worse off than yourself in the clinic (8)
When you come to the clinic, you tend to walk away and think 'well, I'm not that bad really' (10)
You've got to look around and see other people ... you see people a lot worse off than yourself... you see someone in a wheelchair and think 'well at least I can walk' ... it could be worse, I could have cancer (13)

**Religion**
My religious beliefs (5)

**Practical support**
My mum does my ironing (6)
My husband provides practical support (8)
The support from my husband – he does all the ironing and hoovering (13)

**Advice from other RA patients**
I do talk to other patients every week in the hospital (3)
You've got to listen to other people, because if they might have an easier way of doing things (7)

**TENS machine**
I use a TENS machine for the pain (8)
I use a TENS machine for the pain (11)

**Keeping warm/heat treatments**
Make sure that I'm warm (8)
When I'm having a flare-up I'll use a heat lamp (10)
The best thing for pain is lying with a bottle of hot water (11)
I keep my hands warm, were gloves, electric blanket (13)

**Splints**
I do use my splints (9)
If I/m in a lot of pain, I'll put my splints on for a day (10)
I use a neck support (13)

**Don't use emotional support to cope (never have done)**
I don't ever get any support from other people ... there just isn't any ... I have a natter with a friend, but I wouldn't bore her with it because it's not fair on her (3)
I don't talk as much as I used to (4)
I don't really get emotional support (7)
You've got to get on with life, you don't want to depress everybody (10)

**Physical exercise**
Manipulating joints and moving – even though it still produces pain, its still helps (2)
Always try and walk a little (4)
Joint exercises are very important (8)
Keeping moving and physically active has helped. I think that I haven't ended up like a lot of people who are in wheelchairs because I've kept moving (10)
I take the dog out for half an hour walk every morning ... If I have any pains when I start, by the time I've finished I feel so much better (11)
Keeping physically active helps e.g. swimming (12)
Emotional support
Helpful to see my CPN, regarding how I feel. Talking about RA helps when you're talking to someone who understands. Could easily get into a downward spiral, come out feeling better (2)
My friends are a sounding board which is really helpful (6)
Seeing and talking with others in the clinic ... feel that they are in the same position (8)
At the clinic other people feel like you ... it bucks you up because you know you're not on your own ... when you talk to healthy people, they don't understand (10)
Seeking support – I talk to my daughter (12)
I talk to people in my family (13)

**Keeping active**
You could sit in front of the TV and do nothing ... but what kind of life is that?...you might as well not exist (3)
I keep active by going on day-trips, they're worth it even if you feel bad the next day (3)
I'm going to keep doing things ...If I stop because it hurts then I might as well stop living because there is no point (7)
On a nice day I'll jump into the car and go up to the Yorkshire Dales (11)
I keep busy, do tapestries, build model aeroplanes, I'm currently learning the computer my son gave to me... You've got to keep going ... I feel better for being active (11)

**Do something to feel useful**
It is important to feel a sense of purpose, I still feel useful as I do work for the church (8)
I have my grandchild and niece around for tea every week and I'll cook for them, I also take an old aunt shopping every week (11)

**Rest**
When having a flare-up I will rest (3)
When I've had a busy day the day before I've learnt to rest (9)
When you're having a flare-up, there's not a lot you can really do except rest as much as possible (10)

**Increase medication**
When having a flare-up increase your medication (3)
When I'm having a flare-up I'll take more painkillers (10)

**Mental Attitude**
I don't feel that I'm ready to let it win .... so you fight it...you need determination (3)
I give myself positive thoughts each night to wake up to the day after (6)
You just have to get on with it ... because that's the only way that you can cope ... I don't think that giving up is the answer, if you give up, you don't cope (7)
You can't go round feeling sorry for yourself (8)

# Appendix 19

Frequency of strategies to use during a flare-up recommended by participants in semi-structured interview to use during a flare-up:

| Strategy suggested | Number of participants |
|---|---|
| Keep going/exercise - prevent stiffness | 4 |
| Alcohol | 1 |
| More rest | 10 |
| Medication | 2 |
| Silly to keep going | 1 |
| Heat (infra-red lamp) | 5 |
| Pacing/do things slowly | 3 |
| Aromatherapy bath | 1 |
| Splints | 1 |
| Get practical help off others | 1 |
| Emotional support | 1 |
| Know limitations | 1 |
| See doctor | 1 |
| Be optimistic, the arthritis will probably be alot better tomorrow | 1 |

Frequency of methods used to seek RA-related information reported by participants in the semi-structured interview.

| Method of information seeking | Number of participants |
|---|---|
| No/ Did initially, not now/ Know all I need to know i.e. what to do to prevent things | 5 |
| Information from nurses/doctor/hospital leaflets | 4 |
| Subscribe to Arthritis care only some relevant | 2 |
| Information from library | 2 |
| Information from people at clinic | 2 |

# Appendix 20

## Relationships between physical and psychological outcome using Pearson's correlation

| | | depression | anxiety | positive affect | NEWNA | HAQ | pain intensity | NEWESR |
|---|---|---|---|---|---|---|---|---|
| Pearson Correlation | depression | 1.000** | .633** | -.596** | .561** | .163 | .045 | -.231 |
| | anxiety | .633** | 1.000** | -.401** | .744** | .104 | .140 | -.159 |
| | positive affect | -.596** | -.401** | 1.000** | -.500** | .025 | -.053 | -.053 |
| | NEWNA | .561** | .744** | -.500** | 1.000** | .065 | .096 | .023 |
| | HAQ | .163 | .104 | .025 | .065 | 1.000** | .320* | .257 |
| | pain intensity | .045 | .140 | -.053 | .096 | .320* | 1.000** | .027 |
| | NEWESR | -.231 | -.159 | -.053 | .023 | .257 | .027 | 1.000** |
| Sig. (2-tailed) | depression | .000 | .000 | .000 | .000 | .258 | .761 | .169 |
| | anxiety | .000 | .000 | .005 | .000 | .470 | .338 | .348 |
| | positive affect | .000 | .005 | .000 | .000 | .869 | .726 | .763 |
| | NEWNA | .000 | .000 | .000 | .000 | .663 | .525 | .894 |
| | HAQ | .258 | .470 | .869 | .663 | .000 | .025 | .124 |
| | pain intensity | .761 | .338 | .726 | .525 | .025 | .000 | .876 |
| | NEWESR | .169 | .348 | .763 | .894 | .124 | .876 | .000 |
| N | depression | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | anxiety | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | positive affect | 47 | 47 | 47 | 47 | 47 | 46 | 35 |
| | NEWNA | 47 | 47 | 47 | 47 | 47 | 46 | 35 |
| | HAQ | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | pain intensity | 49 | 49 | 46 | 46 | 49 | 49 | 36 |
| | NEWESR | 37 | 37 | 35 | 35 | 37 | 36 | 37 |

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Meanings to the abbreviations used in Appendix 20 - 29

(NEW… = transformed variable)

NEWNA = negative affect

NEWESR = ESR

NEWDENIA = denial

NEWHUMOU = humour

NEWACCEP = acceptance

NEWRELIG = turning to religion

NEWLIM = knowing limitations

NEWADAPT = adapting to activities

NEWPHYSI = physical strategies

NEWALTER = alternative activities

# Appendix 21

## Relationships found between coping and outcome using Pearson's Correlation

| | | depression | anxiety | positive affect | NEWNA | HAQ | pain intensity | NEWESR |
|---|---|---|---|---|---|---|---|---|
| Pearson Correlation | self-distraction | -.484** | -.062 | .218 | -.084 | .273 | .198 | .132 |
| | active coping | -.111 | .202 | .263 | .031 | -.019 | .026 | .037 |
| | NEWDENIA | .043 | .047 | -.088 | .110 | .055 | -.057 | -.009 |
| | NEWALCOH | .312* | .414** | -.378** | .362* | -.291* | -.104 | -.171 |
| | emotional support | -.306* | -.205 | .221 | -.118 | .160 | .417** | .114 |
| | NEWBEHDI | .172 | .177 | -.349* | .237 | .098 | -.040 | -.036 |
| | venting | -.071 | .053 | -.074 | .184 | .183 | .213 | -.026 |
| | positive reframing | -.275 | -.223 | .411** | -.271 | -.120 | .025 | -.066 |
| | NEWHUMOU | -.391** | -.201 | .277 | -.240 | -.063 | -.006 | -.078 |
| | NEWACCEP | -.266 | -.145 | .085 | -.102 | .113 | .112 | .170 |
| | NEWRELIG | -.221 | .040 | -.262 | -.088 | -.047 | .231 | -.040 |
| | NEWLIM | -.121 | -.063 | -.095 | .003 | .069 | .118 | -.087 |
| | NEWADAPT | -.188 | -.121 | .250 | -.085 | .025 | -.136 | .068 |
| | NEWPHYSI | -.159 | -.205 | .261 | -.105 | .107 | .061 | .048 |
| | energy conservation | .231 | .097 | -.410** | .104 | .163 | .355* | .179 |
| | NEWALTER | -.179 | .036 | -.075 | -.109 | -.041 | .033 | -.075 |
| Sig. (2-tailed) | self-distraction | .000 | .667 | .141 | .573 | .055 | .173 | .435 |
| | active coping | .444 | .159 | .074 | .837 | .896 | .858 | .827 |
| | NEWDENIA | .769 | .744 | .556 | .460 | .704 | .695 | .956 |
| | NEWALCOH | .027 | .003 | .009 | .012 | .040 | .475 | .311 |
| | emotional support | .031 | .154 | .136 | .428 | .268 | .003 | .503 |
| | NEWBEHDI | .232 | .220 | .016 | .109 | .498 | .783 | .831 |
| | venting | .625 | .713 | .620 | .215 | .205 | .141 | .878 |
| | positive reframing | .054 | .120 | .004 | .065 | .408 | .864 | .696 |
| | NEWHUMOU | .005 | .162 | .060 | .105 | .662 | .967 | .645 |
| | NEWACCEP | .061 | .313 | .571 | .495 | .436 | .443 | .314 |
| | NEWRELIG | .124 | .782 | .075 | .556 | .744 | .111 | .815 |
| | NEWLIM | .402 | .662 | .527 | .985 | .632 | .420 | .607 |
| | NEWADAPT | .191 | .402 | .090 | .570 | .865 | .352 | .689 |
| | NEWPHYSI | .269 | .153 | .076 | .484 | .461 | .676 | .778 |
| | energy conservation | .106 | .502 | .004 | .486 | .257 | .012 | .290 |
| | NEWALTER | .213 | .805 | .617 | .467 | .775 | .822 | .661 |
| N | self-distraction | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | active coping | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWDENIA | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWALCOH | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | emotional support | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWBEHDI | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | venting | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | positive reframing | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWHUMOU | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWACCEP | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWRELIG | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWLIM | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWADAPT | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWPHYSI | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | energy conservation | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWALTER | 50 | 50 | 47 | 47 | 50 | 49 | 37 |

**Appendix 22** Relationships found between coping and control using Pearson's Correlation

| | | internal LOC | other people LOC | chance LOC | doctor LOC |
|---|---|---|---|---|---|
| Pearson Correlation | self-distraction | .037 | -.031 | .045 | .155 |
| | active coping | -.074 | .070 | -.265 | .246 |
| | NEWDENIA | .108 | .136 | .204 | -.329* |
| | NEWALCOH | -.372** | .025 | -.201 | .151 |
| | emotional support | .129 | .219 | .097 | .125 |
| | NEWBEHDI | -.176 | .181 | .187 | .088 |
| | venting | .335* | .319* | .081 | -.057 |
| | positive reframing | .406** | .009 | -.083 | -.117 |
| | NEWHUMOU | -.070 | -.035 | -.094 | .026 |
| | NEWACCEP | -.042 | -.125 | -.133 | .076 |
| | NEWRELIG | .137 | .062 | -.092 | -.114 |
| | NEWLIM | -.081 | -.113 | -.313* | .233 |
| | NEWADAPT | .024 | -.135 | -.102 | .094 |
| | NEWPHYSI | .219 | -.047 | .033 | .116 |
| | energy conservation | -.191 | .129 | -.185 | .329* |
| | NEWALTER | -.192 | -.039 | -.092 | .070 |
| Sig. (2-tailed) | self-distraction | .797 | .828 | .757 | .282 |
| | active coping | .609 | .630 | .063 | .085 |
| | NEWDENIA | .455 | .346 | .156 | .020 |
| | NEWALCOH | .008 | .861 | .161 | .295 |
| | emotional support | .370 | .126 | .503 | .387 |
| | NEWBEHDI | .221 | .209 | .194 | .542 |
| | venting | .017 | .024 | .577 | .694 |
| | positive reframing | .003 | .952 | .565 | .420 |
| | NEWHUMOU | .629 | .810 | .515 | .857 |
| | NEWACCEP | .773 | .387 | .359 | .601 |
| | NEWRELIG | .342 | .667 | .523 | .430 |
| | NEWLIM | .576 | .433 | .027 | .104 |
| | NEWADAPT | .867 | .351 | .479 | .517 |
| | NEWPHYSI | .126 | .746 | .818 | .422 |
| | energy conservation | .184 | .372 | .199 | .020 |
| | NEWALTER | .181 | .788 | .525 | .630 |
| N | self-distraction | 50 | 50 | 50 | 50 |
| | active coping | 50 | 50 | 50 | 50 |
| | NEWDENIA | 50 | 50 | 50 | 50 |
| | NEWALCOH | 50 | 50 | 50 | 50 |
| | emotional support | 50 | 50 | 50 | 50 |
| | NEWBEHDI | 50 | 50 | 50 | 50 |
| | venting | 50 | 50 | 50 | 50 |
| | positive reframing | 50 | 50 | 50 | 50 |
| | NEWHUMOU | 50 | 50 | 50 | 50 |
| | NEWACCEP | 50 | 50 | 50 | 50 |
| | NEWRELIG | 50 | 50 | 50 | 50 |
| | NEWLIM | 50 | 50 | 50 | 50 |
| | NEWADAPT | 50 | 50 | 50 | 50 |
| | NEWPHYSI | 50 | 50 | 50 | 50 |
| | energy conservation | 50 | 50 | 50 | 50 |
| | NEWALTER | 50 | 50 | 50 | 50 |

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

# Appendix 23

## Relationships between control and outcome; knowledge and outcome using Pearson's Correlation

| | | depression | anxiety | positive affect | NEWNA | HAQ | pain intensity | NEWESR |
|---|---|---|---|---|---|---|---|---|
| Pearson Correlation | internal LOC | -.168 | -.302* | .210 | -.198 | .004 | -.175 | -.169 |
| | other people LOC | .113 | .156 | -.216 | -.055 | -.001 | .177 | -.061 |
| | chance LOC | -.045 | -.099 | .024 | -.084 | .215 | .138 | -.014 |
| | doctor LOC | .059 | .077 | .002 | .004 | .147 | .044 | -.105 |
| | knowledge | -.192 | .013 | .319* | -.200 | .062 | .002 | -.224 |
| Sig. (2-tailed) | internal LOC | .243 | .033 | .157 | .182 | .978 | .229 | .319 |
| | other people LOC | .434 | .279 | .145 | .715 | .997 | .224 | .720 |
| | chance LOC | .758 | .496 | .872 | .575 | .134 | .343 | .934 |
| | doctor LOC | .682 | .595 | .990 | .980 | .307 | .762 | .537 |
| | knowledge | .197 | .929 | .031 | .183 | .679 | .992 | .189 |
| N | internal LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | other people LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | chance LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | doctor LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | knowledge | 47 | 47 | 46 | 46 | 47 | 46 | 36 |

## Appendix 24

Relationships between coping strategies and knowledge using Pearson's correlation

| | | knowledge |
|---|---|---|
| Pearson Correlation | self-distraction | .321* |
| | active coping | .397** |
| | NEWDENIA | -.310* |
| | NEWALCOH | -.128 |
| | emotional support | -.133 |
| | NEWBEHDI | -.399** |
| | venting | -.071 |
| | positive reframing | .061 |
| | NEWHUMOU | .279 |
| | NEWACCEP | .078 |
| | NEWRELIG | -.011 |
| | NEWLIM | .281 |
| | NEWADAPT | .299* |
| | NEWPHYSI | .098 |
| | energy conservation | -.070 |
| | NEWALTER | .217 |
| Sig. (2-tailed) | self-distraction | .028 |
| | active coping | .006 |
| | NEWDENIA | .034 |
| | NEWALCOH | .391 |
| | emotional support | .371 |
| | NEWBEHDI | .005 |
| | venting | .637 |
| | positive reframing | .683 |
| | NEWHUMOU | .058 |
| | NEWACCEP | .604 |
| | NEWRELIG | .942 |
| | NEWLIM | .056 |
| | NEWADAPT | .041 |
| | NEWPHYSI | .510 |
| | energy conservation | .639 |
| | NEWALTER | .142 |
| N | self-distraction | 47 |
| | active coping | 47 |
| | NEWDENIA | 47 |
| | NEWALCOH | 47 |
| | emotional support | 47 |
| | NEWBEHDI | 47 |
| | venting | 47 |
| | positive reframing | 47 |
| | NEWHUMOU | 47 |
| | NEWACCEP | 47 |
| | NEWRELIG | 47 |
| | NEWLIM | 47 |
| | NEWADAPT | 47 |
| | NEWPHYSI | 47 |
| | energy conservation | 47 |
| | NEWALTER | 47 |

# Appendix 25

## Relationships found between physical and psychological outcome using Spearman's Correlation

| | | | depression | anxiety | positive affect | NEWNA | HAQ | pain intensity | NEWESR |
|---|---|---|---|---|---|---|---|---|---|
| Spearman's rho | Correlation Coefficient | depression | 1.000 | .682** | -.629** | .554** | .146 | .106 | -.232 |
| | | anxiety | .682** | 1.000 | -.468** | .690** | .084 | .194 | -.118 |
| | | positive affect | -.629** | -.468** | 1.000 | -.540** | .011 | -.101 | -.021 |
| | | NEWNA | .554** | .690** | -.540** | 1.000 | .010 | .118 | .062 |
| | | HAQ | .146 | .084 | .011 | .010 | 1.000 | .245 | .259 |
| | | pain intensity | .106 | .194 | -.101 | .118 | .245 | 1.000 | .121 |
| | | NEWESR | -.232 | -.118 | -.021 | .062 | .259 | .121 | 1.000 |
| | Sig. (2-tailed) | depression | . | .000 | .000 | .000 | .313 | .470 | .167 |
| | | anxiety | .000 | . | .001 | .000 | .560 | .181 | .487 |
| | | positive affect | .000 | .001 | . | .000 | .941 | .504 | .903 |
| | | NEWNA | .000 | .000 | .000 | . | .948 | .434 | .722 |
| | | HAQ | .313 | .560 | .941 | .948 | . | .090 | .121 |
| | | pain intensity | .470 | .181 | .504 | .434 | .090 | . | .483 |
| | | NEWESR | .167 | .487 | .903 | .722 | .121 | .483 | . |
| | N | depression | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | | anxiety | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | | positive affect | 47 | 47 | 47 | 47 | 47 | 46 | 35 |
| | | NEWNA | 47 | 47 | 47 | 47 | 47 | 46 | 35 |
| | | HAQ | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | | pain intensity | 49 | 49 | 46 | 46 | 49 | 49 | 36 |
| | | NEWESR | 37 | 37 | 35 | 35 | 37 | 36 | 37 |

**. Correlation is significant at the .01 level (2-tailed).

# Appendix 26

## Relationships found between coping and outcome using Spearman's Correlation

| | | depression | anxiety | positive affect | NEWNA | HAQ | pain intensity | NEWESR |
|---|---|---|---|---|---|---|---|---|
| Correlation Coefficient | self-distraction | -.410** | -.083 | .244 | -.105 | .241 | .187 | .127 |
| | active coping | -.050 | .215 | .286 | .019 | -.052 | .074 | .018 |
| | NEWDENIA | .056 | 013 | -.041 | .148 | .087 | -.050 | -.011 |
| | NEWALCOH | .259 | .339* | -.327* | .322* | -.300* | -.112 | -.152 |
| | emotional support | -.248 | -.190 | .239 | -.122 | .203 | .406** | .149 |
| | NEWBEHDI | .104 | .160 | -.292* | .230 | .108 | -.058 | -.058 |
| | venting | -.079 | .002 | -.055 | .186 | .205 | .267 | -.015 |
| | positive reframing | -.300* | -.250 | .426** | -.217 | -.089 | .058 | -.100 |
| | NEWHUMOU | -.416** | -.134 | .318* | -.239 | -.085 | -.019 | -.085 |
| | NEWACCEP | -.243 | -.119 | .104 | -.064 | .064 | .137 | .179 |
| | NEWRELIG | -.214 | .021 | .245 | -.083 | -.049 | .240 | -.033 |
| | NEWLIM | -.146 | .094 | -.058 | .003 | .045 | .117 | -.059 |
| | NEWADAPT | -.188 | -.137 | .278 | -.085 | .035 | -.135 | .072 |
| | NEWPHYSI | -.107 | -.163 | .321* | -.080 | .078 | .016 | .040 |
| | energy conservation | .231 | .154 | -.364* | .126 | .054 | .355* | .103 |
| | NEWALTER | -.133 | .137 | -.072 | -.106 | -.072 | .036 | -.083 |
| Sig. (2-tailed) | self-distraction | .003 | .568 | .098 | .482 | .091 | .199 | .453 |
| | active coping | .732 | .133 | .052 | .899 | .720 | .614 | .915 |
| | NEWDENIA | .702 | .930 | .786 | .320 | .547 | .735 | .950 |
| | NEWALCOH | .070 | .016 | .025 | .027 | .034 | .444 | .369 |
| | emotional support | .082 | .185 | .106 | .415 | .158 | .004 | .380 |
| | NEWBEHDI | .470 | .267 | .046 | .119 | .455 | .693 | .733 |
| | venting | .588 | .991 | .715 | .211 | .152 | .064 | .928 |
| | positive reframing | .034 | .079 | .003 | .143 | .537 | .692 | .557 |
| | NEWHUMOU | .003 | .355 | .030 | .105 | .559 | .896 | .619 |
| | NEWACCEP | .089 | .411 | .486 | .670 | .661 | .349 | .288 |
| | NEWRELIG | .135 | .883 | .097 | .581 | .733 | .097 | .848 |
| | NEWLIM | .310 | .518 | .696 | .986 | .756 | .424 | .728 |
| | NEWADAPT | .191 | .342 | .058 | .569 | .809 | .357 | .672 |
| | NEWPHYSI | .459 | .259 | .028 | .595 | .591 | .912 | .813 |
| | energy conservation | .106 | .287 | .012 | .398 | .711 | .012 | .546 |
| | NEWALTER | .356 | .342 | .631 | .480 | .620 | .808 | .627 |
| N | self-distraction | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | active coping | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWDENIA | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWALCOH | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | emotional support | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWBEHDI | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | venting | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | positive reframing | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWHUMOU | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWACCEP | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWRELIG | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWLIM | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWADAPT | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWPHYSI | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | energy conservation | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | NEWALTER | 50 | 50 | 47 | 47 | 50 | 49 | 37 |

**. Correlation is significant at the .01 level (2-tailed).

# Appendix 27

## Relationships found between coping and control using Spearman's Correlation

| | | | internal LOC | other people LOC | chance LOC | doctor LOC |
|---|---|---|---|---|---|---|
| Spearman's rho | Correlation Coefficient | self-distraction | .051 | -.026 | .019 | .097 |
| | | active coping | -.072 | .078 | -.284* | .214 |
| | | NEWDENIA | .070 | .078 | .229 | -.339* |
| | | NEWALCOH | -.382** | .035 | -.223 | .176 |
| | | emotional support | .063 | .220 | .094 | .154 |
| | | NEWBEHDI | -.204 | .181 | .206 | .099 |
| | | venting | .322* | .351* | .141 | -.086 |
| | | positive reframing | .411** | -.010 | -.036 | -.147 |
| | | NEWHUMOU | -.082 | -.008 | -.150 | .080 |
| | | NEWACCEP | -.019 | -.103 | -.126 | .032 |
| | | NEWRELIG | .085 | .054 | -.003 | -.147 |
| | | NEWLIM | -.067 | -.089 | -.362** | .199 |
| | | NEWADAPT | .025 | -.155 | -.107 | .071 |
| | | NEWPHYSI | -.243 | .071 | .015 | -.043 |
| | | energy conservation | -.223 | .098 | -.191 | .335* |
| | | NEWALTER | -.121 | -.006 | -.124 | .005 |
| | Sig. (2-tailed) | self-distraction | .726 | .856 | .894 | .501 |
| | | active coping | .621 | .589 | .046 | .136 |
| | | NEWDENIA | .631 | .589 | .110 | .016 |
| | | NEWALCOH | .006 | .811 | .120 | .220 |
| | | emotional support | .665 | .126 | .515 | .284 |
| | | NEWBEHDI | .156 | .209 | .152 | .493 |
| | | venting | .023 | .012 | .329 | .551 |
| | | positive reframing | .003 | .945 | .806 | .307 |
| | | NEWHUMOU | .572 | .956 | .298 | .582 |
| | | NEWACCEP | .896 | .478 | .383 | .827 |
| | | NEWRELIG | .557 | .711 | .982 | .308 |
| | | NEWLIM | .642 | .541 | .010 | .166 |
| | | NEWADAPT | .861 | .281 | .461 | .624 |
| | | NEWPHYSI | .088 | .625 | .919 | .767 |
| | | energy conservation | .119 | .497 | .183 | .018 |
| | | NEWALTER | .403 | .968 | .391 | .972 |
| | N | self-distraction | 50 | 50 | 50 | 50 |
| | | active coping | 50 | 50 | 50 | 50 |
| | | NEWDENIA | 50 | 50 | 50 | 50 |
| | | NEWALCOH | 50 | 50 | 50 | 50 |
| | | emotional support | 50 | 50 | 50 | 50 |
| | | NEWBEHDI | 50 | 50 | 50 | 50 |
| | | venting | 50 | 50 | 50 | 50 |
| | | positive reframing | 50 | 50 | 50 | 50 |
| | | NEWHUMOU | 50 | 50 | 50 | 50 |
| | | NEWACCEP | 50 | 50 | 50 | 50 |
| | | NEWRELIG | 50 | 50 | 50 | 50 |
| | | NEWLIM | 50 | 50 | 50 | 50 |
| | | NEWADAPT | 50 | 50 | 50 | 50 |
| | | NEWPHYSI | 50 | 50 | 50 | 50 |
| | | energy conservation | 50 | 50 | 50 | 50 |
| | | NEWALTER | 50 | 50 | 50 | 50 |

# Appendix 28

## Relationships between control and outcome; knowledge and outcome using Spearman's Correlation

| | | depression | anxiety | positive affect | NEWNA | HAQ | pain intensity | NEWESR |
|---|---|---|---|---|---|---|---|---|
| Correlation Coefficient | internal LOC | -.178 | -.325* | .228 | -.196 | -.010 | -.191 | -.199 |
| | other people LOC | .153 | .221 | -.220 | -.028 | .053 | .204 | -.047 |
| | chance LOC | -.051 | -.161 | -.024 | -.060 | .269 | .116 | -.032 |
| | doctor LOC | .144 | .117 | -.024 | .036 | .206 | .093 | -.066 |
| | knowledge | -.107 | .079 | .268 | -.163 | .044 | .012 | -.223 |
| Sig. (2-tailed) | internal LOC | .216 | .021 | .123 | .186 | .944 | .188 | .238 |
| | other people LOC | .288 | .122 | .137 | .851 | .716 | .160 | .784 |
| | chance LOC | .726 | .264 | .873 | .689 | .059 | .427 | .852 |
| | doctor LOC | .317 | .420 | .871 | .812 | .152 | .525 | .699 |
| | knowledge | .475 | .598 | .071 | .278 | .771 | .936 | .192 |
| N | internal LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | other people LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | chance LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | doctor LOC | 50 | 50 | 47 | 47 | 50 | 49 | 37 |
| | knowledge | 47 | 47 | 46 | 46 | 47 | 46 | 36 |

*. Correlation is significant at the 0.05 level (2-tailed).

# Appendix 29

Relationships between coping strategies and knowledge using Spearman's correlation

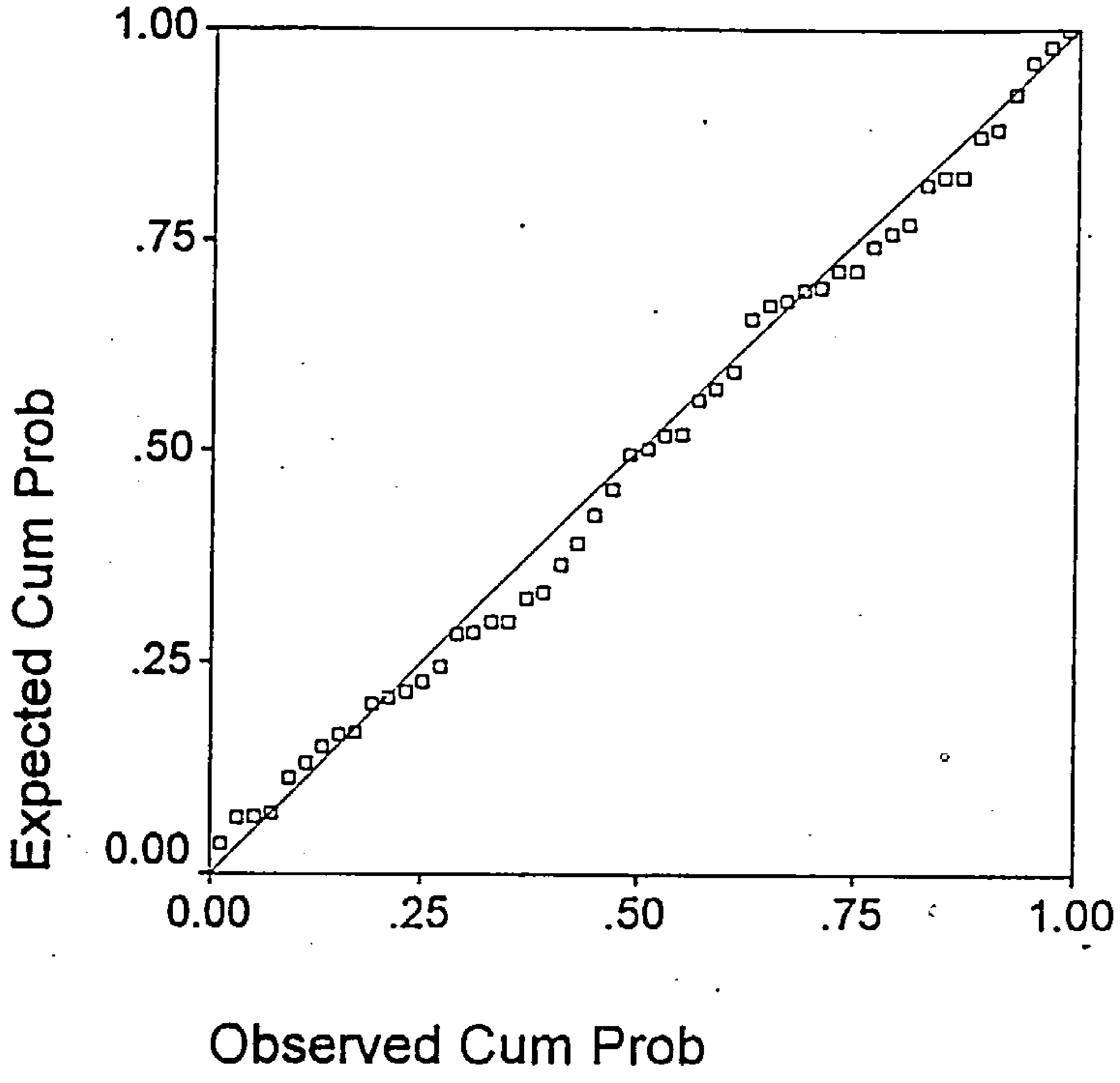
| | | | knowledge |
|---|---|---|---|
| Spearman's rho | Correlation Coefficient | self-distraction | .295* |
| | | active coping | .374** |
| | | NEWDENIA | -.296* |
| | | NEWALCOH | -.042 |
| | | emotional support | -.179 |
| | | NEWBEHDI | -.391** |
| | | venting | -.099 |
| | | positive reframing | .031 |
| | | NEWHUMOU | .305* |
| | | NEWACCEP | .068 |
| | | NEWRELIG | -.053 |
| | | NEWLIM | .288* |
| | | NEWADAPT | -.305* |
| | | NEWPHYSI | .074 |
| | | energy conservation | -.006 |
| | | NEWALTER | .227 |
| Spearman's rho | Sig. (2-tailed) | self-distraction | .044 |
| | | active coping | .010 |
| | | NEWDENIA | .043 |
| | | NEWALCOH | .779 |
| | | emotional support | .229 |
| | | NEWBEHDI | .007 |
| | | venting | .507 |
| | | positive reframing | .839 |
| | | NEWHUMOU | .037 |
| | | NEWACCEP | .648 |
| | | NEWRELIG | .724 |
| | | NEWLIM | .050 |
| | | NEWADAPT | .037 |
| | | NEWPHYSI | .619 |
| | | energy conservation | .966 |
| | | NEWALTER | .125 |
| | N | self-distraction | 47 |
| | | active coping | 47 |
| | | NEWDENIA | 47 |
| | | NEWALCOH | 47 |
| | | emotional support | 47 |
| | | NEWBEHDI | 47 |
| | | venting | 47 |
| | | positive reframing | 47 |
| | | NEWHUMOU | 47 |
| | | NEWACCEP | 47 |
| | | NEWRELIG | 47 |
| | | NEWLIM | 47 |
| | | NEWADAPT | 47 |
| | | NEWPHYSI | 47 |
| | | energy conservation | 47 |
| | | NEWALTER | 47 |

*. Correlation is significant at the .05 level (2-tailed).

# Appendix 30

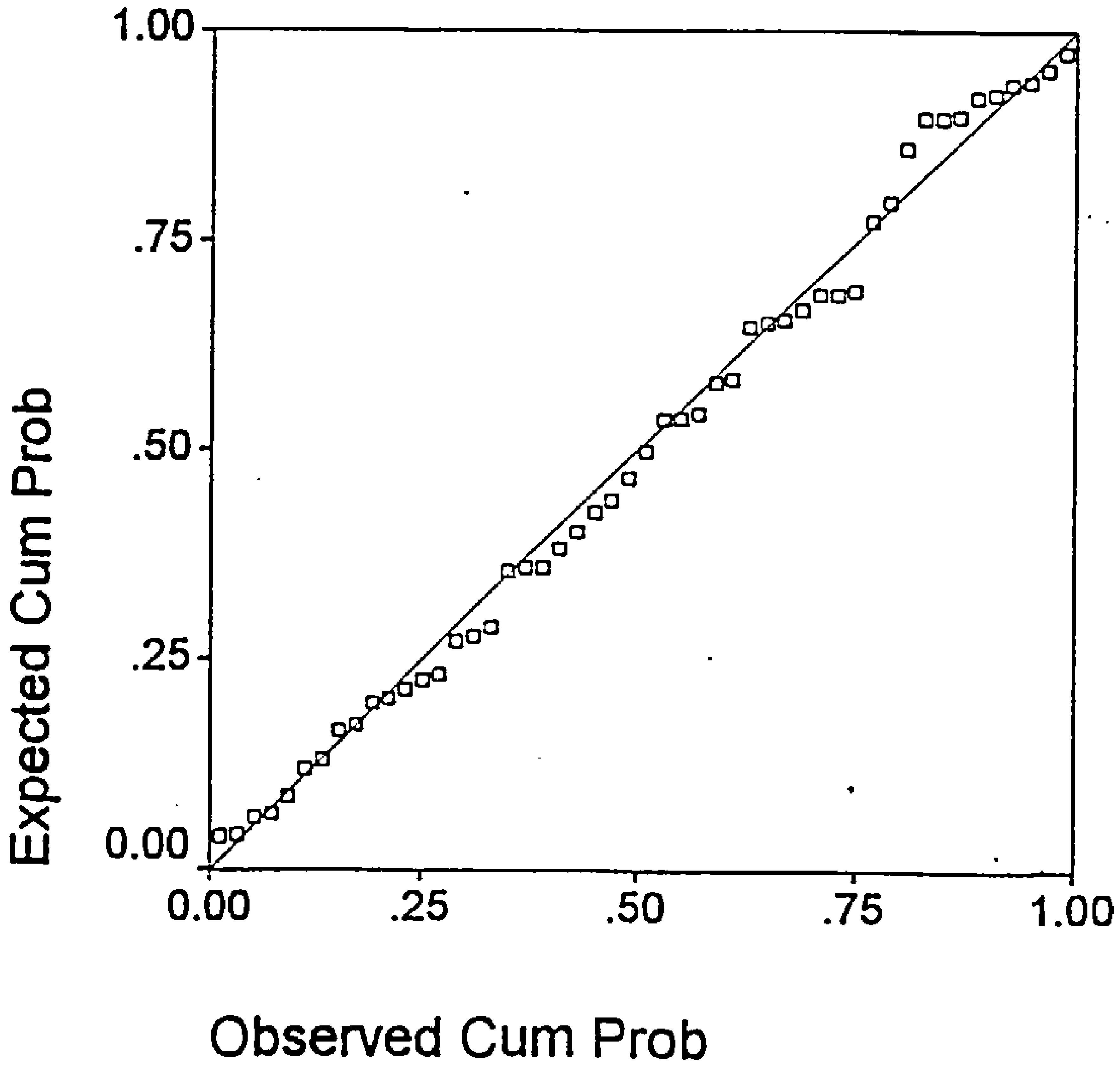
Scatterplot for Regression Equation

Dependent Variable: Anxiety



Scatterplot for Regression Equation

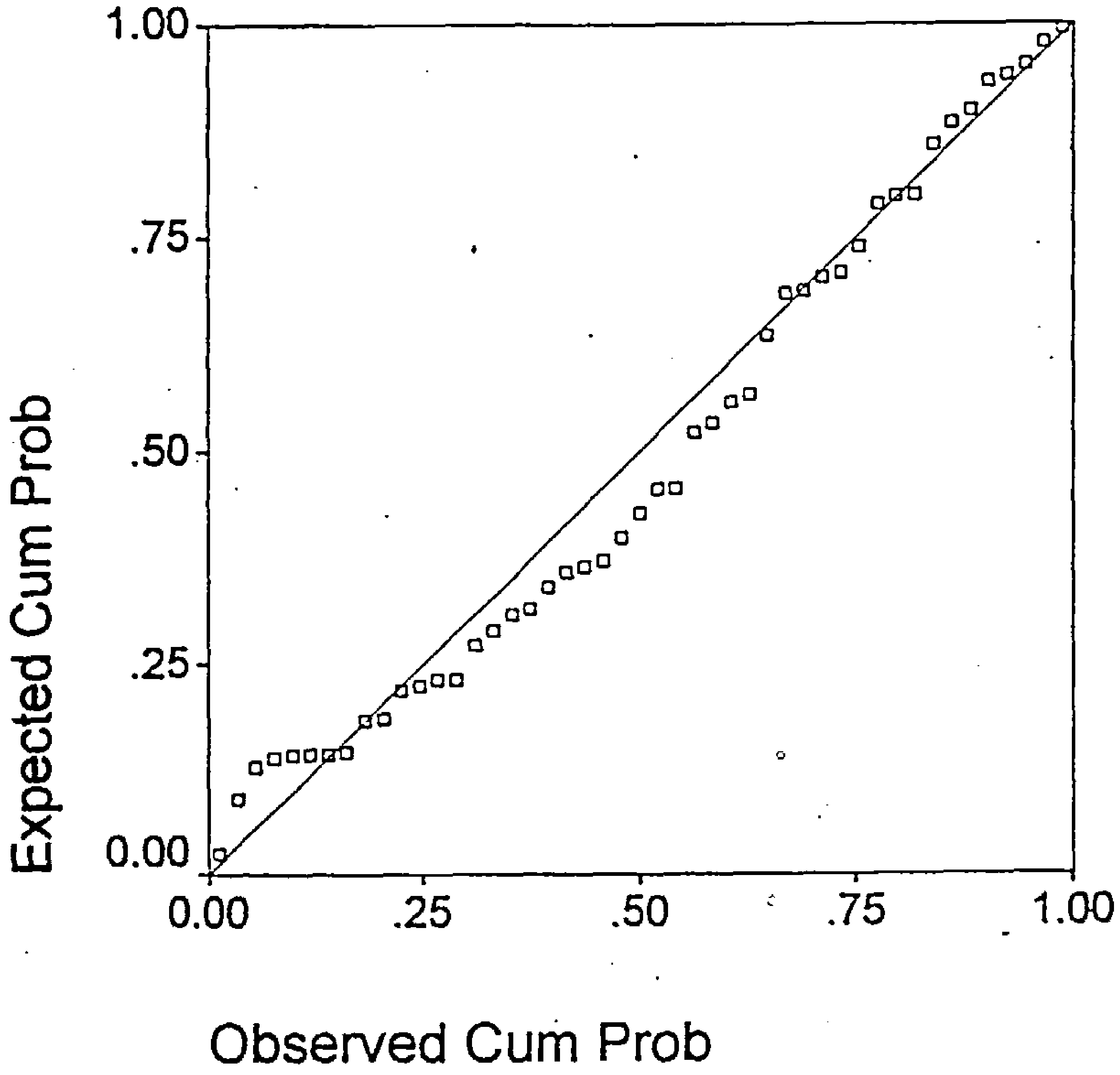
Dependent Variable: depression



# Appendix 31

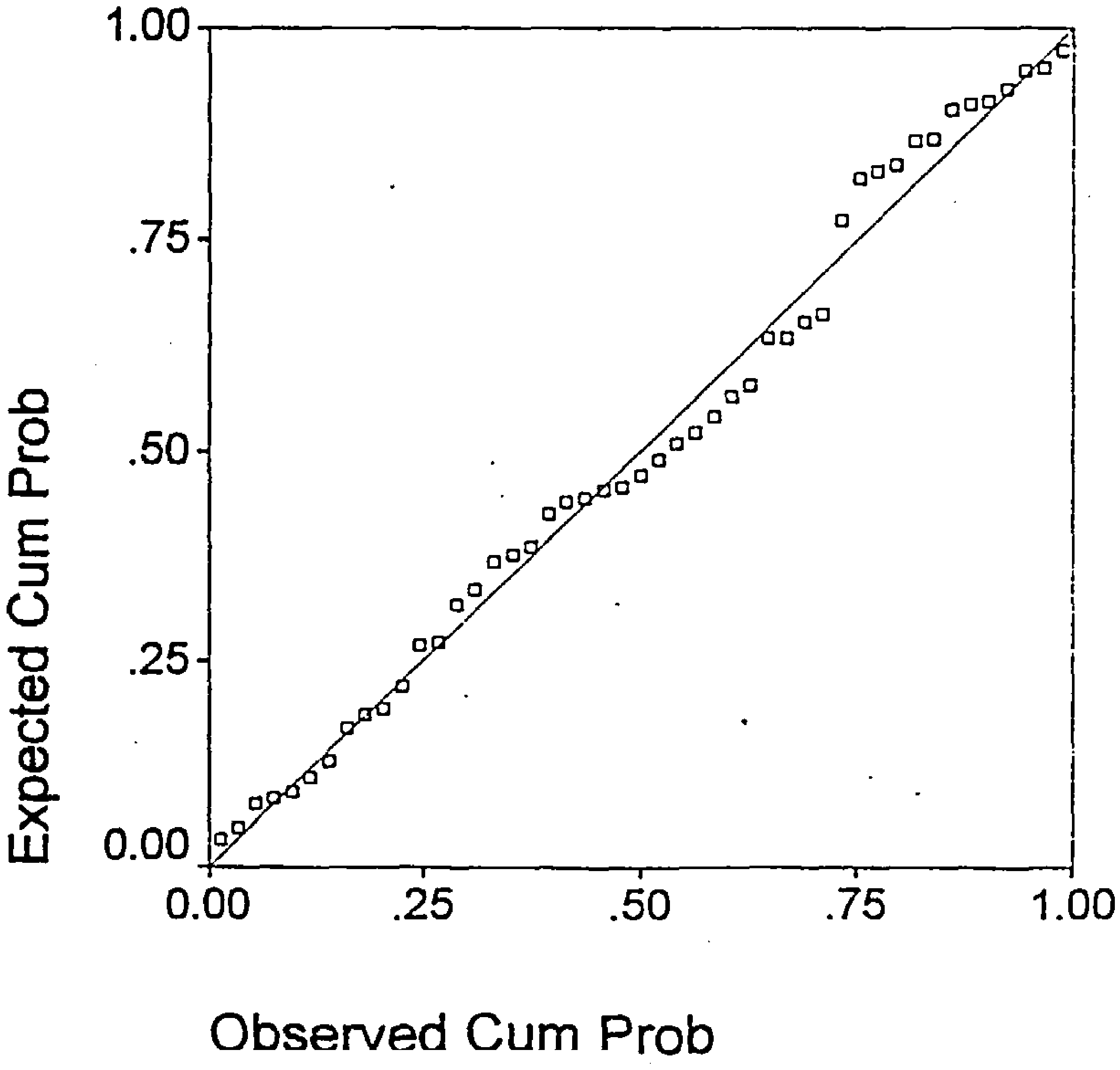
Scatterplot for Regression Equation

Dependent Variable: Negative Affect

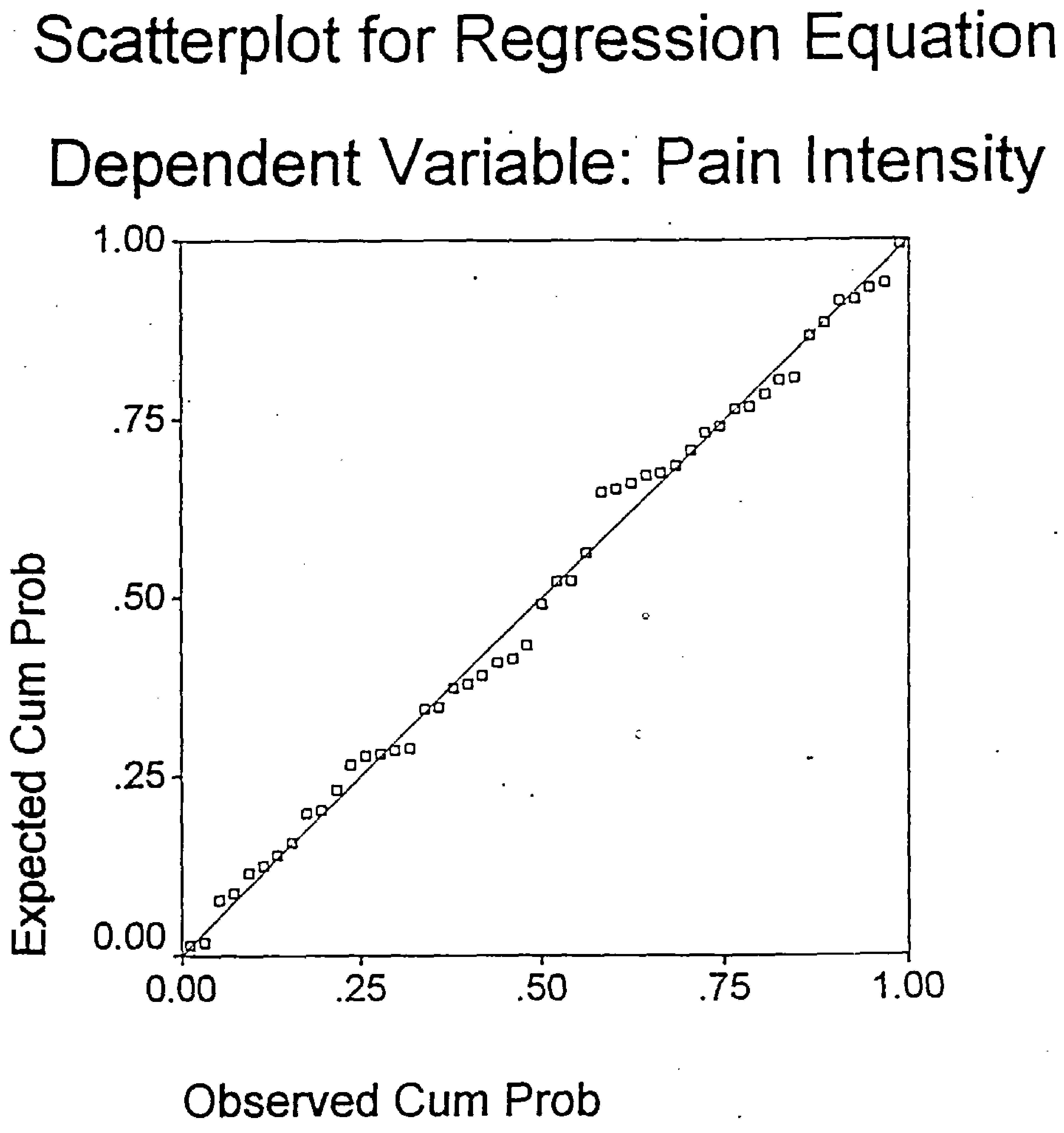


Scatterplot for Regression Equation

Dependent Variable: Positive Affect



## Appendix 32


Scatterplot for Regression Equation
Dependent Variable: Pain Intensity
1.00
.75
.50
.25
0.00
Expected Cum Prob
0.00
.25
.50
.75
1.00
Observed Cum Prob

## Appendix 33

## Stresses Questionnaire

**To what extent have the following aspects of your arthritis caused you distress or bothered you over the past week?**

| | Never | A little | Sometimes | Mostly | Always |
|---|---|---|---|---|---|
| Loss of physical mobility | ☐ | ☐ | ☐ | ☐ | ☐ |
| Pain | ☐ | ☐ | ☐ | ☐ | ☐ |
| Side-effects of medication | ☐ | ☐ | ☐ | ☐ | ☐ |
| Loss of earnings | ☐ | ☐ | ☐ | ☐ | ☐ |
| Unpredictability of disease | ☐ | ☐ | ☐ | ☐ | ☐ |
| Thinking about the future | ☐ | ☐ | ☐ | ☐ | ☐ |
| Effect on family/relationships | ☐ | ☐ | ☐ | ☐ | ☐ |
| Change of physical appearance | ☐ | ☐ | ☐ | ☐ | ☐ |
| Fear of children getting arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| Sexual problems resulting from physical problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| Losing contact with people | ☐ | ☐ | ☐ | ☐ | ☐ |
| Other stresses ................ | ☐ | ☐ | ☐ | ☐ | ☐ |

## Appendix 34

## Illness Perception Questionnaire

Please indicate how frequently you experience the following symptoms as part of your Rheumatoid Arthritis:

| | All of the time | Frequently | Occasionally | Never |
|---|---|---|---|---|
| Pain | | | | |
| Nausea | | | | |
| Breathlessness | | | | |
| Weight loss | | | | |
| Fatigue | | | | |
| Stiff joints | | | | |
| Sore eyes | | | | |
| Headaches | | | | |
| Upset stomach | | | | |
| Sleep difficulties | | | | |
| Dizziness | | | | |
| Loss of Strength | | | | |
| Loss of appetite | | | | |
| Swollen joints | | | | |
| Night sweats | | | | |
| Other | | | | |

We are interested in your own personal views of how you now see your rheumatoid arthritis. Please indicate how much you agree or disagree with the following statements about your rheumatoid arthritis.

| | Strongly agree | Agree | Neither agree or disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 1. Other people played a large role in causing my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2. Diet played a role in causing my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3. My arthritis has serious economic and financial consequences | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4. My arthritis has not had much effect on my life | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. My state of mind played a major part in causing my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| 6. What I do can determine whether my arthritis gets better or worse | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. My arthritis has become easier to live with | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8. A germ or virus caused my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |

| | Strongly agree | Agree | Neither agree or disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 9. My arthritis will improve with time | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10. My arthritis has strongly affected the way I see myself as a person | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11. Stress was a major factor in causing my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| 12. My arthritis has strongly affected the way others see me | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13. My arthritis is a serious condition | ☐ | ☐ | ☐ | ☐ | ☐ |
| 14. Recovery from my arthritis is largely dependent on chance or fate | ☐ | ☐ | ☐ | ☐ | ☐ |
| 15. There is a lot I can do to control my symptoms | ☐ | ☐ | ☐ | ☐ | ☐ |
| 16. My arthritis is largely due to my own behaviour | ☐ | ☐ | ☐ | ☐ | ☐ |
| 17. My treatment will be effective in curing my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| 18 My arthritis was caused by poor medical care in the past | ☐ | ☐ | ☐ | ☐ | ☐ |
| 19. My arthritis has had a major consequence on my life | ☐ | ☐ | ☐ | ☐ | ☐ |
| 20. There is very little that can be done to improve my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| 21. It was just by chance that I became ill | ☐ | ☐ | ☐ | ☐ | ☐ |
| 22. My arthritis will last a short time | ☐ | ☐ | ☐ | ☐ | ☐ |
| 23. Pollution of the environment caused my arthritis | ☐ | ☐ | ☐ | ☐ | ☐ |
| 24. My arthritis is likely to be permanent rather than temporary | ☐ | ☐ | ☐ | ☐ | ☐ |
| 25. My arthritis will last for a long time | ☐ | ☐ | ☐ | ☐ | ☐ |
| 26. My arthritis is hereditary - it runs in the family | ☐ | ☐ | ☐ | ☐ | ☐ |

## Appendix 35

## Generalised Self-Efficacy Scale

1 = Not at all true
2 = Barely true
3 = Moderately true
4 = Exactly true

| | | | | |
|---|---|---|---|---|
| 1. I can always manage to solve difficult problems if I try hard enough | 1 | 2 | 3 | 4 |
| 2. If someone opposes me, I can find means and ways to get what I want | 1 | 2 | 3 | 4 |
| 3. It is easy for me to stick to my aims and accomplish my goals | 1 | 2 | 3 | 4 |
| 4. I am confident that I could deal efficiently with unexpected events | 1 | 2 | 3 | 4 |
| 5. Thanks to my resourcefulness, I know how to handle unforeseen situations | 1 | 2 | 3 | 4 |
| 6. I can solve most problems if I invest the necessary effort | 1 | 2 | 3 | 4 |
| 7. I can remain calm when facing difficulties because I can rely on my coping abilities | 1 | 2 | 3 | 4 |
| 8. When I an confronted with a problem, I can usually find several solutions | 1 | 2 | 3 | 4 |
| 9. If I am in a bind, I can usually think of something to do | 1 | 2 | 3 | 4 |
| 10. No matter what comes my way, I'm usually able to handle it. | 1 | 2 | 3 | 4 |

## Appendix 36

# COPE

Name:............................................................ ............................................................

Date:............................................................ Record Number:............................................................

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.
Then respond to each of the following items by choosing one number for each, using the response choices listed just below.

| | |
|---|---|
| 1 = I usually don't do this at all. | 2 = I usually do this a little bit. |
| 3 = I usually do this a medium amount. | 4 = I usually do this a lot. |

Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for YOU – not what you think 'most people' would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1. I try to grow as a person as a result of the experience. ☐
2. I turn to work or other substitute activities to take my mind off things. ☐
3. I get upset and let my emotions out. ☐
4. I try to get advice from someone about what to do. ☐
5. I concentrate my efforts on doing something about it. ☐
6. I say to myself "this isn't real". ☐
7. I put my trust in God. ☐
8. I laugh about the situation. ☐
9. I admit to myself that I can't deal with it, and give up trying. ☐
10. I restrain myself from doing anything too quickly. ☐

11. I discuss my feelings with someone. ☐
12. I use alcohol or drugs to make myself feel better. ☐
13 I get used to the idea that it happened. ☐
14. I talk to someone to find out more about the situation. ☐
15. I keep myself from getting distracted by other thoughts or activities. ☐
16. I daydream about things other than this. ☐
17. I get upset, and am really aware of it. ☐
18. I seek God's help. ☐
19. I make a plan of action. ☐
20. I make jokes about it. ☐

21. I accept that this has happened and that it can't be changed.
22. I hold off doing anything about it until the situation permits.
23. I try to get emotional support from friends and relatives.
24. I just give up trying to reach my goal.
25. I take additional action to try to get rid of the problem.
26. I try to lose myself for a while by drinking alcohol or taking drugs.
27. I refuse to believe that it has happened.
28. I let my feelings out.
29. I try to see it in a different light, to make it seem more positive.
30. I talk to someone who could do something concrete about the problem.

31. I sleep more than usual.
32. I try to come up with a strategy about what to do.
33. I focus on dealing with this problem and, if necessary, let other things slide a little.
34. I get sympathy and understanding from someone.
35. I drink alcohol or take drugs, in order to think about it less.
36. I kid around about it.
37. I give up the attempt to get what I want.
38. I look for something good in what is happening.
39. I think about how I might best handle the problem.
40. I pretend that it hasn't really happened.

41. I make sure not to make matters worse by acting too soon.
42. I try hard to prevent other things from interfering with my efforts at dealing with this.
43. I go to the cinema or watch television, to think about it less.
44. I accept the reality of the fact that it happened.
45. I ask people who have had similar experiences what they did.
46. I feel a lot of emotional distress and I find myself expressing those feelings a lot.
47. I take direct action to get around the problem.
48. I try to find comfort in my religion.
49. I force myself to wait for the right time to do something.
50. I make fun of the situation.

51. I reduce the amount of effort I'm putting into solving the problem.
52. I talk to someone about how I feel.
53. I use alcohol or drugs to help me get through it.
54. I learn to live with it.
55. I put aside other activities in order to concentrate on this.
56. I think hard about what steps to take.
57. I act as though it hasn't even happened.
58. I do what has to be done, one step at a time.
59. I learn something from the experience.
60. I pray more than usual.

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Appendix 37

# SIGNIFICANT OTHERS SCALE (B)

Name: ........................................................................................................

Date: .............................................................. Record Number: ..........................................

## Instructions

Please list below up to seven people who may be important in the individual's life. Typical relationships include partner, mother, father, child, sibling, close friends, plus keyworker. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed.

The second part of each question asks you to rate how individuals would like things to be if they were exactly as they hoped for. As before, please put a circle around one number between 1 and 7 to show what the rating is.

### Person 1 – ..........................................................................

| | | *Never* | | | *Sometimes* | | | *Always* |
|---|---|---|---|---|---|---|---|---|
| 1 | a) Can you trust, talk to frankly and share your feelings with this person? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | a) Can you lean on and turn to this person in times of difficulty? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | a) Does he/she give you practical help? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | a) Can you spend time with him/her socially? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

### Person 2 – ..........................................................................

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 1 | a) Can you trust, talk to frankly and share your feelings with this person? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | a) Can you lean on and turn to this person in times of difficulty? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | a) Does he/she give you practical help? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | a) Can you spend time with him/her socially? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

### Person 3 – ..........................................................................

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 1 | a) Can you trust, talk to frankly and share your feelings with this person? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | a) Can you lean on and turn to this person in times of difficulty? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | a) Does he/she give you practical help? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | a) Can you spend time with him/her socially? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION**

## Person 4 – ..........

| | | Never | | | Sometimes | | | Always |
|---|---|---|---|---|---|---|---|---|
| 1 | a) Can you trust, talk to frankly and share your feelings with this person? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | a) Can you lean on and turn to this person in times of difficulty? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | a) Does he/she give you practical help? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | a) Can you spend time with him/her socially? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

## Person 5 – ..........

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 1 | a) Can you trust, talk to frankly and share your feelings with this person? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | a) Can you lean on and turn to this person in times of difficulty? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | a) Does he/she give you practical help? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | a) Can you spend time with him/her socially? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

## Person 6 – ..........

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 1 | a) Can you trust, talk to frankly and share your feelings with this person? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | a) Can you lean on and turn to this person in times of difficulty? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | a) Does he/she give you practical help? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | a) Can you spend time with him/her socially? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

## Person 7 – ..........

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 1 | a) Can you trust, talk to frankly and share your feelings with this person? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | a) Can you lean on and turn to this person in times of difficulty? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | a) Does he/she give you practical help? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | a) Can you spend time with him/her socially? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | b) What rating would your ideal be? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION**

## Appendix 38

# Information sheet

I am a trainee clinical psychologist in my final year of a three-year training course. As part of my training, I am required to carry out some research and I would like to invite you to take part in this research.

The research to be carried out has been approved by the Local Research Ethics Committee appointed by the Health Authority. This does not imply any endorsement.

### What is the research about?

In this study I am interested in looking at the factors involved in coping and managing rheumatoid arthritis. The areas that I am most interested in looking at are: which aspects of arthritis people think are most stressful; how people think about their rheumatoid arthritis; the social support that people get; the different ways of coping that people use and how they are currently functioning.

I hope that this information will help identify the processes that are involved in living with a chronic illness. This information might then assist us to develop ways of helping individuals manage rheumatoid arthritis.

### What will happen?

If you agree to take part in the study after you have read this information sheet, an appointment to come and see me will be arranged. When we meet you will be able to ask any questions or express any concerns about the research. I will then ask you to sign a consent form.
You will then be asked to complete a number of short questionnaires related to the topics described above.

I will be also asking you for permission to obtain some information taken by the nurse at your assessment appointment. This will only include information from the Health Assessment Questionnaire, your grip strength score, joint tenderness count and levels of ESR in your blood.

### What will happen to the information that you give?

All the information will be held in the strictest confidence and will not be discussed with anyone.

### What if you don't want to take part?

We understand that some people will not want to take part in a research project and you have every right to decline.
**You are not obliged to participate in the research. If you decide not to participate in the study this will not affect your treatment at the Rheumatology unit.**

### What if you change your mind?

If at any stage you wish to discontinue your participation in this study this decision will be respected immediately.

**Thank-you for your help**

**(Clinical Psychologist in Training) Telephone: 01253 763232 ext. 249**

## Appendix 39

### Research Consent Form

**An Investigation into the Cognitive and Psychosocial Factors in Adjustment to Rheumatoid Arthritis.**

**Please answer the questions below by circling your response:**

| | |
|---|---|
| Have you received and read an information sheet? | YES/NO |
| Have you had a chance to ask questions about the study? | YES/NO |
| Are you satisfied that your questions have been answered? | YES/NO |
| Have you received enough information about the study? | YES/NO |
| Do you understand that you are free to withdraw of the study at any time and without having to give a reason for withdrawing? | YES/NO |
| Do you agree to take part in this study? | YES/NO |
| Do you give permission for the following information obtained in the assessment appointment to be used in this study: grip strength score, joint tenderness count and ESR level? | YES/NO |

**Signed**.............................................................. **Date**..............................

## Appendix 40

### Additional RA stressors generated from participants in the pilot study

Fatigue/tiredness
Deformity caused by RA
Gradual loss of physical skills (e.g. personal care losses, unable to drive a care)
Prevented from performing activities at home/work/leisure
Adherence to medication and other therapies
Misunderstood by others who do not appreciate difficulties
Having to tell someone that you cannot do something
People asking how you are when don't want to be reminded
Uncertain about making plans for taking part in different activities e.g. booking holidays – having to constantly plan ahead if going out/on holiday
Depression
Anxiety
Loneliness
Feelings of guilt
Feeling labelled by others
Sense of loss (wishes unfulfilled)
Loss of dignity
Self-image (attractiveness, fitness, how you feel about yourself e.g. embarrassment at buying shoes/hiding hands and not wearing rings/ looking older/ never feel dressed up or look best – special occasions stressful because flat shoes out of place)
The feeling to have lost control over one's life
Loss of self-esteem
Disease is hard to accept
Sense of not being useful
Fear of falling over with replacement and not being able to get back up
Resentment at having been exposed to other people's lack of understanding of functional impairment caused by disease.
Feeling dependent on others - threat of losing independence (physical?)

### Additional RA coping strategies generated from participants in the pilot study

Adjustment of demands to current physical condition (knowing limitations)

Selecting an alternative activity (adapt activities to what you can do e.g. I can't run but I can walk)

Self-management practical exercises– including: joint exercises, use of heat, cold, exercise, joint protection i.e. splints, adherence to medical regime, occupational therapy (devices to help at home),

'Alternative' therapies e.g. acupuncture

Resting joints - energy conservation/relaxation strategies.