DISEASE SEVERITY AND PSYCHOLOGICAL STATUS IN ANKYLOSING SPONDYLITIS

By

Jane Harriet Martindale
(Grad Dip Phys, B.A.)

A thesis submitted in partial fulfilment of the requirements for the degree of PhD at the University of Central Lancashire

June 2008

STUDENT DECLARATION

Concurrent registration for two or more academic awards

I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award for the University or other academic or professional institution.

Material submitted for another award

I declare that no material contained in the thesis has been used in any other submission for an academic award and is solely my own work.

Signature of candidate: J. H. Martindale

Type of Award: **PhD**

Department: **Lancashire School of Postgraduate Medicine and Health**

Abstract

The findings of this study provide an original contribution to knowledge in ankylosing spondylitis (AS) and have important implications for enhancing clinical practice. The results demonstrate the existence and significance of associations between disease and psychological status in AS, and also demonstrate the value of using longitudinal, repeated measures approach to study this long-term condition. This study is also the first to demonstrate the value of using a mixed methods approach to investigate this issue in AS.

Although existing literature on prospective longitudinal cohort studies in AS is very limited (other than for studies which involve clinical trials of medications and other interventions), this project demonstrates the feasibility of sustaining such a study over an 18-month period and of recruiting large numbers of participants to both the quantitative and qualitative phases.

The results are based upon a hospital-ascertained cohort of 89 adults. Both the quantitative and qualitative phases produced important new findings:

1. In this cohort, mean BASMI, BASFI and BASDAI scores remained consistent throughout the 18-month period. People with BASDAI scores higher than 4 at the beginning of the study continued to score higher than 4 throughout.

2. BASMI, BASFI and BASDAI scores correlated significantly with anxiety, depression and internality scores, but not with levels of belief in chance or powerful others, throughout the study. This demonstrates that AS disease status is closely linked to some, but not all, psychological measures.

3. There was no effect of co-existent psoriasis or iritis on either disease or psychological status, but BASMI and BASFI (but not BASDAI) scores were significantly related to age.

4. Factors which appear to influence the associations between disease and psychological status are highly complex, often differing between individuals, and usually determined by other co-morbidities and life circumstances besides AS.

These results suggest that the major implication for clinical practice would be the development of a more comprehensive and integrated assessment framework for AS set within the context of a biopsychosocial model. Envisaged would be a major programme of work to critically assess and validate potential components of such a framework with the aim of determining efficacy, feasibility and acceptability of such an approach.

TABLE OF CONTENTS

LIST OF TABLES, ILLUSTRATIONS AND FIGURES

ACKNOWLEDGEMENTS

I have been guided, encouraged and helped by wonderful people throughout the past seven years. To these people I will always be indebted and I wish to thank you so very much. There have been so many and I will name just a few. To those whom I do not name forgive me!

John, I can only pray that the 'blonde moments' of which there have been many will always bring a smile! I image that I have been a challenge but your patience, guidance and wisdom have been the guiding force behind my journey and without you it would not have been possible. Lynne, you have been so generous with your help, so enthusiastic and a wonderful mentor – thank you so much. Jane thanks for all your guidance with the psychology aspects and especially for your counselling. Without you I may not have turned that corner on my 'blackest' day. Chris, your help has been invaluable. I only hope that you are not psychologically scared by my statistical ignorance.

Without the support of my colleagues I would have been lost. Jill and Sandra from R and D, my friends in the library and those who encouraged me throughout (including Secret Santa with the PhD survival kit), Maureen and Cheryl for your juggling of diaries – thanks to all. Stuart my fellow PhD sufferer – thanks so much for a shoulder to cry on and laughs along the way!

David, my long suffering husband. My rock who has always been there for me and still hasn't got a clue what I have been doing, thank you! Our darling daughter Emma – I have watched you flourish into an accomplished young woman with your own academic achievements. All your life you have seen me study. I have witnessed your maturity and I realise that I too have developed and grown beyond all recognition. Thank you to all my family and friends and especially to the wonderful patients who still encourage me.

Lastly I wish to dedicate my thesis to a most wonderful colleague and friend Janet Mills (1964 – 2005) without whom I would never have dared to begin this journey. 'If I can do it, then so can you' are the words that I can still hear you say. In my darkest moments when I wanted to give up, you made me carry on. Dearest Janet I do hope that you would have liked the Anky Spond Nerd that I have become!

ABBREVIATIONS

AMED	Allied and Complementary Medicine Database
Anti-TNF	Anti-Tumour Necrosing Factor
AS	Ankylosing Spondylitis
ASAS	Assessments in Ankylosing Spondylitis
ASES	Arthritis Self-Efficacy Scale
ASQofL	Ankylosing Spondylitis Quality of Life Questionnaire
BASDAI	Bath Ankylosing Spondylitis Disease Activity Index
BASFI	Bath Ankylosing Spondylitis Functional Index
BAS-G	Bath Ankylosing Spondylitis Global Score
BASMI	Bath Ankylosing Spondylitis Metrology Index
BASRI	Bath Ankylosing Spondylitis Radiology Index
CAQDAS	Computerised Assisted Qualitative Data Analysis
CINAHL	The Cumulative Index to Nursing and Allied Health
COPD	Chronic Obstructive Airways Disease
COPM	Canadian Occupational Performance Measure
CRP	C-reactive protein
CT	Computerised Tomography
DFI	Dougados Functional Index
DMARD	Disease Modifying Anti Rheumatic Drug
ESR	Erythrocyte Sedimentation Rate
EULAR	The European League Against Rheumatism
GCT	Gate Control Theory
GSES	Generalised Self-Efficacy Scale
HADS	Hospital Anxiety and Depression Scale
HAQ	Health Assessment Questionnaire
HAQ-S	Health Assessment Questionnaire for the Spondyloarthropathies
HLA	Human Leukocyte Antigen
HRQOL	Health Related Quality of Life
IBD	Inflammatory bowel Disease
ICF	International Classification of Function
ICIDH	International Classification of Impairments, Disabilities and Handicap
IgM	Immunoglobulins
LTC	Long Term Condition
LTHC	Long Term Health Conditions
MCID	Minimum Clinically Important Difference
MRI	Magnetic Resonance Imaging
NICE	National Institute for Clinical Excellence
NSAIDs	Non Steroidal Anti-Inflammatory Drugs
OA	Osteoarthritis
OMERACT	Outcome Measures in Rheumatology Clinical Trials
PsA	Psoriatic Arthritis
RA	Rheumatoid Arthritis
ReA	Reactive arthritis
RLDQ	Revised Leeds Disability Questionnaire
SASSS	Stoke Ankylosing Spondylitis Spine Score
SES	Self-Efficacy Scale
SF36	Short Form 36 Questionaire
SpA	Spondyloarthropathy
SI	Sacroiiliac

SLE	Systemic Lupus Erythematosus
USpA	Undifferentiated Spondyloarthropathy
VAS	Visual Analogue Scale
WHO	World Health Organisation

CHAPTER 1

ASSOCIATIONS BETWEEN DISEASE AND PSYCHOLOGICAL STATUS IN ANKYLOSING SPONDYLITIS:

CLINICAL CHARACTERISTICS AND SIGNIFICANCE

ASSOCIATIONS BETWEEN DISEASE AND PSYCHOLOGICAL STATUS IN ANKYLOSING SPONDYLITIS:

CHAPTER 1. CLINICAL CHARACTERISTICS AND SIGNIFICANCE

1.0. INTRODUCTION

Ankylosing Spondylitis (AS) is a chronic systemic inflammatory musculoskeletal disorder that primarily affects the axial skeleton (sacroiliac joint and spine) and is characterised by sacroiliac joint involvement (sacroili-itis) (Khan, 1998). The term is derived from the Greek angky-los - meaning 'bent', ankylosis meaning joint stiffening or fusion, and 'spondylos' meaning spinal vertebra.

1.1.1. Epidemiology of ankylosing spondylitis

The incidence of AS in Caucasians is 0.5-1%, with an estimated prevalence of 0.9% in northern European white populations (Zochling, 2006). Men are two to three times more likely to be afflicted with AS than women (Zink, 2000). The spine and pelvis are most commonly affected in men, with some involvement of the chest wall, hips, shoulders and feet, whereas in women there may be less severe spinal involvement but more peripheral joint involvement mainly affecting the knees, wrists, ankles hips and pelvis (Jimenez-Balderas, 1993).

AS commonly starts in the second or third decade of life. A survey of 3000 people with AS showed a distribution of age at the time of first spondylitic symptoms as 4% <15 years; 90% between 15 – 40 years and 6% >40 (Sieper, 2002). Analysis of a rheumatological database (n 8776) determined a mean age of onset of 28.3 years (Brophy, 2001).

The association between AS and human leukocyte antigen (HLA) B27 is well established and applies in all populations. The prevalence of HLA-B27 in the general population shows considerable geographic variation, occurring in 50% of Haida Indians of northern Canada but being virtually absent amongst black Africans and Guatemalan Indians (Khan, 1998). Although

the evidence strongly supports a direct role for HLA-B27 in genetic susceptibility to AS, the underlying molecular basis has yet to be identified (Khan, 2002).

1.1.2. Clinical features

AS is a chronic condition with no predictable pattern of progression and does not follow a clearly defined course (Sieper, 2002). Some people have severe disease whilst others seem to live without being aware of the condition (Mader, 1999). Some lead severely impaired lives whilst others, with apparently severe disease, do not (Pradeep, 2008).

Findings from an early prospective study suggest that a pattern of AS may emerge within the first 10 years of disease (Carette, 1983). In this study, the natural course of the disease was examined over 23 years in 51 patients with mean disease duration of 38 years. Seventy-four percent of those with mild spinal restriction after 10 years did not progress to severe spinal involvement. In contrast, those with severe spinal restriction were severely restricted within the first 10 years and severe spinal restriction was also associated with iritis and early peripheral involvement.

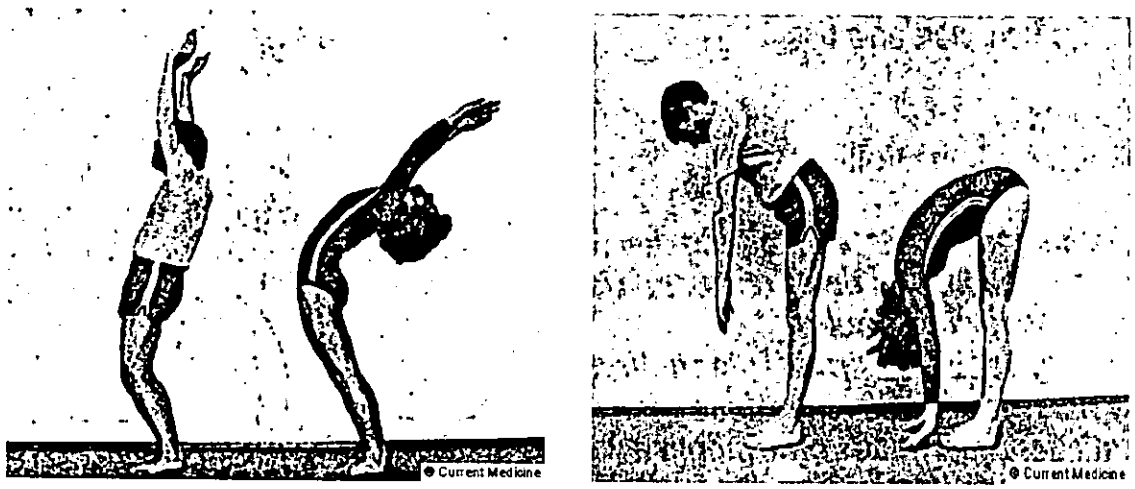
AS is one of a group of related disorders referred to as spondyloarthropathies (SpAs) which include reactive arthritis (Reiter's syndrome), juvenile chronic arthritis, psoriatic arthritis (PsA), arthritis associated with acute anterior uveitis, spondyloarthropathy associated with inflammatory bowel disease (IBD), and undifferentiated spondyloarthropathy (uSpA) (Dougados, 1991, Granfors, 2002). This group of rheumatic disorders share several common factors such as synovitis and enthesitis and association with HLA-B27.

Clinical features of AS comprise skeletal and extra articular manifestations, with the first symptoms usually appearing in late adolescence or early adulthood. Skeletal manifestation present as low back pain, typically dull in character and deep in the gluteal region radiating into the posterior thigh(s) accompanied by morning stiffness in the same area that lasts for a few hours, improves with activity and returns with inactivity. The pain becomes persistent and bilateral within a few months and is usually worse at night (Sieper, 2002).

Tenderness at entheses due to inflammatory reactions at the insertions of tendon to bone can occur and enthesopathy at costovertebral and manubriosternal joints can lead to chest pain and reduced chest expansion. Arthritis in the hips and shoulders occurs in some patients, often early

in the course of the disease. Neck pain and stiffness is characteristic of advanced disease. A patient's posture undergoes characteristic changes if untreated with loss of spinal mobility, restriction of flexion, extension of the lumbar spine and chest expansion. The lumbar lordosis is destroyed; the buttocks atrophy, the thoracic kyphosis is exaggerated and the neck may stoop forward (Sieper, 2002). The limitation of movement may be disproportionate to the degree of ankylosis due to secondary muscle spasms. Figure 1.1 illustrates normal movement in the female participant as opposed to the restriction of movement caused by AS as demonstrated by the male participant.

Figure 1.1. Illustration of the loss of spinal mobility attributable to spinal fusion in AS. Female participant demonstrates normal range of motion.



Extraskeletal manifestations include weight loss, acute anterior uveitis, cardiac and lung involvement. Up to 60% of patients with AS have asymptomatic Inflammatory Bowel Disease (IBD) and symptomatic IBD may develop (Mielants 1987). The condition is characterised by periods of exacerbation, when symptoms including pain, fatigue, early morning stiffness and immobility are intensified. This is referred to as 'flare' and quiescent periods as 'remission' (Brophy, 2002).

Chronic symptomology, unpredictability of flare, vulnerability to physical distress, uncertain disease course and progressive impairment of physical functioning may pose problems in relation to career, family and social life and are likely to be long term and far reaching (Barlow, 2001). In addition to pain and stiffness, fatigue and sleep problems are important concerns which

affect quality of life (Ward, 1999). Fatigue affects other areas of people's lives such as home life, family and leisure (Barlow, (2001) and patients have been shown to complain of fatigue sometimes to a greater extent than pain and stiffness (Calin, 1997). The majority of patients especially those with severe disease experience fatigue and those with severe disease function less well (Jones, 1996). Fatigue is an expression of disease activity and mirrors the degree of a patient's stiffness and pain. However the precise nature of the relationship, disease activity, function and sleep disturbance remains unclear (Calin, 1996).

1.1.3. Non musculoskeletal co-morbidity in ankylosing spondylitis

There are several extra articular manifestations of AS, the most common being acute anterior uveitis (iritis). Patients may present with unilateral pain, photophobia and increase lacrymation. Uveitis may precede the onset of arthropathy and has been associated with restricted mobility of the spine (Carette, 1983). HLA B27 is found in about 40% of individuals with acute unilateral self-limiting uveitis, even in the absence of underlying rheumatological disease (Calin, 1998). Associations between iritis and more widespread spinal disease have also been reported (Gran, 1997). Radiographic change is greatest for those with iritis (Brophy, 2001).

Both oligoarthritis and sacroiliitis associated with psoriasis and inflammatory bowel disease are linked with HLA B27. Inflammatory gastrointestinal lesions demonstrated by ileocolonoscopy, are found in between 20% and 70% of patients, with spondyloarthropathy. It has been found that 6% of patients with spondyloarthropathy but without clinical evidence of inflammatory colitis at the time of diagnosis will subsequently develop inflammatory bowel disease (De Vos, cited by Packman, 2001). Up to 60% of patients with AS have asymptomatic Inflammatory Bowel Disease (IBD) and in some cases frank IBD may develop such as Crohns disease or ulcerative colitis but only rarely (Mielants 1987).

Patients with AS can develop psoriasis and those with psoriasis may develop joint/spinal involvement (Brophy, 2001). Cardiovascular morbidity and mortality, in particular coronary heart disease, have been found to be increased in association with many rheumatic diseases. Chronic systemic inflammation promotes accelerated atherosclerosis which involves complex mechanisms and the effects of treatment and other cardiovascular risk factors also need to be considered (Goodson, 2006).

AS patients have reduced life expectancy and this seems to be due to excess cardiovascular disease (CVD) mortality (Peters 2004, cited by Goodson, 2006). Rates of CVD in men with AS seem to have increased (Symmons, 2004, cited by Goodson, 2006). Inflammation mediated CVD risk factors are increased in AS patients, and it therefore may be that systemic inflammation associated with AS promotes atherosclerosis in these patients (Goodson, 2006). In addition, aortic valve incompetence is said to affect up to 10% of cases with the prevalence increasing with longer disease duration and more severe AS. Inflammation of the ascending aorta causes distortion and dilatation of the aortic ring and fibrotic retraction of the valve cusps gives rise to aortic incompetence. Aortic insufficiency, with possible congestive heart failure is seen infrequently in patients with AS (Sieper, 2002).

Lung involvement is a rare and late manifestation in AS. It is characterised by slowly progressive fibrosis of the upper lobes of the lungs appearing on average two decades after AS onset. Pulmonary ventilation is usually well maintained with increasing diaphragmatic contribution helping to compensate for chest wall rigidity. Vital capacity may be moderately reduced as a consequence of restricted chest wall involvement (van der Linden, 1981).

1.1.4. Pathology of ankylosing spondylitis

Chronic inflammatory lesions occur at entheses. The pathology involves fibrosis and ossification rather than joint destruction and instability as in RA (Calin, 1998). Therefore AS may affect the capsules and intracapsular ligaments of large synovial joints and the apophyseal joints; the ligamentous structures of cartilaginous joints, commonly including the intervertebral discs, manubriosternal joints and symphsis pubis. The ligamentous attachments in sites such as the spinous processes of the vertebrae, iliac crests, trochanters, patellae, calcanei and the clavicle are also affected.

There is initial inflammation of entheses, followed by healing during which new bone is formed. The inflammatory phase may be episodic and brief and new bone tends to fill the defect in the eroded bone, joining the deeper bone to the eroded end of the ligament. This forms a new enthesis above the original level of the cortical surface. Therefore the final outcome of healing is an irregular bony prominence with sclerosis of the adjacent cancellous bone. Spinal manifestations of the disease involve an initial inflammatory and destructive enthesopathy,

followed by a healing process during which new bone formation may result in ankylosis between adjoining vertebrae.

1.1.5. Diagnostic criteria

The current internationally accepted criteria for the diagnosis of AS are the Modified New York Criteria (van der Linden 1984) (Table 1.1).

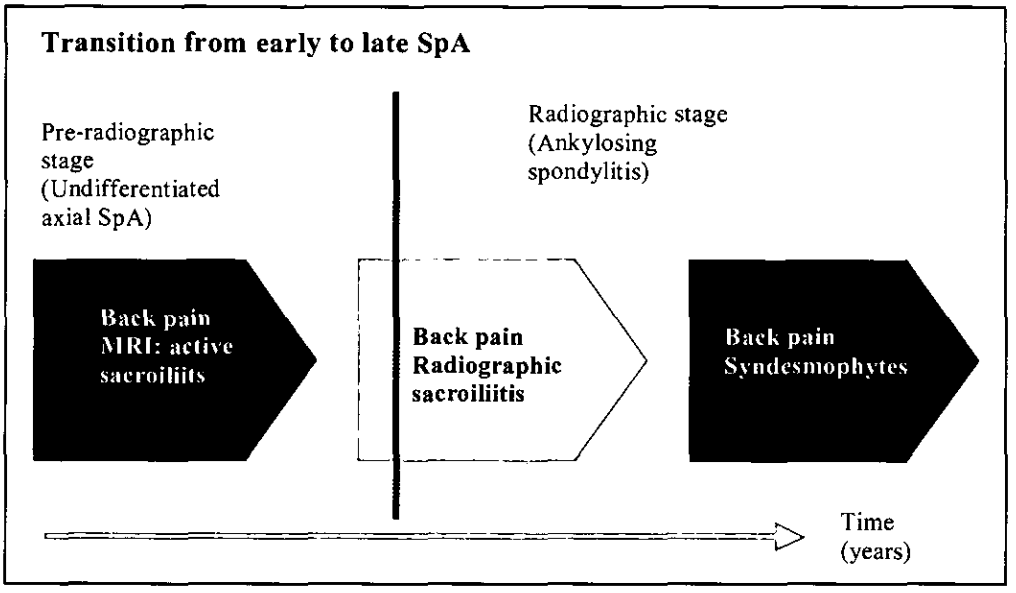
Table 1.1 The Modified New York Criteria (van der Linden 1984)

Radiographic criterion Bilateral sacroiliitis grade 2 or higher or unilateral sacroiliitis grade 3 or higher Clinical criteria • Low back pain and stiffness for more than 3 months that improves with exercise but is not relieved with rest • Limitation of lumbar spine motion of the lumbar spine in both the sagittal and frontal planes • Limitation in chest expansion relative to normal values correlated for age and sex
The condition is definitively AS if the radiological criterion is associated with at least one clinical criterion

It has been suggested however, that dependence on radiographic changes has led to patients experiencing long delays in diagnosis and many cases going unrecognized (Rudwaleit, 2004). Rudwaleit and colleagues (2005) have suggested that AS passes through three phases (Fig 1.2). A 'pre-radiographic' phase in which evidence of the disease is detected via symptoms and MRI abnormalities. A radiographic phase in which symptoms and radiographic sacroiliitis enable diagnosis by the New York criteria, by which time irreversible changes may have occurred and a

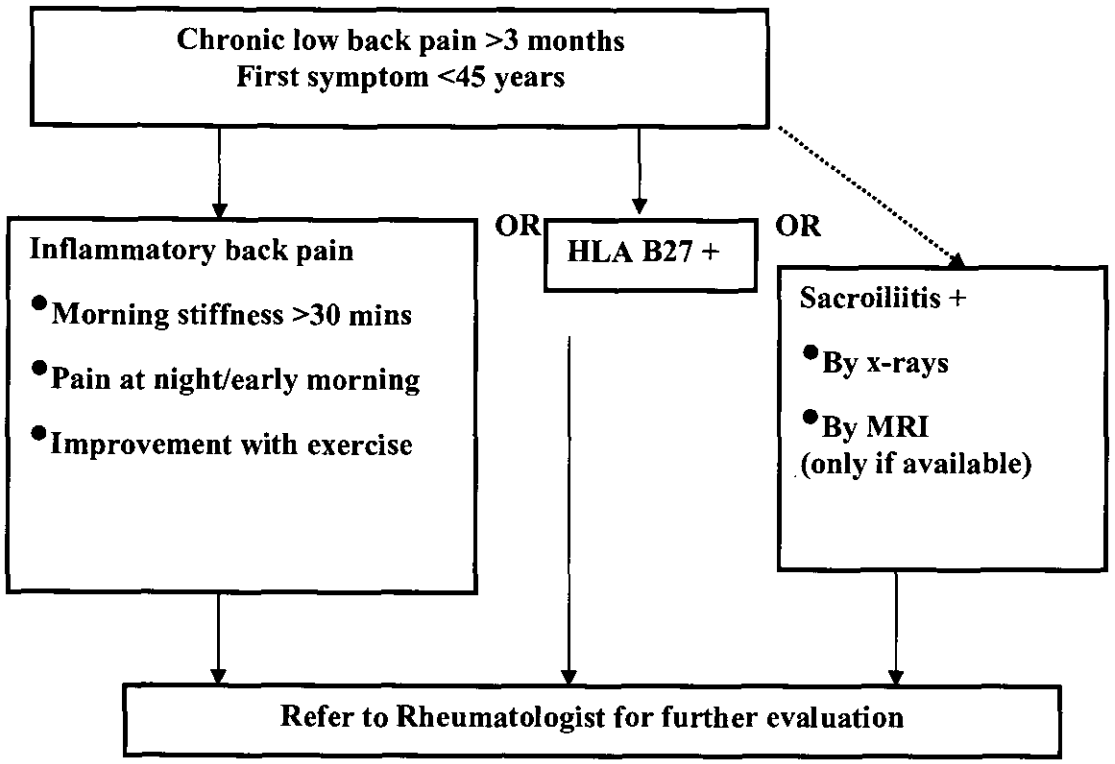
third phase in which radiographic spinal changes such as syndesmophytes and facet joint obliteration, indicate severity and chronicity. By this stage, not only are changes irreversible but they may continue to progress even if the inflammatory element of the disease is suppressed (Schett, 2007).

Figure 1.2. The transition from early to late SpA (Rudwaleit, 2004)



With the introduction of new and effective treatment early diagnosis of AS is essential and therefore criteria have been identified to enable primary care practitioners to detect AS early (Sieper and Rudwaleit 2005, Figure 1.3) .

Fig 1.3. Recommended criteria for screening for patients presenting with low back pain.



This approach to diagnosis may help clinicians to diagnose axial SpA with a high degree of confidence at an earlier stage (Rudwaleit, 2003). There are now compelling data demonstrating that many patients with AS at the start of their illness and for many years after do not show radiographic evidence of sacroiliitis. With the introduction of more effective treatment options there is a need for an early and more effective methods of diagnosis in all patients with AS (Rudwaleit, 2005).

1.1.6. Markers of disease status in ankylosing spondylitis

Measurement of disease activity and severity in AS utilises a combination of objective and subjective methods.

1.1.6.1. Imaging

The single most important feature which distinguishes the spondyloarthropathies from RA is bone proliferation. The sacroiliac joint (SI) is the most difficult joint in the body to image due to the complex anatomy and undulating articular surfaces. Radiological scoring methods have been

developed to assess disease progression. These include the BASRI (Bath Ankylosing Spondyitis Radiology Index) (Mackay, 1998 and Calin, 1999) and the SASSS (Stoke Ankylosing Spondylitis Spine Score) (Averns, 1996). These radiological scoring systems measure the degree of syndesmphyte formation and bony bridging which occurs in AS due to the ossification of ligaments within the spine.

Although these methods are reliable, radiological change may be slow and it may take up to five years to denote significant radiological change (Spoorenberg, 2004). The earliest visible changes in the sacroiliac joints are blurring of the cortical margins of the sub chondral bone, erosions and sclerosis and whilst radiographic evidence of sacroiliitis will present many years may pass before unequivocal changes are evident. Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) can detect AS lesions earlier and with greater consistency (Sieper, 2002). A prospective evaluation of the relative sensitivities of MRI, quantitative sacroiliac scintigraphy and plain radiographs in detecting active sacroiliits was conducted in 44 patients with clinical inflammatory low back pain plus additional features of SpA. This study found MRI to be the most sensitive imaging technique with 95% sensitivity, compared with 19% for plain radiography and 48% for quantitative sacroiliac scintigraphy suggesting that MRI is a more effective mechanism for detecting early AS than radiographs (Blum, 1996). Recent advances in the treatment of AS have led to the use of (MRI) to evaluate efficacy. Utilising MRI imaging, significant regression of spinal inflammation in patients treated with anti-TNFα therapy have been reported (Braun, 2003).

1.1.6.2. Laboratory markers

AS is an 'inflammatory' condition and assessment of inflammation levels using the erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) methods would be expected to be a valuable measure of disease status. However, in contrast with RA, the ESR and CRP values are often not raised in AS and do not necessarily change according to disease status. Taylor (1991), found no relationship between clinical indicators of disease activity (pain, stiffness and sleep disturbance) and laboratory measures (CRP, ESR, orosomucoid and Hb). It has been concluded that these markers are of limited worth in clinical trials (Rouf, 1999; Spoorenberg, 1999).

However, baseline CRP levels have been identified as a predictor of response to biologic therapies (Braun, 2002, Braun, 2003). Bennett et al (2008) report that in their cohort of patients treated with anakinra, 40% had high baseline CRP levels, indicating that high serum markers of inflammation may be predictive of response to treatment. Identification of predictive biomarkers is also of key importance (Pradeep, 2008). In a recent study, high levels of IL-6 and CRP were associated with a good clinical response to infliximab treatment (Visvanathan, 2008). Early reductions in IL-6 were significantly associated with improvements in disease activity and spinal inflammation detected by MRI. There is therefore an urgent need to expand the biomarker repertoire in AS (Pradeep, 2008).

1.1.7. Clinical assessment tools

To provide the most effective management in the care of individuals with AS it is important to determine how the disease and treatment affect health from a patient's perspective. The application of patient-assessed health instruments has become increasingly important within the context of health care (Haywood, 2005).

It was also perceived that the problems of assessment of AS disease status were complicated by the broader clinical spectrum of AS with axial symptoms and signs and absence of useful laboratory measures. Indeed the gold standard of radiographic progression was recognized in the early 1990's as being problematical. Radiographic deterioration cannot be improved and further deterioration could be absent or slow in spite of rapid clinical deterioration (Calin, 1994). The additional dilemma for both researchers and clinicians remained the choice of primary and secondary outcome measures. Calin (1994) highlighted the fact that if a patient could get their fingertips nearer to the floor post physiotherapeutic treatment then would their lives be happier? It was clear that there was a need to know how to translate pain scales, metrological measurements and functional scores into what were meaningful changes in lifestyle or sense of well being for the patient with AS. Additionally, it was recognized that there had been very little input from the patient's perspective in how to recognize disease activity and how this impacted upon their lives (Bakker, 1993).

In 1980 the World Health Organisation published the International Classification of Impairment Disability and Handicap (ICIDH) [WHO 1980]. This classification system informed the conceptual base for many of the outcome measures developed subsequently, especially those

seeking to capture the impact of impairments on a person's ability to perform activities of daily living.

In 1992 an informal international network was brought together under the auspices of the Outcomes Measures in Rheumatology Clinical Trials (OMERACT) (Maasticht 1992) to develop consensus on the outcome measures used in clinical trials in rheumatology. In 1995, an international working group was established to develop consensus regarding assessment of disease activity in AS. The aim of the Assessments in Ankylosing Spondylitis (ASAS) Working Group, was to establish a core set of domains for evaluation of AS and specific assessment methods for each domain (van der Heijde, 1997 and 1999). The ASAS working group selected specific instruments for each domain and having evaluated 105 instruments for feasibility and relevance 70 were ranked and discussed. Instruments were regarded as being applicable when they passed the OMERACT filter (Boers, 1998) summarized as Truth, Discrimination and Feasibility. Each word represents a question to be answered of the measure, in each of its intended settings:

- Truth: is the measure truthful, does it measure what it intends to measure? Is the result unbiased and relevant? The word captures the issues of face, content, construct and criterion validity.
- Discrimination: does the measure discriminate between situations that are of interest? The situations can be states at one time (for classification or prognosis) or states at different times (to measure change). The word captures the issues of reliability and sensitivity to change.
- Feasibility: can the measure be applied easily, given constraints of time, money, and interpretability? The word captures an essential element in the selection of measures, one that in the end may be decisive in determining a measure's success.

The three criteria of the OMERACT filter reflect fundamental principles of clinical metrology, which focuses on the accuracy of measurement. Important properties of any instrument used in clinical practice and research are validity, the extent to which a measure is measuring what it purports to measure, reliability, the extent to which a measure is consistent and responsiveness, the ability of a measure to detect change when change has occurred (Bowling 1997). These

psychometric properties are tested during the process of development and through ongoing use of measures and comparisons between measures.

Validity is established by comparison with other measures which measure the same or similar constructs (criterion validity) and by testing hypothetical constructs by using the measure in an appropriate sample (construct validity), (Streiner, Norman 1995)

Reliability reflects the consistency of a measure and is established in a number of ways. Internal consistency, assessed using Cronbach's alpha, reflects the correlation between individual items in the measures (Streiner, Norman 1995). If a measure is internally consistent all items designed to capture the same dimension should correlate well with each other. Reproduceability is an expression of the extent to which similar results are obtained on repeated applications of the same assessment technique, assuming no change in the phenomenon under study (Bellamy, 1999). Inter and intra-observer reliability are extremely important concepts in the assessment of AS as clinicians and researchers need to be confident that the same assessor produces consistent results (inter-observer error) and where a number of people are involved in assessment that the error between assessors (intra-observer error) is minimised. Inter-observer error is particularly important in AS assessment since measurements are needed over long periods of time and are unlikely to be undertaken by the same observer throughout (Haslock, 1998).

Examples of currently accepted tools for measuring disease activity and function in AS are now discussed and relevant psychometric properties described.

1.1.7.1. Physical Function

Physical function addresses how people perceive themselves as being able to perform specific tasks. The Bath Ankylosing Spondylitis Functional Index (BASFI) (Calin, 1994) includes 10 items on ability to perform and cope with activities of daily living. Each activity is scored on a 10cm visual analogue scale (VAS) with a score of 0 indicating that the activity is easy and a score of 10 indicating that the activity was impossible for that person to accomplish. The mean of the 10 scales yields the total score.

This self assessment instrument was designed through extensive discussion with a team of rheumatologists, physiotherapists and research associates with major input from people with AS.

The final version consisted of 8 questions on activities relating to the functioning anatomy of patients and 2 additional questions that assess the patient's ability to cope with everyday life. In total 163 patients took part in the validation study. The questionnaire was completed on three occasions by 47 consecutive inpatients attending the intensive 3 week physiotherapy course at the Royal National Hospital for Rheumatic Diseases in Bath, UK and once by 116 randomly selected out patients.

The reliability and validity of this measure were established in a number of ways. Inter-observer reliability was assessed by 20 patients being observed performing 8 different tasks by 2 physiotherapists who scored both the BASFI and the Dougados Functional Index (DFI) (Dougados, 1988). Comparison of patient and observer scores on the BASFI resulted in $r = 0.87 - 0.89$, $p < 0.001$ with interobserver consistency on the DFI being $r = 0.90$, $p < 0.001$ indicating good consistency for both measures. Convergence was however superior for the BASFI when compared with the DFI, as the distribution of scores among 149 patients resulted in a mean BASFI score of 4.03 with 95% of the scale used and the DFI 2.85; with only 65% of scale used. Superior sensitivity to change was also demonstrated for the BASFI and reported as 20% ($p = 0.004$) improvement in function over 3 weeks versus 6% ($p = 0.03$) improvement demonstrated by the DFI over the same period. Test-retest reliability was assessed by taking scores 24 hours apart at the same time of day ($r = 0.89$, $P < 0.001$) indicating good reliability (Calin, 1994). During the development and validation of the BASFI, the internal consistency was not assessed. However Cronbach's alpha was later determined using the large database at the Royal National Hospital for Rheumatic Diseases at Bath ($n = 2740$). A value of $\alpha = 0.936$ was reported (Jones, 1996) suggesting that the BASFI has good internal consistency.

The Dougados Functional Index (Dougados, 1988) consists of 20 Likert response items assessing the ability to perform distinct daily activities. A point is assigned to each of three possible answers (0 = yes, 1 = yes but with difficulty, 2 = impossible to do). The total score is calculated as a sum of the 20 item scores (range 0 – 40).

Both instruments are self-administered questionnaires and have been shown to be valid and reliable measures of physical function in AS (Spoorenberg, 1999) and are widely used. However there are important differences and limitations such as the construct and content validity of the DFI being inferior to the BASFI and the distribution of the DFI scores showing a

tendency towards normal scores that may limit its ability to capture improvement in patients with mild disability. The BASFI has been shown to discriminate the effects of a three-week intensive therapy treatment period whereas the DFI could not discriminate (Ruof and Stucki, 1999; Rouf, 1999) and had low sensitivity to change reported in clinical trials (Ward, 1999). Currently the BASFI is the most widely used instrument to assess physical function in AS (van der Heijde, 2002) and remains the instrument of choice for functional assessment (Haywood, 2005).

Additional examples of instruments designed to capture physical functioning include the following:

The Health Assessment Questionnaire for the Spondyloarthropathies (HAQ-S) is a functional status measure for patients with AS using items from the Disability Index of the Health Assessment Questionnaire (HAQ), (Daltroy, 1990). An additional five questions specific to people with AS were included in the revised version. Ward (1999) reported it to be significantly more valid than the Dougados Functional Index, however Heikkila (2002) found it to be relatively insensitive compared to the BASFI. The Revised Leeds Disability Questionnaire (RLDQ) (Abbott, 1994) also assesses disability and function using four categories, namely of mobility, bending down, neck movements and posture. Eyres (2002) in a comparison of psychometric properties of both the RLDQ and the BASFI concluded that both instruments provide a uni-dimensional measure of function in AS consistent with the patient's perception of disease severity.

1.1.7.2. Pain, Spinal Stiffness and Fatigue

The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), (Garrett, 1994) was developed as a response to the fact that no other measure until this point had been able to successfully capture disease activity in AS. It is a self-administered instrument which is scored using 10cm visual analogue scaled items relating to pain and discomfort over the past week ranging from 'none' at the start and 'very severe' at the end of the line. Higher scores reflect greater disease activity. Three locations for pain; overall pain in the back, neck or hip; overall level of pain/swelling in joints other than the back, neck or hips; and overall level of discomfort from entheses which are tender to touch or pressure are included. There are two components to assess spinal stiffness, overall level of morning stiffness from the time of awakening and the duration of the morning stiffness, which is a marked time scale of 0-2 hours marked at every

quarter of the hour. This time scale was derived from analysis of 2000 patient questionnaires, which was unpublished data. The mean of the two scores relating to early morning stiffness is taken to ensure that each symptom is given equal weighting. Finally, overall level of fatigue is included.

This instrument was developed and validated through extensive discussion by a team of rheumatologists, physiotherapists and research associates with major input from patients with AS. Modifications of wording and the inclusion of quality of morning stiffness were made to an initial pilot questionnaire following patient feedback. The final version of the BASDAI was completed by 4 sets of inpatients (n = 46) on 4 separate occasions during their physiotherapy course on days 0, 1, 8 and 18 at the Royal National Hospital for Rheumatic Diseases in Bath, UK. One hundred and eight other people with AS including out patients and members of the National Ankylosing Spondylitis Society (NASS) also completed the instrument with a total of 292 questionnaires being completed by 154 patients (Garrett, 1994).

Test-retest reliability was measured 24 hours apart ($r = 0.93$; $p < 0.001$) and was good. Reliability across the scale responses were also reported to be good (mean score 4.31, SD 2.12), with a mean higher score for inpatients (5.06) than out patients (4.0) with $p = 0.05$. Scores were spread across at least 95% of the scale with a score distribution ranging from 0.5 – 10 (mean 4.31). Intra-class correlations were as follows with fatigue versus pain ($r = 0.34$) the weakest; spinal pain versus local tenderness ($r = 0.66$) and quality and quantity of morning stiffness ($r = 0.79$) the strongest. Criterion validity was tested by comparison with the Bath DAI (earlier version of the BASDAI) and the Newcastle Enthesis Index (Mander, 1987) and the BASDAI was shown to correlate well with the Bath DAI on the validity criteria of time, reproducibility, score distribution, sensitivity and percentage improvement (Garrett, 1994).

BASDAI was shown to reflect sensitivity to change when compared to the DAI (mean inpatient scores improving from 5.34 on day 0 to 4.12 by day 18). Scores on BASDAI reflected a 16% improvement in inpatient scores after 3 weeks treatment. There was no significant partiality among patients for either the Bath DAI or BASDAI in terms of questionnaire preference. However the DAI showed greater change over 3 weeks of treatment than the BASDAI (22% versus 16.4% score improvement) with the authors commenting that this could be due to the bias

of the Bath DAI towards pain and it's inclusion of a scale measuring patient's well-being (Moncur, 2003).

The authors (Garrett, 1994) reported the BASDAI to be superior to the Newcastle Enthesis Index (which was utilised with a cohort of 25 inpatients during the study) due to the limitation in content, insufficient reliability, score range and sensitivity to change in the Newcastle Enthesis Index. Additionally, the Newcastle Enthesis Index required a trained physician or physiotherapist to perform the assessment. Moreover the authors also commented that the Bath DAI omitted reference to fatigue, quality of morning stiffness and localised tenderness and that they now considered the five components of the BASDAI to be vital in viewing a comprehensive picture of the disease activity of the patient (Moncur, 2003). Latterly, the BASDAI has been further endorsed as having good reliability and sensitivity to change (van Tubergren, 2002). As with the BASFI, during the development and validation of the BASDAI, the internal consistency was not assessed. A Cronbach's alpha value was later reported at $\alpha = 0.839$ determined using the large database at the Royal National Hospital for Rheumatic Diseases at Bath (n = 2744) indicating good internal consistency (Jones, 1996).

The ASAS core set of domains for the evaluation of AS includes a combined assessment of tenderness on palpation and limitation of movement due to pain and spasm given as a global grading of 0-4 for the three areas of the spine: cervical, thoracic and lumbar (van der Heidje, 2002).

1.1.7.3. Spinal Mobility

Assessment of spinal mobility provides a sensitive measure of both structural damage and disease activity. The Bath Ankylosing Spondylitis Metrology Index (BASMI) assesses axial status (cervical, thoracic and lumbar spine, hips and pelvic soft tissue), (Jenkinson, 1994) and was designed to derive a metrology index to define clinically significant changes in spinal movement in persons who fulfil the New York Criteria for AS.

To administer the instrument, physiotherapists, rheumatologists or research associates must be trained to complete the clinical examination. The measurements for the five domains are calculated into an overall score of between 0 and 10 with the range of severity reflecting mild (0) or severe (10) disease status.

Historically up to 20 separate measurements had been used in assessing patients attending the Royal National Hospital for Rheumatic Diseases in Bath, UK and one of the aims within the development of the BASMI was to define which would be the most appropriate to utilise. One hundred and ninety three consecutive inpatients were studied. According to the authors, these patients reflected the entire spectrum of disease in AS meeting the New York criteria and metrology was performed on 327 separate occasions. The metrology for the first 43 patients was analysed by the research team which consisted of physiotherapists, rheumatologists and research associates with a special interest in AS. 'Intuitively' and following an extensive literature review, five clinical measurements were considered to most accurately reflect axial status; cervical rotation, tragus to wall distance, lumbar side flexion, lumbar flexion and intermalleolar distance. In an attempt to relate clinically important changes in spinal mobility to function, further analysis of measurements enabled the team to create a table from which a score ranging from 0 -10 could be derived.

Each measurement was assessed for inter-observer, and intra-observer variation and reliability. The observers were 3 physiotherapists who had experience in assessing AS and 20 patients completed the inter-observer assessments. Each patient was measured using the 5 clinical measurements by each of the 3 observers separately with removal of the skin markings following each assessment. The results were documented separately blinding the results from their colleagues. The intra-observer assessments were determined by each of the 3 observers measuring a further 20 patients on consecutive days at approximately the same time. Measurements were recorded at mid morning to allow for resolution of early morning stiffness and were documented separately so that the observers were blinded to their previous results and those of their colleagues (Jenkinson, 1994).

Inter-observer variation between the three physiotherapists was found to be for cervical rotation ($r = 0.98$, $P < 0.001$); tragus to wall ($r = 0.99$; $P < 0.001$), lumbar side flexion ($r = 0.94$; $p < 0.001$), modified schober ($r = 0.99$; $P < 0.001$) and intermalleolar distance ($r = 0.98$; $P < 0.001$) indicating a high level of reliability. Intra-observer variation was reported as cervical rotation ($r = 0.99$, $P < 0.001$); tragus to wall ($r = 0.99$; $P < 0.001$), lumbar side flexion ($r = 0.98$; $P < 0.001$), modified Schober ($r = 0.99$; $P < 0.001$) and intermalleolar distance ($r = 0.99$; $P < 0.001$) again

indicating a high degree of reliability. The authors also reported a 30% improvement in BASMI scores over a three-week period of treatment of 56 patients with BASMI improving from 3.34 (SD 2.71) to 2.16 (SD 2.42) indicating good sensitivity to change (Jenkinson, 1994).

Examples exist of measurements other than those utilised within the BASMI. One such example is recommended by Heuft-Dorenbosch (2004) who advocate the occiput to wall distance measurement over the tragus to wall measurement, postulating that a value of zero distinguishes normal thoracic spine extension. Haywood (2004) also assessed spinal mobility measures for reliability, validity and responsiveness and concluded that fingertip to floor distance and cervical rotation were the most responsive to self-perceived changes in health at six months. The modified schober's test, fingertip to floor distance and cervical rotation measurements are also used for both clinical practice and research (van der Heijde, 1999).

Clinicians are faced with translating change in disease measures and interpreting the results of therapeutic interventions. It is essential to determine whether the observed difference establishes a minor or important effect on a person's health. Jaesche (1989) created the concept of 'minimum clinically important difference' (MCID) defined as 'the smallest difference in score in the domain of interest, which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive costs, a change in the patient's management.' A prospective study by Pavy (2005) established the MCID for the Bath Ankylosing Spondylitis Indices, which enable the clinicians to translate observed changes in values. The MCID was reported as BASFI 7mm or 15% change (sensitivity = 0.60/specificity = 0.85), BASDAI 10mm or 22.5% change (sensitivity = 0.65/specificity = 0.82), and BAS-G 15mm or 27.5% change (sensitivity = 0.61/specificity = 0.74).

1.1.7.4. Health status and quality of life

A widely accepted definition of health is that of the World Health Organisation (WHO) which states that "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946). This definition was updated in the 1986 WHO "Ottawa Charter for Health Promotion" to say health is a "resource for everyday life, not the objective of living", and "health is a positive concept emphasizing social and personal resources, as well as physical capacities". Because "health" is in many ways an abstract

concept, it cannot easily be assessed directly. Instead, indirect indicators such as a response to a question or a clinical observation are used. Quality of life is a descriptive term referring to people's emotional, social and physical wellbeing, and their ability to function in the ordinary tasks of living. Health-related quality of life assesses the impact of treatments and disease processes on these holistic aspects of a person's life (Donald, 2003).

Health status and health-related quality of life (HRQOL) are core components of health outcomes. Measures of health status and HRQOL are primarily patient-reported because symptoms, perceived difficulties in doing tasks and valuation of health are subjective (Ward, 2004). An example of a disease specific measure of health status for AS is the Bath Ankylosing Spondylitis Global Score (BAS-G) (Jones, 1996) which incorporates two questions on a 10cm visual analogue scale assessing the effect of AS on well being over the past week and the past six weeks. The Short Form–36 (SF-36) (Ware, 1992), has also been utilised for AS. This is a questionnaire designed to assess eight dimensions of health status, which includes physical functioning (10 items), role limitations due to physical problems (4 items), bodily pain (2 items), social functioning (2 items), mental health (5 items), role limitations due to emotional problems (3 items), vitality and overall/general health (5 items). It is the most widely used health status measure worldwide. Overall, the SF36 in a recent review of existing outcome tools struck the best balance between length, reliability, validity, responsiveness and experience in large populations of patients with back pain (Bombardier 2000). The SF36 has also been utilised widely in trials of biologic therapies (Braun, 2002, Brandt, 2003, Gorman, 2003, Maksymowych, 2002, Davies, 2003, 2005).

Utilised in general population surveys and clinical trials, the standardization of measurement across studies has produced much information about norms and benchmarks enhancing comparisons of scores. The use of this generic measure makes it possible to compare results across studies and populations accelerating the accumulation of interpretation guidelines, which are essential in determining the clinical, economic and social relevance of differences in health status and outcomes. Moreover, the brevity of the SF36 allows for additional and more specific measures to be included within a questionnaire booklet (Ware, 2000). The SF 36 has been used in many studies of rheumatic disease to document relative health status of different conditions, assess the effectiveness of interventions or to assess the validity of disease specific questionnaires (Angst, 2001, Wilson, 2002, cited by Moncur, 2003). The SF-36 has been used widely to

establish responses to biologic therapy in AS, thus creating disease specific data to enable between-study comparisons (Davies, 2003 and 2005, Gorman, 2002, Brandt, 2003, Braun, 2003).

The SF 36 is a shortened version of the questionnaires designed for use in the Rand Corporation's Health Insurance Study where the target population was adults aged 14 – 61 years with a full spectrum of medical conditions. Interpretation of scores ranges from zero indicating poor health status and 100 indicating very good health status. For norm-based scores, any score above or below 50 can be considered above or below the population average health status for that dimension and each point on the scale is 1/10 of the standard deviation. Population norms are available for the US and the UK. In the UK they are given by age, sex, socioeconomic class and for chronic health conditions (Moncur, 2003).

Internal consistency is good with median Cronbach's alpha across several studies >0.80 for all dimensions except social function (0.76). Studies suggest that all dimensions are reliable for comparisons between groups of patients and that the physical function dimension may be reliable for comparison within individuals (Moncur, 2003). Good correlation coefficients for test-retest over a two week period of >0.80 across all dimensions are reported. Criterion validity is available with many studies showing associations between the SF36 and other health status measures such as the Nottingham Health Profile (NHP) and the EuroQoL. The SF36 is able to distinguish between known groups such as ill and healthy, severe and mild disease, chronic medical condition from medical condition combined with psychological problems (Moncur, 2003). There are mixed results from studies regarding responsiveness and sensitivity to change with evidence for responsiveness in some chronic conditions. However floor and ceiling effects with specific patient groups such as floor effects of role dimensions in people on haemodialysis. In other studies responsiveness has been shown to be superior to other health status measures such as the SF36 identified minor impacts on health status which the NHP was unable to identify (Moncur, 2003). Moncur (2003) warns that it should be used with caution for patients >60 years old as criticisms have been raised that elderly patients find it difficult to complete because some questions do not have significance for them.

Although the range of measures developed suggests significant progress, continued work is needed to improve the existing measures and fill the gaps within the spectrum of relevant outcomes (van der Heijde, 2002). Haywood (2005) was unable to identify AS-Specific multi-

item measures for the assessment of pain, stiffness, fatigue and global health. When these domains are included in measures they are measured by single-item visual analogue scales, which only provide a limited reflection of these important domains. To address these limitations two AS specific HRQOL measures have been developed, namely the Ankylosing Spondylitis Quality of Life questionnaire (ASQoL), (Doward, 2003) and the Patient-Generated Index, (Haywood, 2003).

1.1.8. Management of ankylosing spondylitis

AS creates variable degrees of pain, reduced spinal mobility and limitations in physical functioning. The principle objective for treatment is to reduce pain and stiffness. Longer-term objectives are to maintain posture and general fitness. ASAS/EULAR recommendations (Zochling, 2006) advocate that the optimal management of AS requires a combination of non-pharmacological and pharmacological treatments. Although no studies exist to test this, the consensus is that non-pharmacological and pharmacological treatments are complementary and of value in the initial and continuing treatment of AS. Furthermore, the importance of non-pharmacological treatments is emphasised throughout the course of the disease (Koopman, 1997, Calin, 1998).

1.1.8.1. Physical therapy

Physiotherapists play a central role in maintaining and improving spinal mobility, overall general fitness and pain reduction. They have a key role in educating and also motivating patients who live with this long-term condition. Historically, vigorous physical therapy has been recommended as a treatment for AS since the mid-1950's (Russell, 1993, citing Lenoch, 1956). The prescription of regular, lifelong exercise is a most daunting prospect and patients need to be encouraged to take responsibility for their own programmes and to be motivated to do so.

Current physiotherapeutic management consists of the prescription of tailored exercise programmes aiming to prevent spinal stiffness and strengthening of postural muscles. Ergonomic issues are addressed to promote normal posture and pain relieving techniques are also promoted. During flares of the condition, exercise frequency is increased with patients receiving intensive, supervised exercise, which may also include hydrotherapy. Specific physiotherapy treatment interventions can also be utilised to reduce pain, muscle spasm and inflammation. Examples of such modalities include acupuncture, ice, heat therapy and massage.

As described earlier, tools to measure disease status have been developed within the Hospital for Rheumatic Diseases in Bath. Utilising these tools, studies evaluating the effectiveness of physical therapy following the three-week intensive in patient treatment courses at the hospital demonstrated short-term effectiveness of a regular exercise programme (Bulstrode, 1987, Tomlinson, 1986). Band, (1997) also suggested that women improve more than men and that age of disease onset has little effect. Moreover, younger patients improve more than older patients following in-patient treatments.

Viitanen (1992) demonstrated that most patients improved from between 2% to 8% in range of motion following in-patient treatment. The ability of inpatient treatment to stabilise disease progression over a two-year period from baseline has also been demonstrated (Sweeney, 2002). However expense and lack of resources has led to the need to develop educational and exercise interventions at home. Sweeney (2002) demonstrated that a home exercise package of care can also effectively improve self-efficacy to exercise and improve functional status. Compliance to exercise remains a significant issue and a Swedish study attempted to evaluate exercise habits discovering that most patients undertake exercise but with a low frequency, the main obstacles being fatigue and lack of time (Sundstrom, 2002).

An American meta-analysis of just nine studies pointed out that the evidence base for exercise is predominately from inpatient studies in Europe (Gall, 1994). Early studies relied on metrological measures only. Tomlinson (1986, cited by Gall, 1994), showed statistically significant benefit when comparing pre- and post-test scores for vital capacity, chest expansion, finger tip to floor distance, tragus to wall distance and lumbar flexion in 180 inpatients following intensive land and aquatic exercise. Hidding (1994) concluded that supervised physical therapy for nine months was superior to individualised programmes for improving thoracolumbar mobility, fitness and general overall health and found that global health and functioning were sustained or even improved if group exercise was continued. Group exercise improved global health status, relieved stiffness, and improved fitness although not all meteorological measurements improved (Hidding, 1995).

The study group for assessment in AS (ASAS) suggested a core set of outcome measures in physiotherapy (van der Heijde, 1999) which included pain, stiffness, spinal mobility, physical function, patient global assessment and other relevant outcome measures. The most recent

Cochrane review (Dagfinrud, 2004) identified six trials with a total of 561 participants which met their selection criteria based on these outcome measures (Kragg, 1990; Sweeney, 2002; Analay, 2003; Helliwell, 1996; Hidding, 1993; Van Tubergen, 2002). Table 1.2 contains a summary of the study design and results for each of these studies.

Table 1.2 Summary of the six trials identified as meeting the selection criteria for the Cochrane review (Dagfinrud, 2004)

AUTHOR	STUDY DESIGN	OUTCOME OF STUDY	
Kragg, 1990	N = 53 Compared 4 month home exercise and educational program (supervised one to one design) with no intervention	P	No difference between 2 groups
		S.M.	Finger tip to floor – intervention group improved significantly compared to control ($p < 0.001$) but no difference in Schober test.
		P.F.	Physical function better in experimental group ($p < 0.001$)
Sweeney 2002	N = 155 Compared 6 month home based exercise intervention with non-intervention control group. Intervention consisted of exercise/ information video, exercise progress chart, patient education booklet and exercise reminder stickers.	P	No significant differences between groups
		P.F.	No significant group difference in BASFI ($p = 0.08$)
Analay, 2003	N = 45 Compared 6 week intensive supervised physiotherapy program – stretching, mobilising, strengthening, aerobic exercises and postural and breathing exercises with individualised home exercise program	P	No significant differences
		S	No significant difference
		S.M	Chest expansion, cervical rotation, finger-tip-to-floor distance or tragus to wall and Schober showed no significant difference.
		P.F.	No significant differences in self reported physical function
Helliwell, 1996	N = 44 Randomised into 3 groups; In patient – 3 week programme (1 hour exercise 5 days weekly and hydrotherapy 3 times per week) Out patient – Hydrotherapy and home exercise group	P	Pain and stiffness as one variable – 48% improvement in intervention group immediately after intervention but not maintained at 6 months

	Home exercise – individualised home exercise only	S.M.	No difference in cervical rotation
Hidding, 1993	N = 144 (76% men) Group exercise programme – one hour physical training, one hour sporting activity and one hour hydrotherapy for a 9 month period. Intervention compared to individualised home exercise programme	S.M.	Statistically significant improvement in thoraco-lumbar mobility for additional group physiotherapy
		P.F.	No significant difference
		P.G.A.	Supervised group reported better scores on global assessment at 9 months. Mean difference between groups was 1.46cm (CI 95% 1.05 to 1.87)
Van Tubergen 2002	N = 120 2 spa groups (Austria and The Netherlands) 3 week spa exercise, group physical therapy, walking, correction therapy (lying supine), hydrotherapy, sports and sauna. Control stayed at home following weekly group physiotherapy sessions for 37 weeks follow up	P	Significant effects of spa exercise intervention 1month WMD was – 1.07 (CI 95% - 2.02 to – 0.12) and at 4 months WMD was – 1.09 (CI 95% - 2.04 to – 0.14). Absolute benefit at one and four months was 0.9 cm and RPD 18% in favour of spa exercise group
		S	No significant difference
		P.F.	BASFI evaluated as a separate variable the WMD was not significant but the absolute benefit was 24% and 17% at one and four months respectively
		P.G.A.	Significant effects at one month (WMD -0.93; 95% CI -1.78 to -0.09), four months (WMD -0.93; 95% CI -0.184 to -0.02) and seven months (WMD -1.00; 95% CI -2.02 to -0.02). RPD in favour of the spa groups was 27% at one month and 29% at four and seven months. At ten months no differences were found

Table 1.2: KEY: P = Pain, S = Stiffness, S.M. = Spinal Mobility, P.F. = Physical Function and P.G.A. = patient global Assessment

Their conclusions were that a home exercise programme is better than no intervention, supervised group physiotherapy is better than home exercises, and that combined in-patient hydrotherapy (spa-exercise) followed by supervised outpatient weekly group physiotherapy is

better than weekly group physiotherapy alone. They found no randomised trials investigating relevant physiotherapy interventions other than exercise programs. Trials investigating other physiotherapy modalities such as 'hands on approaches' and specific educational programs were lacking.

Although there is some evidence that physiotherapy is beneficial it is clear that further trials are needed not only to investigate different physiotherapy modalities but also to determine the types and intensity of exercise training.

1.1.8.2. Medical treatment

Key treatment objectives are to relieve pain and stiffness and to regulate the underlying inflammatory process to avoid or delay the permanent structural damage that causes the severe deformities in AS. The relief of pain allows freer movement and therefore exercise programmes can be performed more proficiently.

Non-steroidal anti-inflammatory drugs (NSAIDs) are recommended as the first line drug treatment for patients with AS (Zochling, 2006). NSAIDs reduce the signs and symptoms of axial involvement in AS. Numerous studies have demonstrated that NSAIDs provide relief of inflammatory back pain (Dougados, 2002). Comparative studies between NSAIDs have not shown one preparation to be better than another. However a recent randomised controlled trial which compared continuous use of celecoxib treatment to 'on demand' use suggested that continuous use retarded radiographic progression at two years. (Wanders, 2005). This new generation of NSAIDs (coxibs) are less toxic although their use is limited by adverse gastrointestinal effects such as nausea, dyspepsia, epigastric pain and diarrhoea. There is also emerging evidence for cardiovascular toxicity that may limit their use with patients who have risk factors for cardiovascular disease (Zochling, 2006).

A further ASAS/EULAR recommendation is that corticosteroid injections directed at the local site of musculoskeletal inflammation may be considered (Zochling, 2006) on the basis of weak evidence to suggest that intra or periarticular corticosteroid injections may be effective for the pain of sacroiliitis. Braun (1996) demonstrated that 25/30 patients had reduced sacroiliitis as shown with MRI imaging and reduced inflammatory back pain following the intervention.

Long-term systemic corticosteroid management is not considered as the AS spine is at increased risk of osteoporosis therefore theoretically steroid use may increase this. However short term high dose intravenous treatment (pulse therapy) may reduce symptoms during intensive physical therapy interventions (Haslock, 1998).

1.1.8.3. Disease-modifying medications

Until very recently, the alleviation of symptoms was the only outcome achieved by medication as no established treatments had been found to arrest demineralisation of bone or ossification of ligaments and tendons (Dougados, 2002). Patients with AS despite conventional treatment have been found to have significantly reduced health related quality of life across a wide range of domains. Moreover, within physical domains these are the most pronounced and exceed those seen in other chronic conditions (Davies, 2005). Evidence exists that suggests medication does not adequately control symptoms. Oniankitan (2005), from a postal survey of patients with spondyloarthropathies (n=507), reported that 75.9% of patients received NSAIDS with 55% reporting inadequate control of their disease. Almost all the second line drugs used in the management of RA have been tried at some time in AS with the majority being ineffective although sulphasalazine may be used in those with peripheral joint involvement (Haslock, 1998). The ASAS/EULAR recommendations (Zockling, 2006) further endorse this, stating that there is no evidence for the efficacy of disease modifying antirheumatic drugs for the treatment of axial disease.

Tumour necrosis factor alpha (TNFα) is a cytokine known to mediate key inflammatory pathways in AS and other chronic inflammatory conditions. Efficacy of anti-TNFα treatments has been reported in several open label and randomised controlled trials of Infliximab and Etanercept which are the two main anti-TNF agents currently available (Braun, 2002, Brandt, 2003, Gorman, 2003, Maksymowych, 2002, Davies, 2003). These trials have demonstrated significant improvements in disease activity, function, and quality of life (Braun, 2002). Adalimumab, the most recent anti-TNFα treatment to become available has also been found to be as effective as the other anti-TNFα blocking agents not only clinically but also on MRI outcome measurements (Haibel, 2006).

Due to the high costs of these biological medications (approximately £10,000 per patient per annum) the challenges for clinicians revolve around the identification of which patients require the intervention and demonstrating the efficacy of treatment. The current ASAS/EULAR recommendations (Zockling, 2006) advocate that patients with persistently high disease activity despite conventional treatments should be given anti-TNFα treatments and that there is no evidence to support the obligatory use of DMARDs before, or concomitant with, anti-TNFα treatment in patients with axial disease. There is now published guidance on how to identify appropriate therapeutic candidates for the initiation of anti-TNFα treatment. These include a comprehensive, evidenced based consensus statement by the ASAS group (Braun, 2003, Braun, 2006) and the current British Society of Rheumatology Guideline for prescribing TNF α blockers in adults with AS (Keat, 2005). Within this context of anti-TNFα targeted therapies BASDAI assessments are the pivotal scores informing clinical decisions and assessment of responsiveness to treatment. Largely due to the responsiveness of this measure in clinical trials for TNF therapies decisions in clinical practice, informed by BSR guidelines have been based upon setting BASDAI scores at 4 or above to meet the criteria for treatment. The National Institute for Clinical Excellence (NICE) have recently issued guidelines for the treatment of patients with anti-TNFα targeted therapies. The current recommendations for patients to meet these criteria to be treated with anti-TNFα targeted therapies are shown in Table 1.3

Table 1.3 Criteria for treatment with anti-TNFα targeted therapies (NICE, 2008)

1. Satisfies the modified New York Criteria (van der Linden, 1994)	
2. Demonstrates active disease	BASDAI 4 ≥ Spinal pain in the last week is ≥ 4 on the 0 -10 cm pain VAS. Measured on two occasions at least 12 weeks apart without any change in treatment
3. Failed on conventional treatment	The patient has failed on conventional treatment with ≥ 2 NSAIDS each taken sequentially at maximum tolerated dose or recommended dosage for 4 weeks has failed to control symptoms

There is a paucity of data relating to long-term disease activity in AS highlighting that in clinical practice guidance for the interpretation of the BASDAI had been absent. It has been extremely difficult to determine what happens to people with BASDAI scores of 4 or greater over time. Robertson (2005) reported annual BASDAI scores over a five-year period for 74 patients with at least 3 BASDAI scores available for each patient. From their data 50% to 60% of patients met the eligibility criteria for active disease on at least one occasion and over the five-year period, 38% (28/74) always met the current BSR criteria for active disease. This would suggest that there might be a considerable demand for biologic treatments with ensuing cost implications.

Achieving acceptance from the National Institute for Clinical Excellence (NICE) for biologic medications has been a difficult process complicated by the fact that evidence for the natural history of AS is sparse. The question of whether AS 'burns out' was addressed by Kennedy (1993) using a tool, which was the forerunner to the BASDAI. Following patients over a two-year period they determined that less than 1% of patients entered into long-term remission and that the prognosis for those with 'active' disease was poor. What this study however did not capture was the concept of flare only being able to report that 20% of patients in remission developed active disease two years later. Brophy and Calin (2002) published the only study to address the concept of flare in AS. Engaging in group discussions involving 214 patients (25 years average disease duration) the normal experience consisted of periods of relative stability which are interrupted by unpredictable 'flares' of disease activity lasting for a few days to a few weeks. When the flare subsided however, the disease activity was described as returning to baseline in three quarters of the groups who participated in the study. This would therefore suggest that 'spontaneous recovery' is a concept to be considered which would have important consequences for those involved in economic modeling or simply trying to determine eligibility for biologic treatments.

These are early days in this exciting new era for patients with AS. However, it is yet to be determined if the treatment can fully arrest the long-term structural damage which is the major characteristic of this condition.

1.1.8.4. Surgery

Surgical management may be needed in some patients (Khan, 1990); for example those with severe advanced hip joint involvement have benefited considerably from total hip arthroplasty showing marked functional improvement.

ASAS/EULAR (Zochling, 2006) recommendations are that total hip replacement surgery should be considered in patients with refractory pain or disability and radiographic evidence of structural damage, independent of age. A prospective cohort study of patients with AS showed good pain relief (83% reported good to excellent pain relief) and functional improvement (52% good to excellent functional improvement) with surgery (Sweeney, 2001). This is the largest case series to date and reviewed 340 patients with a mean follow up of 14 years. Findings from this study also indicate that the mean age of onset of AS for those requiring hip replacement was 19.5 years as compared to the mean age of onset of AS at 24.4 years for those not requiring hip replacement.

Age and sex predict revision rate but in AS this is not high (Furnes, 2001). Rates of heterotropic bone formation and re-ankylosis after hip replacement are not increased in patients with AS (Sochart, 1997).

Spinal surgery for fixed kyphotic deformity, which causes major disability, can lead to functional improvement by restoring balance and horizontal vision. It can also be indicated for painful spinal pseudarthrosis, pain and/or segmental instability of spinal fractures, neurological complications such as spinal stenosis, myelopathy and rarely cauda equina syndome. Corrective surgery for the cervical spine should be reserved for those with specific indications (Zochling, 2006).

1.1.9. Prognostic indicators in ankylosing spondylitis

It is generally felt that patients with younger disease onset have more severe disease evolution than those with older onset. A ten-year longitudinal cohort study of 151 patients identified factors during the first two years of the study which correlated with poor long term outcome, including hip arthritis, ESR over 30mm, poor efficacy of NSAID therapy, restricted lumbar axis, oligoarthritis, and onset before the age of 16 years (Amor, 1994). Others found that AS may

remain active after 40 years, with females having higher disease activity and more functional impairment than males despite better metrology (Taylor, 1998). Moreover, Kennedy (1993) found that disease status was independent of disease duration with less than 1% of patients with AS entering into long term remission and that the prognosis over 2 years for those with active disease was poor in a cohort of 1,492 patients.

Both psoriasis and inflammatory bowel disease may be associated with increased severity in terms of function and disease activity in AS (Brophy, 2001). Patients with axial psoriatic arthritis have also been found to have worse pain and function than those with peripheral psoriatic arthritis (Zink, 2006).

Risk factors for functional limitations in AS have been identified. These include duration of AS, smoking status, the number of co-morbid conditions, recalled level of recreational activity in teens and twenties, occupational physical activity throughout life and a history of AS in a first degree relative. It was also noted that patients with higher levels of education had less severe functional limitations. Withdrawal from work is higher in patients with AS than in the general population. Higher age at diagnosis, manual work, unfavourable coping strategies characterised by limiting or adapting strategies, coming from a lower social class, peripheral arthritis and having had a total hip replacement are important determinants (Ward, 2005). Moreover, patients without a job experience a lower quality of life and report worse physical function (BASFI) (Boonen, 2001).

1.2 BIOPSYCHOSOCIAL MODELS OF HEALTH AND ILLNESS

The introductory section of this chapter outlined the clinical features of AS along with current assessment and management of this condition. The aim of this section is to discuss the current biopsychosocial models of health and illness and the utilisation of this model within clinical practice.

1.2.1. The development of a biopsychosocial model

For several centuries the bio-medical model has been the dominant model of disease in the Western world (Engel, 1977). This model was based upon the assumption that disease is generated by specific aetiological agents which lead to changes in the structure and function of the body. Within this model, the body has been perceived as a machine, which if a part malfunctions, should be amenable to repair, or replacement. The focus of attention has been on treating the disease not necessarily the illness, which included the subjective experience of dysfunction. The mind and the body were treated as functioning independently and although it was acknowledged that the disease may lead to psychological disturbances, psychological factors were not perceived as being involved in the aetiology of physical disease (Sarafino, 2006). Challenges to this model argued that it focused too narrowly on the body and on technology rather than on people within their social context. Social scientists suggested that individuals should be viewed as complex systems and that illness is caused by a multitude of factors involving a combination of biological, psychological and social factors (Bowling, 1997). Increasing recognition of the role played by psychological and social factors has led to the biopsychosocial model of health and illness (Engel, 1977).

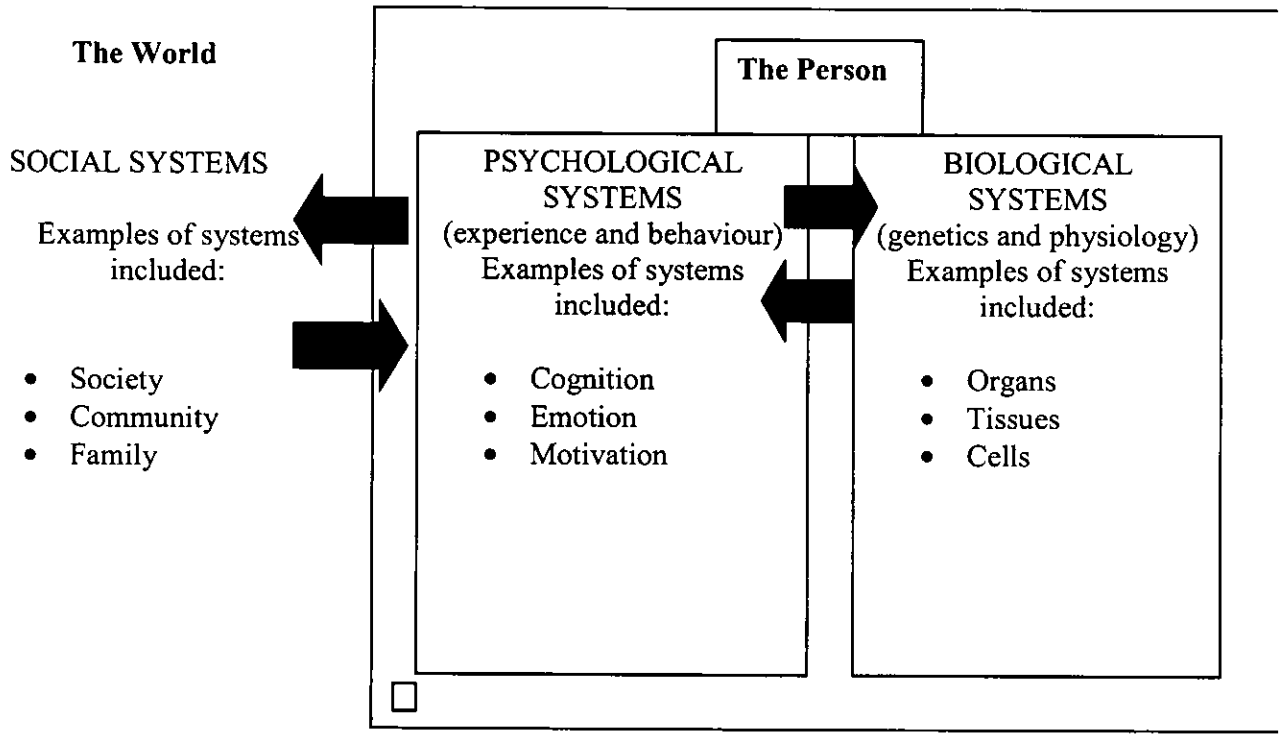
Engel (1977) advocated that clinicians need to evaluate all the factors contributing to illness rather than giving primacy to biological factors alone. He advocated that a biopsychosocial model would make it possible to explain why some individuals experience 'illness' conditions which others regard as merely 'problems of living' and Engel suggested that it was the doctor's responsibility to establish the nature of the problem and to decide whether or not it was best handled in a medical framework.

The biopsychosocial model as proposed by Engel (1980) is based upon a systems theory in biology which is a commonsense observation that nature is ordered as a hierarchically

arranged continuum, with more complex, larger units super-ordinate to the less complex, smaller units in which nothing exists in isolation (Engel, 1980).

A diagram illustrating the interplay of the systems in the biopsychosocial model is given in Figure 1.4. The person consists of biological and psychological systems which interrelate and the person interrelates with the social systems of his or her world (Sarafino, 2006).

Figure 1.4. The interplay of the systems in the biopsychosocial model (Sarafino, 2006).

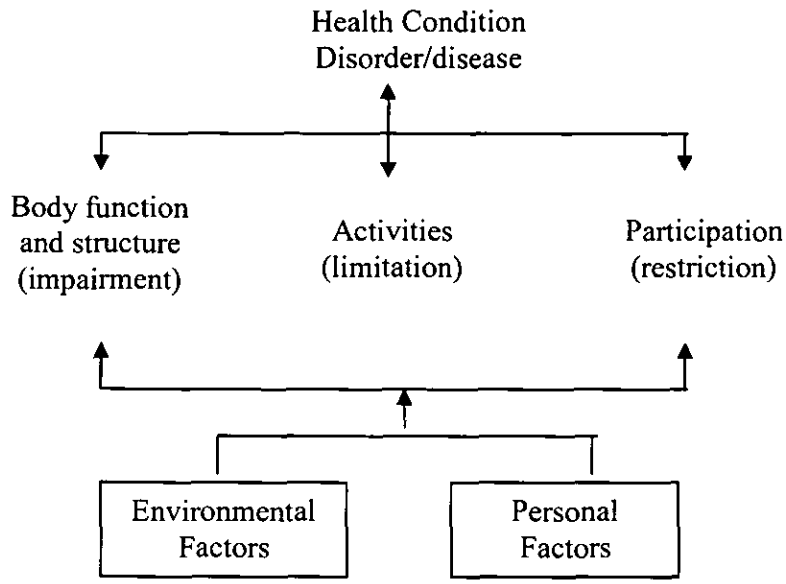


The introduction of the WHO ICIDH (WHO, 1980) recognised in the concept of handicap that disease has consequences which could be affected by the context of the person. Further development of the ICIDH-2 (WHO, 1997) sought to provide a standard framework for the consequences of health conditions and attempted to avoid negative connotations of certain terms used in the ICIDH adopting positive terminology (Gray, 2000). The ICIDH-2 provided an opportunity for building a consensus of terms used to describe disability (Gray, 2000).

In 2001 the WHO approved the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) which integrated the biomedical and social model of disability

providing a way of describing the totality that is the experience of the illness Figure 1.5.. Informed by a biopsychosocial approach to impairment this model acknowledges the inherent links between biological, psychological and social factors and how personal and environmental factors impact upon illness experience.

Figure 1.5. Framework of the International Classification of Function, Disability and Health (ICF), 2001



A study by Sigl (2005) has analysed the linkage between the ICF and the Bath Ankylosing Spondylitis Functional Index (BASFI), the Dougados Functional Index (DFI), the Health Assessment Questionnaire for the Spondyloarthropathies HAQ-S and the Revised Leeds Disability Questionnaire (RLDQ). This study suggested that the mapping process is a valuable mechanism for undertaking a critical analysis of instruments as it shows which health domains, relevant to the ICF they capture. The specification of major limitations in patients with AS could provide a reference framework to identify which measures should be selected in detail to provide the most comprehensive picture of patients with AS (Sigl, 2005). The complete conceptual framework of the ICF comprises over 1,000 items and work has been undertaken since its publication to develop core sets for specific impairments. Core Sets

for Ankylosing Spondylitis have been developed in collaboration between the ICF Research Branch of the WHO Collaborating Centre for the Family of International Classifications and University Hospital Maastricht. In 2007 a consensus meeting identified 55 categories from the ICF for the Core Set and 19 for the Brief Core Set in which each ICF component was represented. Within the context of the assessment of AS, advances are being made to ensure that assessment is informed by a biopsychosocial approach, however the application of this approach within clinical practice is currently not as advanced with some evidence of its relevance to the management of other spinal impairments (van der Heijde and Boonen, 2007).

1.2.2. Utilisation of the biopsychosocial model of health and illness

The biopsychosocial model has been used to provide important insights into how health and recovery from illness might be promoted (Sarafino, 2006). Examples can be found in studies involving patients with acute low back pain. A single blind randomised controlled trial of education, manual therapy and exercise (Wand, 2004) found that the group receiving early active treatment and advice had better outcomes and it was the timing of the intervention which affected the development of psychosocial features such as social function, anxiety, depression mental health and vitality. If treatment was given later these psychosocial benefits were not achieved. Smith (2002), within a review of the literature on early intervention for acute low back pain, emphasised the understanding of psychological determinants by the multidisciplinary team. A biopsychosocial approach could then assist in the prevention of acute low back pain progressing to the chronic state. A Cochrane review of multidisciplinary biopsychosocial rehabilitiation for subacute low-back pain among working age adults (Karjalainen, 2001), also supported the use of the biopsychosocial model to promote health and recovery from illness. This review of current evidence concluded that multidisciplinary rehabilitation, involving a work place visit or more comprehensive occupational intervention, showed a positive effect with regard to return to work, sick leave and subjective disability.

Social factors have been reported to be indicators of outcome, with lower social class and lower work satisfaction indicating worse prognosis for recovery in patients with low back pain (Bekkering, 2003). Truchon (2000) within a literature review of biopsychosocial determinants of chronic disability and low-back pain concluded that studies which investigate the biopsychosocial determinants of chronic disability and low back pain by focusing on

predictive factors for chronic disability would pave the way for the development of appropriate interventions. Indicators identified included previous low back pain, a subjective negative appraisal of ability to work, and job dissatisfaction. Psychological factors including attitudes, beliefs and coping strategies were also identified. Crook (2002), also within a literature review focusing on back pain, identified other prognostic indicators including the time since onset of back pain, demographic factors, functional disability, psychological distress, pain reports, previous episodes of pain and the work environment.

Further examples exist regarding the identification of biopsychosocial factors in other chronic conditions. Keefe (2002), in an overview of a literature investigating biopsychosocial assessment and treatment of arthritis, acknowledged that people with osteoarthritis (OA) or rheumatoid arthritis (RA) may become physically deconditioned over the course of the disease. This paper highlighted that the biological responses contributed to pain, muscle weakness and difficulty tolerating activity, and acknowledged psychological factors had the potential to influence pain and disability. Additionally, social factors, such as social support (Manne and Zautra, 1990) and low socioeconomic status is related to higher functional disability, depressive symptoms and mal-adaptive coping styles (Berkenovic, 1996, Downe-Wamboldt and Melanson, 1995). Therefore, it was suggested that an increase in disease activity might lead to increased anxiety and depression and decreased ability to work or perform household tasks, which in turn can increase pain and disability. Keefe (2002) highlighted that psychological factors are important in understanding how people with arthritis respond to their disease and that social factors are also increasingly being shown to being important in understanding arthritis pain and disability.

Parker (1991) suggested that immunophenotypic subsets were predictive of disease activity and that psychological factors (helplessness and depression) were significantly related to swollen joint counts in RA. They concluded that the biopsychosocial perceptive was useful in estimating RA disease activity. A later study, within the same setting, by Schoenfeld-Smith (1996), identified pain and helplessness as significant mediators of the relationship between disease activity and future disability, suggesting that these are key factors that may affect the development of disability in RA. Moreover, Covic (2003) also identified helplessness and passive coping to be significant mediators of the relationship between physical disability, future depression and pain in RA patients. This study highlighted the use of a biopsychosocial

approach, which acknowledged that the physical aspects of the condition may dominate but that they are mediated by psychological factors, which can be targeted with an appropriate intervention. Conversely, however, Dekkers (2001) reported limited support for the notion that interactions between life stress and biopsychosocial factors have an impact on health. In RA they reported that life events were correlated with psychological distress but not with disease activity.

1.2.3 The challenge of identifying key biopsychosocial factors in AS

Identifying key biopsychosocial factors remains a challenge. One attempt to do this was a study by Koch (2001) in which the INTERMED measure (Huyse, 1999) was utilized to assess case complexity and care needs in order to document biopsychosocial profiles in RA. The INTERMED synthesizes information in four domains: biological, psychological, social and health care. These domains are assessed in the context of time (history, current status, prognosis) and include clinical and scientific variables, which reflect the degree of case complexity and related health care needs. The aim of the study was to correlate the results with conventional methods of disease assessment and health care utilisation. Patients were compared with regard to severity of illness, functional status and health care utilisation. The authors described complex patients as those with somatic and psychosocial comorbidities who required adjustments to care delivery. The results indicated that 'complex' patients (approximately half of the study group) scored high in the psychosocial domain and were significantly more disabled. However, although the two groups did not differ in severity of illness and functional status, 'complex' patients rated their illness as more severe on subjective measures, including most of the SF 36 questionnaire. The 'complex' patients also showed increased health care utilisation despite a similar biologic profile. Therefore this suggested that assessments which provide meaningful and comprehensive patient information are more advantageous than conventional disease assessment. However the challenge would be to demonstrate if management strategies based upon type of assessment profile would improve treatment response and outcome of complex patients.

Clinicians face the challenge of putting research into clinical practice. Sirmali (2003), in a short case study of a thirty-year-old man with AS described a patient who was alcohol dependent, had low socioeconomic status and suffered from severe episodes of depression. This case highlighted the perturbing psychosocial concerns which potentially could influence

many more who are affected by AS. Harland (2003), having identified the need for a biopsychosocial approach to the assessment and treatment of chronic low back pain, warned however that although 'biopsychosocial' is a familiar phrase, its meaning is often lost or ignored within clinical practice.

The use of a biopsychosocial model of health to inform the clinical assessment and management of patients with AS could provide a more holistic approach. This may lead to the identification of factors beyond the condition itself, which are potentially inhibiting clinical management. What is however clear that is unlike the biomedical model, the biopsychosocial model acknowledges that psychological determinants also influence patient's lives. AS is a dynamic health condition. It is a life long condition with unpredictable periods of increased disease activity which gives rise to physical symptoms which impact upon a person's ability to live their lives. Potentially, all life domains could be affected by this health condition be these contextual factors, personal relationships, physical problems, psychological, societal or attitudinal issues. A biopsychosocial profile of how AS affects a person's life could potentially be pivotal in not only identifying appropriate medical interventions but also in understanding the more complex inter-relationships influencing a person's ability to live with this life long condition.

1.3. PSYCHOLOGICAL FACTORS IN HEALTH AND ILLNESS

The previous section outlined the components of the biopsychosocial model and their involvement in health and illness. The aim of this section is to further elucidate the influence of psychological factors. At initial diagnosis it is possible that the impact of the diagnosis could have psychological implications, living with the consequences of a long-term condition such as pain, fatigue, unpredictability and functional limitation also have a significant psychological impact. Macleod (1998) underlined the fact that for people facing a future with the challenge of physical disability, progression of that disability over time may well lead to the development of psychological distress. As chronic disease management requires ongoing interaction between an individual and their medical team health professionals need to be aware of the problems faced by their patients. However, providers often demonstrate little

understanding of the personal impact that chronic disease has on a patient's life (Heijmans, 2001).

The ability to predict outcome is indeed advantageous for long-term health conditions. One such example is that of asthma. Wright (1998) in a review of psychosocial stress and asthma found that life stress might influence immune function and increase the risks of infections in asthma patients. It was suggested that environmental factors might impact on asthma morbidity through the neuroimmunological mechanisms, which are mediated by social networks, social support and psychological functioning. Additionally life stress may impact on health beliefs and behaviours that may also affect asthma management. The authors provided evidence that there is a complexity within these interactions and that this should not be underestimated. High levels of denial in subjects may be life threatening in that patients were slower to seek medical intervention. This study underlined the urgency to educate doctors about the risk of associated psychiatric disorders including high levels of denial in asthmatic patients, which could ultimately potentially reduce the risk of death in asthma patients.

1.3.1. Psychological factors in the pain experience

Psychological factors have been recognised as playing an important role in understanding pain. Melzack and Wall's Gate Control Theory (GCT) (Melzack, 1965, 1979, 1982) describes pain as 'a complex experience comprising sensory, emotional and cognitive dimensions'. This model suggests that whilst pain can be understood in terms of a stimulus-response pathway this pathway is complex and is mediated by a network of interacting processes leading to an integration of psychological factors into the traditional biomedical model of pain. The GCT suggests that a 'gating' mechanism exists at spinal cord level and it is at this level that several sources of information influence the opening or closing of the 'gate'. These sources include peripheral nerve fibres (such as site of injury pain, pressure or heat), which send information about pain to the gate. The brain also sends information relating to the psychological state of the individual to the gate. The large and small fibres constitute part of the physiological input to pain perception. The gate integrates all the information from these different sources and produces an output. This output is information, which is sent to an action system, which results in the perception of pain. The more that the gate is opened, the greater is the perception of pain. Factors, which have been identified as 'opening' the gate, include physical

factors such as injury, emotional factors such as anxiety, depression, worry and tension, and behavioural factors such as focusing on the pain and boredom. When the gate is closed, this reduces pain perception and the GCT also suggests that certain factors influence this. These would include physical factors such as medication, emotional factors such as happiness, and optimism and behavioural factors such as relaxation, concentration and distraction.

There are other influences on the perception of pain. Skevington (2004) described perceptions of pain as being bound up with the person's history of illness in general and pain in particular. It is suggested that people seek reassurance and information from others about what is the appropriate action to take and in addition that there are very complex biopsychosocial processes at work, which interact in a multiplicity of ways. Examples include the individual's cultural background, past experiences of pain, social environment, their attitudes and beliefs about pain, their personality and emotional state. The relationship developed between the health professional administering treatment and the patient's beliefs about the effectiveness of treatment could also potentially influence the outcome of interventions. Therefore, pain is now no longer seen as just a sensation but as an active perception, which can be influenced by a range of factors (Ogden, 2000).

1.3.2. The role of anxiety and depression in the pain experience

There have been numerous attempts to explain the influence of anxiety and depression on health and their impact on a chronic condition and the perception of pain (Ogden, 2004, Skevington, 2004). In order to explore these issues, many studies have first recognised that it is important to separate out the depressed from the non-depressed pain sufferers prior to studying the differences in pain perception. This has been necessary to investigate different responses to interventions due to the influence of psychological status. This is further complicated by effects of factors such as gender, age, predisposing depression and depression caused by the inability to work or to interact. Moreover, other factors contribute such as the uncertainty of the future, the prognosis, social support and coping abilities.

Studies in RA have suggested that low socioeconomic status is related to higher functional disability, depressive symptoms and maladaptive coping styles (Berkanovic, 1996, Downe-Wamboldt and Melanson, 1995) and have suggested that predictive factors can be identified. Doeglas (1994) found that people with RA who received higher daily emotional support

experienced much higher levels of psychological well being. In addition those who had a higher degree of social companionship were also less depressed.

Whilst it is evident that anxiety and depression have influences on pain perception it is difficult to fully measure the extent to which this happens. An example, which illustrates the influence of anxiety, comes from James and Hardardottir (2002). Within their experimental study, which involved the cold pressor task where participants are required to place their hand and arm into icy water as a means to induce pain, trait anxiety was assessed. Some of the participants were actively distracted from thinking about their pain with the results showing that both distraction and low trait anxiety reduced the pain experience. Additionally, Carr (2005) examined experiences of anxiety, depression and acute pain following major gynaecological surgery. Pre-operative anxiety was found to be predictive of postoperative anxiety by the second postoperative day. By the fourth day both the anxiety and depression scores increased as the pain increased with one third of the sample experiencing psychiatric levels of anxiety whilst under one third experienced similar levels of depression. Their conclusion was that those who were anxious had higher pain scores than less anxious patients and that changes in anxiety were significantly related to changes in pain. Moreover preoperative scores for both anxiety and depression were predictive for post operative scores suggesting that those who entered hospital feeling anxious or depressed were predicted to continue to do so post operatively and that day four was the day when patients were psychologically at their most vulnerable.

Evidence for the influence exerted by depression on pain intensity levels can also be found. Williams (2006) conducted a literature review on the nature, prevalence and co-morbidity of depression and pain. It was suggested that pain as a physical symptom of depression impacts upon diagnosis and treatment which can lead to greater health care utilisation and can complicate prognosis and outcomes in chronic pain patients. What is more, the experience of pain can be intensified by the coexistence of a depressive disorder, which may reduce pain thresholds and tolerance. A decreased mood is thought to affect conceptualisation of pain. It has been suggested that depressed patients might have a lower tolerance for pain (Gildenberg, 1984). A controlled laboratory experiment has also been able to demonstrate that an induced depressed mood was associated with alterations in response to pain (Willoughby, 2002).

1.3.3. The influence of anxiety and depression on Long Term Conditions (LTC)

The influence of anxiety within many chronic conditions is also evident. McCracken (1999) reported that patients with chronic pain could be classified into sub types by using anxiety, behavioural factors and psychological assessments. This revealed that those within the dysfunctional group demonstrated greater pain related anxiety and less acceptance of pain. Furthermore, when determining the potential for effective and ineffective outcomes in patients with Chronic Obstructive Airways Disease (COPD) Narsavage (1994) found that psychological status, problem solving coping, and challenge were the best predictors of exercise ability and that psychological status and commitment to exercise were the best predictors of functional status.

Pincus et al (1986) describe arthritis patients as having flares of their disease and as a result experience increased somatic symptoms. This, they suggest, may lead to the endorsement of somatic items on depression scales and therefore could lead to an overestimate of depression levels in arthritis populations. Moreover, depressed chronic back pain patients have been found to experience greater pain intensity, greater interference with activities such as social, outdoor and household and increased pain behaviours. However depressed pain patients were similar to non-depressed in the type of chronic pain experience, their use of medications and their disability (Haythornthwaite, 1991). Hasenbring (1994) also identified risk factors for chronicity in lumbar disc disease patients and that depressive symptoms appear to influence outcomes of treatment and intensify pain perception. These included the degree of depressive mood and the use of specific pain coping strategies. The greater the degree of depressive mood pre treatment, the stronger the patients' tendency to avoid social and physical activities. Interestingly, in contrast, those who 'stuck it out' in spite of severe pain, had a tendency to communicate their pain indirectly. This was by non-verbal behaviours (groaning, facial expressions and rubbing the painful area) and less direct speech (asking for help because of being in pain), and it then became more probable that such patients complained of persistent pain on discharge. Furthermore, Pincus, (2002) from a systematic review of psychological factors as predictors of chronicity/disability in low back pain, concluded that there was an increased risk of chronicity from psychological distress or depressive mood. Acceptable evidence was not however found for other psychological factors other than weak support for the role of catastrophising, as a coping strategy.

Studies also illustrate a reduction in treatment adherence for those with increased depression and/or anxiety levels. One such example is from Kulkarni, (2004), who found one fifth of psoriatic patients within their study had depressive symptoms and that these patients were less likely to adhere to medication or to utilise health care resources. Moreover, if depression was left untreated, Doan (1989) reported that there was poor response to pain treatment. This study investigated the relationship between depressive symptoms and the descriptions of chronic pain. Interestingly, two thirds of this study group had mild depressive symptoms, which was consistent with other studies illustrating the prevalence of depression within the province of chronic pain.

There is also evidence that within a variety of disease populations' there are differing levels of anxiety and depression. For example people with RA have been shown to have a wide range of anxiety scores (VanDyke, 2004). Indeed those with concomitant depression exhibited levels of anxiety that are higher than that of the normative group of age equivalent working adults. They also found that anxiety was not related to RA disease duration. Furthermore, adding to this complexity, Treharne (2005) examined whether there were differences in anxiety and depression in patients with Rheumatoid Arthritis (RA) with co-morbid Cardiovascular Disease (CVD) and those without CVD. No differences in anxiety levels were identified, although anxiety appeared to be more common than depression. However, RA patients with co-morbid CVD had significantly higher depression levels. This study is also a further example of the potential benefits of identification of those who are depressed by systematic screening. There would therefore be an opportunity for the implementation of targeted interventions. Patients with psoriasis have also been shown to have significantly higher levels of anxiety, depression and worry than their partners (Richards, 2004). In addition, in a study of patients with Systemic Lupus Erythematous (SLE), Ward (2002) was able to demonstrate that both anxiety and depression scores ran parallel with changes in subjective assessments of disease activity. However they found no evidence to support the hypothesis that psychological distress increased SLE activity.

Studies also demonstrate that psychological status can be altered. One such example is that Rheumatoid Arthritis (RA) patients who completed a stress management-training programme demonstrated pain reduction and that levels of depression had been reduced due to changes in self-efficacy, coping strategies and helplessness (Rhee, 2000). A further example is the study

by Coughlin (2000), which demonstrated that a multi-disciplinary pain management programme could increase a patient's self-efficacy in their control over their pain. Furthermore, exercise rehabilitation in older adults with COPD was found to improve not only physical functioning and endurance but also enhanced cognitive functioning and psychological well being (Emery, 1991). This may however not always be the case as Ries (1995) found that depression and general quality of well being measures were not influenced by rehabilitation in COPD patients. It was exercise performance that was improved for a year with the benefits of this diminishing after that time.

1.3.4. Assessment of anxiety and depression

Several measures of depression and depressive symptoms have been developed and used extensively both clinically and in the research setting. Examples include the Beck Depression Inventory (BDI) (Beck, 1961), the Centre for Epidemiological Studies-Depression Scale (CES-D) (Radloff, 1977) and the Geriatric Depression Scale (GDS) (Brink, 1982). However, the Hospital Anxiety and Depression Scale (HADS) (Zigmond, 1983), has proved to be a reliable and valid tool to assess emotional distress in medical populations (Herrmann, 1997). Moreover, despite its brevity, it also screens for possible anxiety and depressive symptomology similar to more comprehensive clinical measures.

HADS consists of 7 depression items measuring cognitive and emotional aspects of depression (HADS – D) and 7 anxiety items focusing on emotional aspects of anxiety (HADS – A). Somatic items relating to emotional and physical disorders are excluded. It was developed for general medical out patients between the ages of 16 to 65 and has been used extensively primarily with psychiatric and medical patients, as well as the general population, students, non-patients and people with chronic medical conditions.

HADS utilises a 4 point Likert scale ranging from 0 to 3 with higher scores indicating greater severity. The authors recommended cut off scores for the sub-scales which are 0 to 7 considered non-case, 8 to 10 considered possible case and 11 to 21 considered probable case. Internal consistency indicated by Cronbach's coefficient alpha ranges were from 0.78 to 0.93 for HADS – A and from 0.82 to 0.90 for HADS - D. High test-retest correlations ($r = 0.80$) were found after 2 weeks and gradually decrease as time lapses (2 to 6 weeks 0.73 – 0.76, and >6 weeks 0.70). Significantly higher correlations were found between HADS - D and

observer ratings and self-assessments for depression than with observer and self-ratings of anxiety. Compared to other well used depression and anxiety measures (such as BDI, state Trait Anxiety Inventory), correlations with HADS - D and HADS - A ranged between 0.60 (good) to 0.80 (very good) (Bjelland, 2002).

HADS has been identified as relating to prospective measurements in renal transplant patients. Baseline HADS also predicted follow up psychiatric morbidity using a clinical interview. In coronary patients, baseline HADS - D predicted quality of life more than 2 years later and also predicted surgical outcomes in urology patients. The HADS is not a diagnostic tool as it is a poor predictor of making a specific diagnosis (Silverstone, 1994). It was designed to identify probable 'cases' of anxiety or depression. Average sensitivities and specificities are >0.80 which is similar to other self-rating screening tools (Herrmann, 1997). HADS depression sub-scales have also been compared with standard clinical assessments in medical patients with sensitivity estimates ranging from 56 (reasonable) to 100% (very good) and good specificity estimates ranging from 73 (good) to 94% (very good). Positive predictive values ranged from 19 (poor) to 70% (good) (Silverstone, 1994, Goldberg, 1985) and these estimates compare favourably with studies using the BDI and CES-D. HADS scores are also responsive to pharmacological and psychotherapeutic interventions (Herrmann, 1997).

HADS therefore can be utilised in both the clinical and research setting and has been found to be particularly useful when studying the cognitive processes associated with depressive symptoms and anxiety due to the fact that it is free from physical symptoms such as insomnia and weight loss. Due to good psychometric properties it also becomes a good choice to measure psychological distress, to differentiate symptoms of anxiety and depression and to examine the impact of cognition on depression and anxiety (Moncur, 2003).

1.3.5. Control Theory and potential links with anxiety and depression

The concept of Locus of Control addresses the influence of the individual's beliefs relating to different sources of control over their lives. The concept suggests that individuals may believe in their own (internal) control over aspects of their life, the control of powerful other people or of chance factors. The concept of Locus of Control was first proposed by Rotter (1966) The

extent to which patients believe in their own control of health outcomes is regarded as being relevant to how they are able to cope with their condition (Skevington, 1995)

Control is therefore a key concept in health psychology with important implications for the management of the relationship between patients and health care professionals. Although control is frequently used to refer to personal control, control may also be achieved through the activities of others, or even belief in external force. 'Others' in health context may include family, relatives, friends, doctors and other health professionals. Although frequent reference is made in the literature of 'control theory', there is to date no accepted unifying theory of control but a multiplicity of theories which include perceived control, personal control, locus of control, self-efficacy and learned helplessness (Walker, 2001).

Perceived or personal control reflects the beliefs of an individual about the actual or potential amount of control achievable in different types of situation. Most research supports the view that perceived personal control is generally advantageous in relation to physical and psychological health outcomes. However, total reliance on personal control is likely to be maladaptive in uncontrollable situations.

A theory of anxiety based on uncertainty and lack of control would predict that those with a belief in their own control (internals) would be less anxious than those with a belief in the control of powerful others or chance factors (externals). Additionally, a belief that health is controlled by chance factors has been shown to be linked with poor motivation to engage in preventative or protective health behaviours and poor health outcomes. Murray and McMillan (1993), when investigating the role of health locus of control in predicting woman's adherence to attend for cervical screening demonstrated that those with a high belief in the control of chance factors were less likely to attend. Additionally, within the same study adherence to breast self-examination was found to be carried out less frequently by those with a high belief in the control of powerful others.

Wallston, (1994) has argued that the belief in internal and external control is a relatively stable personality characteristic: something that a person carries from one situation to the next. However, conversely, it has also been suggested that people are not fixed at one point along the continuum as 'internals' or 'externals' and therefore their behaviour may depend on

a particular situation. In other words, individuals may perceive themselves as being in control of some aspects of life such as personal finances, whereas they may not perceive themselves as being in control of other aspects such as health (Smith 1970).,

Phares (1976) describes a linear relationship between externality and anxiety and adjustment. Extreme externals and internals might be more maladjusted and anxious. This could be due to externals being incapable of influencing events and internals because they are sensitive to failure. The whole notion of locus of control has been challenged even by Wallston (1992) himself, who contributed much to the control literature. He concluded that the locus of control construct was only a relatively small portion of the larger and more important construct, which is that of perceived control over health. However, the construct may provide 'some clues to help to unravel the mystery of health perceptions in people with acute or chronic pain' (Adams, 2002).

The Multi-dimensional health locus of control scale (MHLC) was designed to inform on the three theoretically distinct and empirically different dimensions of health locus of control (Walker, 2001). The first unidimensional health locus of control (HLC) scale was published by Wallston (1976) and was used to confirm the hypothesis that health related information seeking is a joint function of a person's locus of control beliefs and the value placed by the individual on their health. In 1978, Wallston went onto publish the Multidimensional Health Locus of Control scales (MHLC), which were based on the work of Levenson (1974). However as Walker (2001) pointed out, this scale was able only to provide one indication of contributing factors that play a significant role in the explanation of health behaviour. Later a third form (Form C) was created to be used for specific health conditions (Wallston, 1994) and was developed to address increased understanding of the locus of control and health locus of control constructs.

The original health locus of control was conceptualised as a uni-dimensional construct (internal or external locus of control over health); later factor analysis of this measure and new research in more generalised locus of control scales identified the need to measure locus of control in 3 dimensions. It was hypothesised that health locus of control beliefs about a specific health condition may correlate with health outcomes differently than more general health locus of control beliefs. Several researchers observed that there were some problems

on Forms A and B, which were problematic for individuals with chronic medical conditions. Form C was therefore designed as a general purpose, condition-specific locus of control scale (Moncur, 2003).

It was suggested that health locus of control beliefs about a specific health condition may correlate with health outcomes differently than more general health locus of control beliefs (Moncur, 2003). Form C was designed as a general-purpose condition-specific locus of control scale that could be easily adapted for use by individuals with specific medical conditions. The version of the instrument chosen for this study related to beliefs concerning back problems and therefore was considered appropriate due to the significance of spinal involvement associated with AS. Moreover, the concept of Locus of Control has been evaluated within AS providing the potential for comparative data. Moncur (2003) warned that as a generalized measure, it is not expected to explain large amounts of variation in health behaviours if used in isolation. It is only by combination with other contributing factors that it is likely to help to explain health behaviour.

The instrument was designed for adults and validated with adults waiting at airports (Forms A and B) (Wallston, 1978) Form C was validated with groups of patients with rheumatoid arthritis, chronic pain, cancer and diabetes (Wallston, 1994). Other uses include studies involving pain, spinal cord injury, alcohol dependence, arthritis and other chronic conditions (Moncur, 2003). Means and standard deviations are only available in a rheumatoid arthritis sample for the Form C sub-scale.

Cronbach's alpha for internal consistency ranges from 0.87 to 0.79 for the 6-item subscales (Internality and Chance) and 0.71 to 0.70 on the 3 item sub-scales (Powerful others-Doctors-powerful others-Other people). In re-test reliability, the stability co-efficents ranged from 0.66 to 0.54 for a year retesting period with no active intervention to change beliefs (Moncur, 2003). Preliminary predictive validity was tested using a two-item health status measure and as expected showed a positive and significant correlation with internal health locus of control (IHLC) ($r = 0.403$); a significant negative correlation with chance health locus of control (CHLC) ($r = - 0.275$) and no correlation with powerful other health locus of control (PHLC) ($r = -0.055$). The concurrent validity of Form C showed modest correlations with the

appropriate subscale from Form A/B (correlations ranging from 0.59 to 0.38 in a rheumatoid arthritis sample) (Moncur, 2003).

Construct validity for Form C has been demonstrated in that subscales correlated in a theoretically expected direction with distinct but related concepts of pain, depression and helplessness in a rheumatoid arthritis sample. Additional evidence was also demonstrated in a sample of individuals with chronic pain who engaged in an intervention designed to change locus of control beliefs. Internality beliefs were shown to increase whilst external subscales (Chance and Powerful others) all decreased as was expected (Moncur, 2003). Sensitivity and responsiveness to change is unknown.

A strength of the MHLC Form A/B is the availability of alternate forms with nearly identical psychometric properties to accommodate repeated measures research designs. Moreover, Form C has been designed to be condition specific and can be easily adapted to a variety of chronic conditions in a standardised manner. The authors caution that health locus of control is a health-specific indicator of generalised expectation of control. Thus as a measure it is not expected to explain large amounts of variation in health behaviours if used in isolation. When used in combination with other contributing factors, the MHLC becomes more likely to explain health behaviour (Moncur, 2003).

1.3.6 Locus of control in Long Term Conditions (LTC)

Uncertainty of outcome in chronic illness has been identified by Weiner (1975) and Brown and Nicassio (1987) found that patients with more active ways of coping had stronger beliefs in internal locus of control, less depression, pain and functional impairment. Passive coping was related to stronger beliefs in chance and control of others and had overall poorer adjustment to chronic pain. Crisson (1988) reported that chronic pain patients with strong beliefs about their health being controlled by chance or misfortune were more likely to be depressed or anxious. This is compared to those who believed that they themselves exerted a measure of control over their health outcomes. Moreover, beliefs in the control of chance factors are also associated with failure to engage in health-protective behaviours and depression (Walker, 2001).

One example that health locus of control can also be a predictor of outcomes has been demonstrated by Harkapaa, (1991). Within the field of chronic low back it was shown that those patients with stronger internal control beliefs gained more from treatment. These patients learned the exercises and undertook them more frequently compared with those who believed in the control by powerful others or chance factors. Thus, greater belief in an individual's own control of their back pain indicated better prognosis as measured by changes in self assessed low back pain disability. Moreover, echoing the association with depression, those with strong beliefs in chance factors had higher levels of psychological distress.

Additionally, Harkapaa (1996), investigating locus of control beliefs, cognitive coping strategies and other pain related cognitions, found that distress and internal locus of control were related to disability in back pain patients. Distress was also related to pain. Internal locus of control and distress correlated with disability: those with a high belief in their own control having less disability and less distress than those with weaker beliefs in internality. Patients with strong internal beliefs reported less intense pain and had less pain related behaviours than those with weaker internal beliefs. Harkapaa (1996) further stated that these results supported the theory by Johnston (1993) that pain related disability is not simply due to underlying impairment but is additionally influenced by psychological mechanisms.
It has also been suggested that gender differences in locus of control are present. Roberts (2002), investigating change in perception of control over a one year period in people with acute low back pain identified two trends. Firstly for both the 'powerful others' and 'chance' sub-scales, the differences between men and women were more marked with time and that secondly, clear differences existed between male and female perceptions of control. Men scored higher on external sub-scales compared to women suggesting that males perceived a greater influence of powerful others and chance factors in their back pain management than the female participants.

Summary of the role of psychological factors in long term health conditions

The role of psychological factors in health and illness is complex and multifaceted. By exploring relationships between psychological status and illness it can be seen that an illness viewed solely from a clinical viewpoint will not provide the full picture. The recognition that

other factors have a role to play will not only help a person to live with their illness but will also help to identify interventions which will be best suited to the individual.

1.4. PSYCHOLOGICAL FACTORS IN ANKYLOSING SPONDILYTIS

It follows from the literature focusing on other long term health conditions that psychological factors may also be relevant to AS. People with AS face a chronic, painful and progressively stiffening disease process. They also have the added uncertainty of exacerbation and remission from symptoms, and psychological status may well be an important influence. In addition, psychological dimensions might be important predictors of adherence to treatment as has been highlighted in a variety of chronic conditions.

Unfortunately there is paucity of literature regarding psychological status in AS. In one of the earliest studies, Basler, (1991) used a cognitive-behavioural treatment program for pain control within a self-help setting for AS patients in Germany. The aim was to improve 'self-control' strategies that included relaxation and imagery techniques, modification of thoughts and feelings and pleasant activity seeking. Pain severity, anxiety, depression, psychophysiological complaints, and sleep disturbance were assessed. Following the treatment programme reductions in pain intensity, anxiety and psychophysiological symptoms were demonstrated and maintained at twelve months. Emotional stabilisation and increased feelings of well-being were deemed to be the most important aspects of the treatment. This was confirmed by the patients who said, following the intervention, that pain was not having as great an influence on their life and that they were able to learn that there were more important things in life besides their pain. This study highlighted the benefits of alternative interventions other than conventional medical treatments in pain management in AS patients.

A small study investigating the relationship between functional disability and depression in both rheumatoid arthritis (RA) and AS patients (Karatay, 2004) revealed associations between depression scores and age, disease duration, pain and functioning scores in RA patients. Similar associations between AS and depression were also revealed as were those of disease duration, pain and physical functioning domains. This suggested that the degree of functional disability might play an important role in depression. In addition further influence of the

impact of depression has been identified (Wells, 2003). This study focussed on information-processing biases amongst chronic pain patients and AS patients investigating the impact of diagnosis. Diagnosed chronic pain patients demonstrated recall bias away from depression related stimuli, whilst non-diagnosed chronic pain patients did not. The diagnosed AS group showed a bias towards sensory stimuli, perhaps reflecting the presence of an enduring and over-riding pain schema which it was suggested could be a result of living with pain for so many years.

As well as having to cope with the pain of AS there is the prospect of physical deformity. The influence that this has on a person's perception of body image was investigated by Hider (2002). The presumption was that the physical deformities of AS would have a negative effect on the patient's body image. Interestingly it was found that body image was not related to regular AS exercises but that it was related to a person's general acceptance of their illness as well as their overall mood. Normally, regular exercise has a positive effect on body image, but in AS this study highlighted the fact that the recommended exercise program does not have such an influence. Feeling good about yourself underpins most human emotions and from this study it suggests that the factors which motivate patients to exercise regularly may be more complex than originally appreciated.

Coping strategies have been investigated in AS patients. Gunther (1994) demonstrated that the coping behaviour of AS patients was characterised by a significantly higher degree of 'playing down' of the stressful situation and less self-accusation and resignation compared to healthy controls. These coping mechanisms did not change significantly in the course of the illness as those with different disease durations did not differ from one another with regard to the coping strategies that they used. Those with low pain intensity used strategies such as 'playing down of the stressful situation through comparison to others' and 'positive self-instruction'. Furthermore, Boonen (2004) investigated the suggestion that avoidant coping might be independent of disease status and stable over time in patients with AS. The two avoidant coping strategies in question were the decreasing of activities in order to cope with pain and also pacing in order to cope with limitations. The time span for the study was four years and at first assessment, worse physical function (BASFI) and more pain (BASDAI) were associated with 'decreasing activities to cope with pain'. 'Worse physical function', but not pain was associated with 'pacing to cope with limitations'. Disease duration was not a

determinant of avoidant coping, but greater age was associated with 'pacing to cope with limitations'. The variation, which was seen in avoidant coping over the four years, could not be explained by a change in disease status.

Da Costa (2004) reported that mental health status and leisure time incorporating physical activity contributed to fatigue intensity in patients with spondyloarthropathy. They found that greater duration of weekly exercise participation was related to less fatigue only in patients who were in better mental health. This suggested that for the sub group of patients with more intense fatigue and poorer mental health status, a more multi-modal intervention incorporating the encouragement to exercise and psychosocial components may be advantageous. This is an example of how identification of sub groups might modify treatment interventions.
It has been suggested that quality of life can be influenced by AS. Davis (2005) found that patients with AS had significantly reduced health-related quality of life across a wide range of domains, particularly physical domains. In fact, patients with AS had significantly lower scores than the US general population on all SF-36 scales, and these exceeded those seen in other chronic conditions. Moreover, scores for the psychosocial domains were also lower, indicating that the quality of life when living with AS is considerably reduced.

The work by Barlow and colleagues (1992, 1993, 1996, 2001, 2002 and 2005) has contributed significantly to this field. Her initial study compared members and non-members of self help groups. Based on the theme that long-term treatment adherence is facilitated by the presence of supportive others, the hypothesis was that members would be more knowledgeable, would adhere to exercise and would seek information more than the non members. Utilising the health locus of control dimensions, this study showed that group members placed significantly less reliance on 'powerful others' for control over health than non-members. It would seem that people who join self-help groups may feel less reliant on medical personnel to control their health. Beliefs in the value of exercise also differed with group members exercising more often. They also sought more information about their disorder and perceived greater social support. These findings demonstrated the utility of including psychosocial variables in AS assessment and treatment. Barlow, (1993) also showed that one third of AS patients within a population of 129 men and 48 women had depressive symptoms and that women were more susceptible to depression than men. Pain was the main determinant of depression for women but was of less importance for men. AS patients had periods of psychological

distress but depression was expressed in terms of somatic rather than psychological symptoms. Barlow also emphasised that despite the stereotypical view of AS patients being well adjusted psychologically, they may also be susceptible to periods of psychological distress during the course of the disease. She recommended that future research should attempt to identify when episodes of depression are most likely to occur for example whether or not they occur during a flare. She also recommended that research should focus on the identification of effective methods of dealing with psychological problems.

The concept of self-efficacy has been shown to influence a variety of health behaviours, including exercise, and is related to several other constructs known to be important for health and well-being. These include locus of control, perceived control, helplessness and coping. Barlow (1996) suggested that patient education should be seen as a means of promoting self-efficacy amongst people with AS, thus enhancing psychological well-being and performance of health behaviour (exercise). She demonstrated that self-efficacy improved psychological well-being and reduced depression following group patient education sessions. However, she also found that exercise adherence was not sustained over six-months.

There had been increasing recognition of the role that expert patients can play in the management of their own disease which resulted in the growth of psychoeducational interventions designed to facilitate adaptation to challenges of chronic disease and promote self management (Barlow, 2002). Expert Patient Programmes have been designed with the premise that many patients are expert in managing their disease, and this could be used to encourage others to become 'key decision makers in the treatment processes'. Furthermore, these expert patients could 'contribute their skills and insights for the further improvement of services'. It is hypothesized that self-management programmes could reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy. It is stressed that this is more than just patient education to improve compliance. Instead there should be 'a cultural change ... so that user-led self-management can be fully valued and understood by healthcare professionals' (Tattersall, 2002).

The question of determining whether changes can be sustained over time following self-management training for people with chronic disease has been addressed by Barlow (2005). Using a generic intervention designed for people with all types of chronic disease, some

evidence was found that Expert Patient courses may lead to longer-term changes in self-efficacy. Use of some self-management behaviours and some aspects of health status such as fatigue and depressed mood could also be influenced, and these were maintained at twelve months. A similar intervention is the Chronic Disease Self Management Course (CDSMC) (Lorig, 1999), which is an intervention delivered by pairs of lay leaders in weekly sessions for six weeks. Topics include cognitive symptom management, communication, dealing with anger and depression, exercise, problem solving, contracting and living wills. The overall aim of the course is to enhance participants' sense of control over their condition.

One further aspect is the relationship between AS and work disability. Barlow (2001) investigated relationships between coping strategies and work disability, and found that 31% of their patient population (133) were unable to work due to their AS. Work disability was associated with being older, longer disease duration, lower educational standards, co morbidity, greater physical impairment, pain, fatigue, stiffness, anxiety, depression and lower self-esteem. This study therefore highlighted the psychosocial implications of AS and the effect that it has on the ability to remain in employment. Previous work had also demonstrated a similar link between AS and employment status. Roussou, (1997) compared 50 employed patients to 50 unemployed patients (all males), and found that those who were unemployed had higher disease activity and lower psychological well-being. In contrast, employed patients from the higher occupational group had less disease activity, lower pain and depression than those from the lowest occupational group.

1.5. SUMMARY

AS is a chronic inflammatory condition, characterised by unpredictable periods of exacerbation and remission, causing pain, stiffness and fatigue. The reduction in spinal mobility creates limitations in physical function and influences patients' perceptions of their body image. It is difficult to measure disease activity in AS and there are ongoing attempts to develop gold standard measures. These attempts have been driven by emergent medical innovation, and this has been shown to be effective in controlling this disabling condition, although conventional treatments of NSAIDS and physiotherapy remain the mainstay of treatment.

Tentative steps have been taken to identify risk factors for functional and social limitations for those living with AS although the biopsychosocial model has yet to be fully explored. However, some important suggestions not only as to how health is affected by biological processes but also on how psychological status and social issues may also be evident. Further expansion of a biopsychosocial model raises the possibility that predictive factors could be used to identify individuals, who may be helped by more appropriate targeted interventions in addition to conventional treatment.

The biopsychosocial model could potentially be an important development with benefits for clinical practice. Unfortunately, there has been only a small amount of work in AS to date addressing personal and environmental factors as the consequence of the disease process. Additionally, there have only been a small number of studies, which have investigated psychological factors in AS. Research has however highlighted the influence of psychological status on a variety of conditions, and models exist which attempt to explain illness interpretation and how people adjust their lives according to their disease status. The potential to screen for targeted treatment interventions has also been identified which obviously could be of considerable clinical benefit especially if those identified may have been at greater risk of non-adherence to conventional treatment.

Although there are as yet few studies to address biopsychosocial issues in AS, it should in principle be possible to explore this to enhance understanding of how living with this condition impacts upon a person's life. Overall, the published work reviewed in this chapter suggests that there may be associations between disease and psychological status in AS and it would be intriguing to discover the nature of these associations. This study will seek to explore these associations, to enhance understanding of the influence of disease and psychological factors on each other, and to consider their implications for clinical practice.

Therefore the aims and objectives of this study will be to investigate relationships between disease status and psychological status in a cohort of people with Ankylosing Spondylitis (AS). A combination of quantitative and qualitative techniques will be used to identify associations between disease and psychological status, in order to provide a detailed understanding of the underlying basis for these associations and insights into the implications of the findings for clinical practice.

In the first phase of the study, a longitudinal quantitative approach will be used to repeatedly measure a range of disease and psychological parameters, utilising well-established assessment tools, in a large AS cohort over an 18-month period. The objectives are:

1. To repeatedly measure disease and psychological status at six monthly intervals.
2. To determine the consistency of disease and psychological measures over 18 months.
3. To determine associations between disease and psychological status.
4. To identify patient sub groups based upon associations between disease and psychological status.
5. To identify individuals who demonstrated concomitant changes in disease and psychological status over the 18-month period.

In the second phase of the study, the nature of the associations between disease and psychological status will be explored in detail with individual patients whose scores over the 18-month period of study indicated concomitant change in disease and psychological status. The objectives are:

1. To understand individuals' perceptions of change in disease status and the associations, if any, of this with psychological status.
2. To add meaning and depth to descriptions of associations between disease and psychological status identified in the first phase.
3. To explore factors perceived by participants to influence disease and psychological status.

The integration of the quantitative and qualitative findings should therefore lead to greater understanding of the implications that disease and psychological status have for people challenged by living with AS. A greater understanding of the possible links between disease and psychological status could potentially enhance current management programmes and have the potential to inform new treatment strategies which would otherwise have not been considered for those with AS.

CHAPTER 2

METHODS

2. METHODS

2.1. STUDY DESIGN AND METHODS

A thorough review of the literature was undertaken to critically appraise existing knowledge in this field. The search strategy was repeated periodically throughout the study and was aimed at retrieving references relating to AS assessment outcomes and psychological status. There were no limitations on the year of publication for any of the searches. Databases searched included AMED, CINAHL, EMBASE, MEDLINE and PsycINFO. A list of the routine search terms is included in Appendix (1).

Eligibility criterion was set as English language and the title and abstract fields were included in the search. Results from the searches are included in Appendix (1a and 1b). Abstracts from the searches were read to identify key terms with specific emphasis upon links with psychological status. Reference lists of articles were also reviewed together with reference lists of reviews, texts and compendia. Predominant authors were also identified as were key publications by citation. Each paper was critically appraised to judge the quality of the research.

2.1.1. Overview of Mixed Methods Design

All researchers bring their own 'worldviews' or 'paradigms' which influence how they design and conduct their projects (Guba and Lincoln, 2005). Historically researchers were perceived to work within either a positivist or constructivist paradigm with each paradigm being informed by different theoretical and philosophical foundations relating to the belief about the nature of the social world and what we know about it (ontology) and the nature of the knowledge and how it can be acquired (epistemology).

The positivist paradigm is based upon determinism or cause and effect thinking. By focusing on selected variables, detailed observations and measurements are made to the test theories, which can be continually refined. Therefore the researcher works from the 'top' down, from a theory to hypotheses to data to add to or contradict the theory. Emphasis is placed on the distance and impartiality of the researcher who is perceived to undertake value free research in which personal biases and interpretations are not

acknowledged as being inherent in the research process, or as having an impact on data generation or interpretation (Cresswell, 2007).

A constructivist paradigm adopts an interpretive, naturalistic approach to the world with researchers studying things in their natural settings, attempting to make sense or interpret phenomena in terms of the meanings that people bring to them (Denzin and Lincoln, 2000). Participants provide their understanding or meaning of phenomena, which has been shaped by social interaction with others, and from their personal histories and within this context constructivist research acknowledges the existence of multiple realities. Research is shaped from 'the bottom up', from individual perspectives to broad patterns and ultimately to theory (Creswell, 2007). Researchers working within this paradigm acknowledge their role in all stages of the research process and do not see themselves as detached or unbiased.

Increasingly the divide between methodologies is being challenged and an increasing number of researchers are undertaking mixed methods research with the emphasis on adopting the right methods to address the question (Sandelowski, 2000, Pope and Mays, 2000). Qualitative and quantitative methodologies are not seen as competing or contradictory but complementary strategies that are appropriate to different types of research questions (Bowling, 1997). Mixed methods are regarded as being 'practical' in the sense that the researcher can use all relevant methods to address a research question using both inductive and deductive thinking therefore providing the most complete analysis using multiple forms of evidence (Creswell, 2007).

Creswell (2007) argues that we are social, behavioural and human sciences researchers first and that the adoption of either quantitative or qualitative approaches in some areas of research only serves to narrow the enquiry. By adopting a mixed methods approach it is thought that the researcher can provide a better understanding of the problem than if either approach were used on its own.

Additionally, the use of mixed methods often involves the use of more than one method of data collection (multiple methods). By adopting multiple methods it is suggested that error due to the methods being utilised average out and that different complementary questions within a study also assess the plausibility of threats to validity of the primary research technique used (Robson, 1993). Creswell (2007) suggests that mixed methods

encourage researchers to collaborate across what are sometimes regarded as adversarial relationships between quantitative and qualitative researchers. A mixed method encourages multiple worldviews or paradigms rather than the typical association of certain paradigms for quantitative researchers and others for qualitative researchers.

However in using a mixed methods design it is essential that informed decisions are made about how the methods are integrated in the different states of the research process and requires careful thought and clear presentation to provide a more complete picture of the problem (Creswell, 2007). When choosing the design, decisions need to be made about the use of concurrent or sequential timing for the different methods, whether the methods have equal or unequal weighting and how best the methods will be mixed. There have been several approaches to mixed method design described: merging and converging the two data sets by bringing them together in the process of analysis, connecting the two datasets by having one build upon the other, or embedding one dataset within the other so that one type of data provides a supportive role for the other data set (Creswell, 2007).

2.1.2 Design of this study

This project was designed initially as a quantitative study. However following analysis of the quantitative data a further question was posed which may not have been best answered by continuing with a quantitative methodology. At this point it was realised that to explain the findings of the initial study that a qualitative approach would be more appropriate. Creswell (2007) described four approaches to mixed methods design but the Explanatory Design possibly best explains the method that was chosen. The Explanatory Design is a two-phase mixed methods design with the overall purpose of having qualitative data to help to explain or build upon initial quantitative results. This design is therefore well suited to a study in which the researcher needs qualitative data to explain significant (or non significant) results, outlier results or surprising results (Morse, 1991). The second, qualitative phase is designed so that it connects to or follows on from the results of the quantitative phase.

There are two variants of the Explanatory Design: the follow-up explanations model which focuses upon results to be examined in more detail and the participant selection model which focuses on the appropriate participants to be selected to explore an issue in more detail. This study needed to add greater depth and meaning to the quantitative

results derived from a specific group of participants and therefore adopted a follow-up explanations model. The two-phase structure of the explanatory design makes it more straightforward to implement than other mixed method designs as the researcher conducts the two methods in separate phases and collects one type of data at a time rather than simultaneously. Therefore single researchers can conduct this design. The final report can also be written in two phases, making it straightforward to write up and provide a clear delineation for readers (Creswell, 2007).

There are however challenges for researchers who use the Explanatory Design model as this requires a lengthy amount of time to implement the two phases. The researcher may also face the challenge of deciding whether to use the same individuals for both phases, to use individuals from the same sample for both phases or to draw participants from the same population for the two phases. This was less of an issue in this study as the quantitative phase identified a specific subgroup of participants. It could also be more difficult to gain ethical approval as utilizing this design usually means that the researcher is unable to specify how many participants will be selected for the second phase until the initial findings are obtained (Creswell, 2007). Within the context of this study a second ethical committee application was required to conduct the qualitative phase.

2.2. DESIGN OF FIRST PHASE: PROSPECTIVE LONGITUDINAL COHORT STUDY

It has been recognised that AS is a difficult condition to study because of its heterogeneous nature, long disease duration and, until recently, the lack of appropriate, validated outcome measures. There is therefore a paucity of published data describing the natural history, course and prognosis of the AS (Robertson, 2004). Examples which exist include a thirty-three year follow up study with 22/51 AS patients from an original cohort developing severe mobility restrictions after just seven years of disease duration (Carette, 1983, cited by Robertson, 2004); Carbone (1992) also reported that there was an adverse survival rate for those who had received radiation treatment whilst Robertson (2004) found that the disease activity and function in their hospital based cohort had remained reasonably constant over a five-year period.

Invaluable data can be collected utilising longitudinal studies and currently there are examples of groups who are currently working to address this need. The German Spondyloarthritis Incept Cohort (GESPIC) is as ongoing prospective multi-centre study on patients with early spondyloarthropathy with a disease duration of symptoms of less than 10 years for AS; The Outcome in Ankylosing Spondylitis International Study (OASIS) is an ongoing prospective study of consecutive patients with AS from three different countries (Belgium, France and the Netherlands) and the Bath SMART (Spondyloarthropathy Metrology and Research Therapeutics Program) prospective cohort with many of the patients enrolled who have attended the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath for 10-15 years.

Such longitudinal studies have the capacity to capture trends with greater precision than would be obtained when measuring change with a series of cross sectional surveys (Bowling, 1997). Additionally, they can provide historical and unique insights into the experiences of individuals (Robson, 1999). For this study it was determined that in order to identify associations between disease and psychological status in AS, a prospective longitudinal cohort study would be the most appropriate design which could take account of possible changes in such associations over time in this long-term condition. Ethical approval was obtained both from the Wrightington, Wigan and Leigh Local Research Ethics Committee and the University of Central Lancashire Ethics Committee.

At Wrightington Hospital, a review group for monitoring disease status in AS and providing regular group exercise was established in 1983. Referrals to the group are taken from Consultant Rheumatologists on a regional basis. Patients with AS are diagnosed according to the Modified New York criteria (van der Linden, 1984). There are more than three hundred patients within this cohort. A large geographical area is covered by the service, which includes Preston, Chorley, Skelmerdale, Wigan and Leigh. People with psoriatic spondyloarthropathy are also included. This service offers patients assessment of their disease status at mutually agreed periods of time. It triages and responds to exacerbation of disease status providing further access to both physiotherapy and consultant care. The group offers open access to all participants and meets weekly to provide gym and hydrotherapy sessions.

On average, twelve patients receive appointments to attend for reassessment every week. For the purposes of this study and to rule out biased sampling, all booked appointments commencing April 2002 were sent out in the usual manner but these also included the information letter for the study. Individuals were asked as if they wished to be included within the study. A time period of three months was designated for recruitment as data collection was restrained within an eighteen-month time scale. Consent to participate was sought and 110 patients were recruited. It was noticeable that the majority of patients who were informed of the study agreed to participate. Patients with recent serious illness or pregnancy were excluded from the study. Patients' written consent was obtained according to the Declaration of Helsinki. (Appendix: 2a. Invitation letter, 2b. Consent Form and 2c.Patient Information Sheet).

It was recognised that there are challenges in developing and sustaining this type of study which include requirements for careful definition of the groups for study, careful selection of the variables for measurements, the use of sensitive instruments, which have the capacity to detect changes and a clear rationale to support the timing of repeated survey time points. Longitudinal studies can also be expensive; need robust administrative systems such as updates of addresses, deaths or losses of sample members, effective databases and inputting of data and a sustained effort to minimize sample attrition.

Participants could also become conditioned to the study and learn the responses that they believe are expected of them as they become more familiar with the questionnaire. It is also known that participants may remember previous responses, become sensitised to the research topic, become biased in some way or simply change because they are being studied (Hawthorne effect) (Bowling, 1997). There is also the issue of the 'healthy survivor effect' where the most vulnerable of the group or ill participants die or drop out which leaves the healthiest participants with potential to bias the results. Depressed people have also been shown to drop out which can improve the post-baseline psychological measurements (Bowling, 1997). The least healthy participants are also more likely to have incomplete assessments resulting in missing data. The length of the study may also lead to participants becoming uninterested and some may also lack the cognitive skills required and drop out owing to the demands placed upon them (Bowling, 1997). Robson (1999) also warned that participants may receive a

diffusion of treatments and that 'compensatory equalization of treatments' can occur as some participants receive 'special treatment'.

When designing this longitudinal study it was acknowledged that there are inherent difficulties with this design (Robson, 1999). However, this study was designed to fit in with the participant's usual assessment routines. It was felt that by performing the study in this way, that this would maintain attendance rates and not incur additional costs. Participants were also encouraged to recognise that their responses were being used in the clinical context thus avoiding sensitisation to the questionnaires. An eighteen-month time period was also regarded as not being excessively long. Therefore, in contrast to a cross sectional study, it was hoped that this design would be able to increase knowledge about the course and nature of the condition over time.

Baseline assessments of clinical and psychological measurements were completed at recruitment. Patients were then sequentially reassessed at 6-monthly intervals until 3 further assessments had been completed. Other demographic data, such as current work status including retirement on medical grounds and marital status, were also collected at baseline via a self-completion questionnaire. Co existent disease (including iritis, psoriasis, inflammatory bowel disease), date of birth and age of onset were retrieved from the current physiotherapy records. Age of onset was defined as the patient's recall of their age when their first symptoms occurred. If age of disease onset was not available from the records, this was obtained via patient self-report at baseline. Disease duration was obtained by subtracting age of onset from the age at recruitment into the study.

Each participant was given a unique identification number. The study record sheet was kept within the physiotherapy record and this was stored in the usual manner at the hospital. The investigator was responsible for calculating results from all the assessment tools. The data sheet from the participant's notes was copied but contained only their identification number with no personal details and these were stored in a locked filing cabinet at the hospital. A copy of the consent form was given to the participant, one was stored within their physiotherapy record and the third copy was kept within a separate folder and stored within a locked filing cabinet.

The investigator stored the data on a password-protected computer with all data anonymised using the identification number only. All completed assessment booklets were stored within a locked filing cabinet at the hospital and were identifiable with the identification study number only. This study generated vast amounts of data and the principal investigator was solely responsible for data collection, questionnaire calculations and data inputting. Therefore at each assessment in an effort to minimise data loss, the data was calculated and inputted into the database until every participant had completed four assessments. Participants who 'dropped put' also had their data included within the analysis. The analysis included comparison of data over time in relation to the same participants who took part at each data collection point (including baseline stage) so as to compare 'like with like'. It was deemed important to analyse those who dropped out to ascertain any differences between them and the remaining sample members in order to modify biasing effects of only analysing the survivors. Cross-sectional comparisons of the total samples at each stage were also made.

2.3.1. Assessment tools for disease status

2.3.1. Metrological status

The Bath Ankylosing Spondylitis Metrology Index (BASMI) (Jenkinson, 1994), was selected to assess axial, hip and pelvic soft tissue status and to determine clinically significant changes in spinal movement. Extensively reported within clinical trials in AS, this instrument provides reliable data regarding disease status in AS. It is quick to complete, valid, reliable reproducible and sensitive to change across the disease spectrum (Moncur, 2003). BASMI assessments were performed by 2 senior physiotherapists fully trained in this method in order to minimize inter observer error. The measurements for the five domains are calculated into an overall score range of between 0 and 10 with the range of severity reflecting mild or severe disease status.

Within this study, the principal investigator was designated to perform all BASMI assessments. However the study ran for two years and therefore if the investigator was absent, the other fully trained assessor deputized. As appointments were arranged in advance at a mutually agreeable date, every effort was made to avoid potential absences by the investigator. An estimation of the proportion of assessments completed by the investigator during the entire study would be between 90-95%. All assessments were completed at approximately the same time in the late afternoon to minimise variation

due to timing of assessment. A standardised assessment protocol was followed and the method for obtaining each measurement is shown Table 2.1

Table 2.1 BASMI Assessment Protocol

Schober – Lumbar flexion	• Patient standing erect, mark PSIS (S2) • Mark 10cm above and 5cm below this line • Ask patient to try to touch toes • Measure change in tape distance
Intermalleolar Distance – Hip abduction	• Lie patient in supine as flat as possible • Ensure knees are extended • Ask patient to separate feet as wide as possible • Measure distance between medial malleoli
Cervical rotation – Neck mobility	• Patient sitting • Rotometer resting on relaxed shoulders • Rotometer close to neck • Centre zero to centre chin • Ask patient to turn as far as possible to the right reading angle of turn from the centre of the chin • Repeat to the left • Calculate mean measurement
Tragus to wall distance – Posture	• Stand patient against a flat wall • Ensure heels, hips and shoulders (if possible) are touching the wall • Ask patient to tuck chin inwards and try to touch the wall with the back of the head • Measure distance between tragus and wall using metal tape • Measure right and left sides • Calculate the mean measurements
Lumbar side flexion – Spinal mobility	• No shoes • Standing against a flat surface with heels and if possible shoulder blades touching • Feet 12 inches (30 cms) apart • Measure middle finger tip to floor distance with a metal tape • Ask patient to slide right arm down right leg measuring middle finger tip to floor distance at the end of the movement • Ensure that knees remain straight and that heels do not lift during the movement • Calculate the difference

Overall calculations were made using the BASMI scoring guide (Appendix 2.d).

2.3.2. Functional Status

The Bath Ankylosing Spondylitis Functional Index (BASFI) (Calin, 1994) was used to assess functional status, This self-complete questionnaire asks respondents about their perception of their functional ability and how well they are able to function in every day life over the past month. The BASFI includes 10 items on ability to perform and cope with

activities of daily living. Each activity is scored on a 10cm visual analogue scale (VAS). The mean of the 10 scales yields the total score between 0, indicating that the activity is easy, to 10 indicating that the activity was impossible for that person to accomplish. It is a reliable instrument which is quick and easy to complete and sensitive to change across the spectrum of the disease (Moncur, 2003). An example of the questionnaire can be found in Appendix 2.e.

2.3.3. Disease activity

To measure disease activity, the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) (Garret 1994) was chosen. This instrument has been utilized and reported throughout the clinical trial literature for AS and has become a significant component for identification of persons to meet selection criterion for biologic therapies. It is a self-administered instrument which is scored using a 10cm visual analogue ranging from 'none' to 'very severe' over the past week. Items relating to pain and discomfort, fatigue, areas tender to touch or pressure and stiffness ranging from 'none' at the start and 'very severe' are assessed with higher scores reflecting greater disease activity. An example of the questionnaire can be found in Appendix 2.e.

2.4. Assessment tools for psychological and health status

2.4.1. Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) (Zigmond, 1983) was chosen to measure both anxiety and depression,. Not only had this been used as part of the standard assessment schedule for the AS Review Group, but it was regarded as being quick and easy to complete. HADS within the clinical and research setting and has been found to be particularly useful when studying the cognitive processes associated with depressive symptoms and anxiety due to the fact that it is free from physical symptoms such as insomnia and weight loss (Herrmann, 1997). This self administered questionnaire consists of 7 depression items measuring cognitive and emotional aspects of depression (HADS – D) and 7 anxiety items focusing on emotional aspects of anxiety (HADS – A). HADS utilises a 4 point Likert scale ranging from 0 to 3 with higher scores indicating greater severity. The authors recommended cut off scores for the sub-scales which are 0 to 7 considered non-case, 8 to 10 considered possible case and 11 to 21 considered probable case. An example of the questionnaire can be found in Appendix 2.e.

2.4.2. Locus of control

To provide information on three theoretically distinct and empirically different dimensions of health locus of control, the Health Locus of Control – Form C Questionnaire (Wallston, 1994) was chosen. This self-complete questionnaire collates responses as indicated on a 6-point Likert scales ranging from strongly disagree to strongly agree. Higher subscale scores indicate greater belief in each of the locus of control domains. An example of the questionnaire can be found in Appendix 3. Form C was also chosen as it was designed for patients with back pain and therefore would be more suitable for patients with AS.

2.4.3. Generic Health Status

Finally, to assess generic health status, the Short Form (SF)-36 questionnaire (Ware & Sherbourne, 1992), was used. The SF 36 is a questionnaire designed to assess eight dimensions of health status, which includes physical functioning (10 items), role limitations due to physical problems (4 items), bodily pain (2 items), social functioning (2 items), mental health (5 items), role limitations due to emotional problems (3 items), vitality and overall/general health (5 items). For the SF 36 domains, lower scores indicate worsening status and more limitations. An example of the questionnaire can be found in Appendix 2.e.

All questionnaires were formatted within a booklet (Appendix 2.e). Prior to the commencement of the study, five hundred copies of the booklet were made to ensure accuracy of the 10-cm VAS lines. One advantage was that participants were familiar with all but two of the assessment tools chosen, since HADS, BASFI and BASDAI had been utilised for several years as routine assessment parameters. Formatting of the booklet was designed to present the questionnaires in a logical order. The HADS questionnaire with which patients were familiar was presented initially. The unfamiliar Locus of Control Form C followed this. BASFI and BASDAI were presented opposite to one another as the central component. Finally the SF36 generic measure, which was the longest questionnaire, was included as the last component.

The questionnaire booklet took approximately 30 minutes to complete. At the initial assessment the investigator issued the booklets and gave a full explanation on how to complete each questionnaire. Subsequently, the questionnaires were posted to the participants along with their appointment dates. This allowed the participant time to complete the questionnaires at home and also allowed the investigator an opportunity to

check for completion and answer any queries as they attended for review. It was stressed to participants that the questionnaires were to be completed as near to the appointment date as possible.

2.5. Statistical analysis

Data were stored and analyzed in SPSS (Release 12). Relationships between each of the three measures of disease status (BASFI, BASDAI and BASMI) and each measure of psychological and generic health status were assessed using Spearman's rank correlation coefficients (Robson, C, 1999). It was important to identify subgroups of patients to ascertain if there were differences between groups attributable to determinants related to AS (e.g. iritis). Age, gender and psychological differences (e.g. those who were anxious as compared to those who were depressed) potentially could also be influential factors. Therefore, based on data collected at enrolment, subgroups were defined by: presence or absence of iritis, presence or absence of psoriasis, Health Locus of Control sub scale scores, gender, age and disease duration. Variables (age, disease duration and Health Locus of Control sub scale scores) were dichotomised close to their medians, thereby generating two subgroups of similar size in each case. Correlations between disease status measures and HADS anxiety and depression scores within subgroups were also explored. Table 2.2 shows the number of participants within each sub group.

Table 2.2. Number of participants within each sub group

Variable	Numbers within each sub group	
Beliefs in powerful others (≥ 30)	High beliefs n = 43	Low beliefs n = 46
Iritis	With n = 48	Without n = 41
Psoriasis	With n = 14	Without n = 75
Gender	Male n = 74	Female n= 15
Age (median = 50 years)	< 50 n = 44	>50 n = 45
Disease duration (median = 20 years)	<20 n = 49	>20 n = 40
Hip Involvement (median = 99cms)	<99cms n = 42	>99cms n= 47
Beliefs in internality (≥ 30)	High beliefs n = 43	Low beliefs n = 46
Beliefs in chance (≥ 30)	High beliefs n = 44	Low beliefs n = 45

Subgroups were also formed at each assessment point based on anxiety and depression scores. Cut-off scores of 11 were used to define clinically anxious and depressed subgroups (Herrmann, 1997). Table 2.3 shows the number of participants in each sub group for anxiety and Table 2.4 for depression at each of the four assessment points.

Table 2.3. Number of participants in each sub group with or without anxiety at each assessment point (cut-off score of 11 on HADS scale)

Assessment 1		Assessment 2		Assessment 3		Assessment 4	
Non Anxious	Anxious	Non Anxious	Anxious	Non Anxious	Anxious	Non Anxious	Anxious
74	15	69	20	69	20	71	18

Table 2.4. Number of participants in each sub group with or without depression at each assessment point (cut-off score of 11 on HADS scale)

Assessment 1		Assessment 2		Assessment 3		Assessment 4	
Non Depressed	Depress	Non Depress	Depress	Non Depress	Depress	Non Depressed	Depress
82	7	74	15	78	11	71	18

Between-group differences in outcomes on interval scales were analysed using independent-samples t-tests, using its approximate form when group variances appeared different. Characteristics potentially associated with study non-completion were assessed using independent-samples t-tests (Hazard, Munro, 2001) for characteristics measured on an interval scale and the Fisher's exact test otherwise. Tests resulting in p-values less than 0.05 were classed as statistically significant. The sensitivity of findings to parametric assumptions was assessed when these were in doubt. The sensitivity to exclusion of those not completing all assessments was also investigated.

Further analysis was also performed in Stata (Release 6). The stability of each outcome measure over time was investigated using repeated measures ANOVA (Diggle, 1994). The Huynh-Feldt correction for non-sphericity (Huynh, 1976) was used to obtain p-values. This data was presented only in Table 3.6, which is located in the Group analysis results in the following chapter. Data analysis was carried out in conjunction with a statistician based at the university.

2.6. IDENTIFICATION OF CONCURRENT CHANGES IN DISEASE AND PSYCHOLOGICAL STATUS ON AN INDIVIDUAL BASIS

To explore the nature of the associations between disease and psychological status identified in Phase 1, identification of individuals who had demonstrated concomitant changes in disease and psychological status was crucial. These individuals would potentially be able to provide insights into these associations most clearly. The approach therefore was to identify individuals whose disease and psychological scores changed in concert over at least 2 consecutive assessments during the 18-month period. To investigate changes in individual scores over time, correlations between changes in disease status measures and HADS anxiety and depression scores for each individual were explored. Potential associations were identified using graphs of sequential data plots. Percentage change for each time point was then calculated to provide a quantitative expression of change in each case.

2.7. DESIGN OF SECOND PHASE: INSIGHTS INTO ASSOCIATIONS BETWEEN DISEASE AND PSYCHOLOGICAL STATUS

Analysis of data from Phase 1 of this study identified a cohort of 16 participants who demonstrated a linkage between their disease and psychological status. The aim of the second phase of the study was to explore in depth the associations these participants' made between their disease and psychological status. This approach enabled the findings obtained in Phase 1 to be extended by exploring further the linkage between disease and psychological status at an individual level, and to gain insights into possible mechanisms for this. A qualitative approach was used to provide insights into people's own perspectives on and interpretations of their beliefs and behaviours and the meaning they attach to them (Ritchie and Lewis, 2003). Thus the use of a multi-method approach sought to produce a more holistic view of the issue under investigation.

2.7.1. Methods

Two methods were used to gain insight into participants' experiences, namely, personal reflective diaries and in-depth interviews.

2.7.2. Personal diaries

Personal diaries were chosen as a method which would provide an ethnographic context to the data by obtaining an in depth, first hand account of the participants' lives which would otherwise be difficult to obtain direct access to (Burgess, 1984). Whilst interviews provide first hand accounts they are inevitably constrained by the researcher and the timing of the interview. As suggested by Burgess (1984) diaries provide greater freedom enabling people to record events as and when they want, in as much detail as they want and in the way that they want. Therefore in seeking to explore the impact of change in disease status on mood it was felt that diaries would enable people to record their feelings at the time when changes were being experienced and could potentially provide a more detailed insight into the impact of such changes. The likelihood of an interview coinciding with such an event would be relatively small.

As suggested by Alaszewski (2006) diaries have the potential to provide greater insights into how people interpret situations and give meaning to events and because they can be relatively unstructured minimise the distortions and enabling diarists to express themselves. Whilst interviews seek to create a naturalistic setting they are structured discussions (Rubin, 1995) during which the researcher is able to direct the discussion and choose to pursue specific topics. Within the context of a diary no such influence is possible as the diarist chooses how they wish to maintain the diary and the level of information they wish to share.

Therefore this approach was chosen as a mechanism to help participants record the impact that their disease activity had upon their psychological status. The aim of using the diary was to provide an opportunity for the participant to record a descriptive account of any changes in their disease status, which occurred over a period of time and their thoughts about how this was impacting upon their lives, and their psychological status.

In choosing to use this method consideration was given as to how much structure to impose on the diary. A highly structured diary has the potential to limit freedom and expression and the range of insights offered, conversely an unstructured diary which provides no guidance has the potential to capture data which are tangential to the focus of the research (Alaszewski 2006). It was decided to adopt a semi-structured approach which would provide guidance on the kind of information that was being sought but

allow the participants to interpret this in their own way in terms of the content and length of entries.

A time scale of one month was chosen, informed by clinical experience, as this was perceived to potentially allow for changes in disease status to occur although this could not be guaranteed.

Appointments were made with each participant to explain the structure of the diary and to provide guidance for completion. It was emphasised that the participant should describe how any changes occurring in their disease status impacted on their psychological status i.e. mood. The fact that entries were not necessary every day was also emphasised and that they only needed to complete it at times when participants felt that they had 'something which they wished to share'.

The investigator designed the diary (Appendix 4) which was A4 sized and pages held within a folder. There were sufficient entry pages to cover the time scale. Each page asked for the date and entry number. It consisted of an explanatory page containing instructions on the use of the diary, which emphasised the aim of describing how AS affected emotional status and the agreed start and finish date. A contact telephone number was included and the participant was encouraged to contact the investigator should they have queries about this.

For each entry a person made they were also asked to respond to the following 2 questions:

- Please mark the line below with a cross to tell me how your AS has been today?
- Please mark the line below to tell me how much your AS has affected the way that you feel emotionally today?

The responses to these questions were marked on a 10cm VAS line.

This particular design utilising a VAS line was chosen as the participants were already aware of this format from the questionnaires utilised in the quantitative study. There was an additional instruction that the participant should not feel obliged to fill in all the space on the page and that they should use as little or as much space as they required.

This was felt to be important due to the A4 size of the page, which could prove to be a daunting amount of space particularly for participants who may have literacy problems or who may find it difficult to express their feelings using the written word.

2.7.3. Interviews

In-depth interviews provide the opportunity for detailed investigation of personal perspectives and also provide insights into the worlds of others to find out what is going on, why people do what they do and how they understand their worlds (Rubin, 1995). The aim of the interview was to explore in-depth the participant's perceptions of how changes in their disease status impact upon their emotional status. The interviews provided a unique opportunity to explore personal accounts and to illuminate meanings that participant's associate with their disease and psychological status. Clarification of thoughts and descriptions are also possible as are explanations, which are a paramount aim of this study. The opportunity for a participant to be interviewed also provides a unique and unusual experience in that someone is dedicated to listening to them. Therefore this encourages freedom of speech, an opportunity to reflect and a reinforcement of value and worth to what they are saying.

A semi-structured approach was adopted using an interview schedule to guide but not constrain the discussion. The interview schedule reflected the flexible, iterative approach central to qualitative research and was changed as the research progressed to reflect insights gained from participants. The semi-structured nature of the interviews enabled relevant issues identified and disclosed within the study by participants to be explored alongside questions included within the schedule.

2.8. Study Design

Ethical approval was obtained from Wrightington, Wigan and Leigh NHS Trust Local Ethics Committee and the Department of Psychology Ethics Committee at UCLan.

An information letter was sent to each of the 14 participants who had been identified as demonstrating associations between their disease and psychological status over time. Two of the participants from the original 16 identified by the analysis were not approached to continue in the study due to the fact that their diagnosis of AS was being questioned and asking them to participate was regarded as being inappropriate in the circumstance. The letter contained a description of the qualitative study and an

invitation for consent to participate (4a.invitation letter, 4b.consent form and 4c.patient information sheet).

2.8.1. Diary completion

Once volunteers had agreed to participate, an appointment was made to obtain informed consent and to explain the use of the diary. This ensured that participants were aware of the kind of information that was being sought in the diary and understood that they were being asked to write in it, when they felt that it was appropriate rather than keeping a daily record, which would place too many demands upon them. Every attempt was made at the consent stage to redefine the role of the investigator and to advocate an investigation into disease coping strategies and the affect of disease upon the individual rather than focusing on exercise and physiotherapeutic management. A time scale for completion of the diary was agreed, along with a time for its collection. Halfway through the agreed period the investigator telephoned participants to ensure that they were not experiencing any difficulties.

2.8.2. Interview

Once the diary had been completed it was collected and an appointment made to complete the interview. The diary was read in detail and it was utilised to inform the interview schedule. The key areas explored in the interview were: participants' perceptions of changes in disease status; the perceived impact of changes in disease status on daily life and family dynamics and participant's perception of how changes in disease status affected their psychological health and coping strategies. The topic of how psychological status may affect their disease status was also addressed.

Of the 14 people sent information letters, 2 failed to reply and 12 people volunteered to participate. One participant had recently undergone hip replacement surgery, which was complicated by dislocation and subsequently did not take any further part in the study. Therefore 11 interviews were conducted. The interviews were conducted in either the participant's home or at the hospital. It was felt to be important that the participant should have the choice of venue. The participant's preference was for the interview to take place at the hospital (seven as compared to four at participant's homes).

Due to the investigators clinical relationship with the participants within both settings the investigator reinforced the distinction between the interview being conducted for

research rather than for clinical purposes. Consideration was given to the investigator being the clinician responsible for the participants and the potential for disclosures from the participants of information, which could be deemed to be sensitive. However there were instances when the participant disclosed that they were prepared to share more with the investigator than they would have done with a person less well known to them. This was attributed to the level of trust, which was already established. Participants were also advised that they should not disclose anything with which they were not comfortable. They were reassured that their interview would be treated with confidentiality and that should they disclose anything which the investigator was concerned was detrimental to their well being, their permission would be sought to contact and disclose this to a third party. The participant's consultant had been informed prior to commencement of the study that they were to be involved and their consultant was asked to support the participant should the need for intervention arise (Appendix 4d).

Prior to the interview commencing, permission was sought to tape record the interview. Interviews lasted for one hour on average, the shortest being thirty minutes and the longest being an hour and a half.

The interview and diary contents were then transcribed verbatim on a password-protected computer, by the investigator for the purposes of analysis. Copies of the transcripts of the interview and diaries were made available for those participants requesting them. All data was stored using the participant's identification number from the initial study. Tapes and diaries contained the identification number only and the investigator was the only person able to identify the individual. No personal details were used to identify the participant. Transcriptions and data analysis were stored on a password-protected computer and used identification numbers only. All quotations used within the text were anonymous. Tapes, diaries and transcripts of the interviews were stored within a locked filing cabinet at the Hospital. The Research and Development Department at Wrightington, Wigan and Leigh NHS Trust recently performed a Research Governance Audit on the study, and found that the study met in full all of the set criteria.

When the interview was conducted within a person's home, the investigator made others aware of the location and time scales and complied with the hospital lone workers guidance. A mobile phone was also available.

2.8.3. Data analysis

Thematic analysis was used to establish key themes from the transcripts. Analysis was an iterative, interpretative process in which a systematic and rigorous approach was utilised to ensure that codes, code frameworks and themes were grounded within the data. Ritchie and Lewis describe a three-stage hierarchy of analysis, comprising data management, descriptive accounts and explanatory accounts (Ritchie and Lewis, 2003).

Initially familiarisation with the raw data was achieved by repeated readings of both the transcriptions of the diaries and interviews. This facilitated the identification of themes/codes and gave an overview of the data before it was fragmented. As each code was identified, a meaning was defined for the code. Codes were then applied across the transcripts using computer assisted qualitative data analysis software (CAQDAS) to facilitate this process. The specific CAQDAS package chosen was ATLAS. Ti V 5.0. The data was then sorted by creating 'families' of codes (supercodes) which allowed codes which where similar to be linked together. The supercodes were also assigned meanings. Summarisation of the data involved a synthesis of the supercodes, which enabled identification of elements and dimensions contained within the data. At each stage of the analysis, data was shared and coding crosschecked with a member of the supervisory team. Discrepancies were explored and meanings explained and discussed until mutually agreed upon.

The investigator acknowledged that the skills required to both under take and analyse qualitative research are an entirely different entity to quantitative research methods. In order to address this issue, the researcher worked closely with one member of the supervisory team who was experienced in qualitative research methodologies.

Examples of a transcript (Appendix 5) and the supercodes (Appendix 6) created within the analysis have been provided.

2.9. SUMMARY

The aim of this study was to investigate relationships between disease status and psychological status in a cohort of people with AS, utilising a combination of quantitative and qualitative techniques to identify associations between disease and psychological status. The study was designed to provide a detailed understanding of the underlying basis for these associations and insights into the implications of the findings for clinical practice. For the principal investigator, who had to combine clinician and researcher roles there were ethical and transparency considerations throughout the study. However awareness of potential influences, which could arise, remained of paramount importance and as such was addressed throughout the study.

CHAPTER 3

RESULTS FROM THE LONGITUDINAL PROSPECTIVE COHORT STUDY

RESULTS FROM THE LONGITUDINAL PROSPECTIVE COHORT STUDY

3.1 CHARACTERISTICS OF STUDY PARTICIPANTS

One hundred and ten participants (86 men, 24 women) consented to participate and completed the initial assessment. Characteristics of this group were: median age 47 years, median age of reported disease onset 25 years, median duration of disease 18.5 years. Fifty-eight participants worked full or part-time, 46 were unable to work or were unemployed (data for 6 participants was missing). Eighty-one participants were married, 7 divorced and 18 single, with 8 living alone (data for 4 participants was missing). Eight people had co-existent inflammatory bowel disease, 47 had previous iritis and 14 had psoriasis. These data are shown in Table 3.1.

Table 3.1. Characteristics of study participants (n = 110)

	Median	Interquartile Range (IQR)	Range
Age (years)	47	38-55	18-77
Reported disease onset (years)	25	18-32	9-58
Disease duration (years)	18.5	13-27	1-50
Working fulltime/part time	58		
Unable to work/unemployed	46 (6 missing)		
Married	81		
Divorced	7		
Single	18		
Living alone	8 (4 missing)		
Inflammatory bowel disease	8		
Iritis	47		
Psoriasis	14		

3.1.1 Group scores on entry to the study

On entry to the study, mean scores for disease status in study participants (n = 110) were BASMI 3.36, BASFI 4.63 and BASDAI 5.0. Mean score for anxiety was 6.86 and for depression 5.41. Mean scores for locus of control domains were chance 23.47, powerful others 26.37 and internality 29.70. Mean scores for SF36 domains were physical functioning 56.25, role limitation physical 34.0, role limitation emotional 24.43, social functioning 58.61, mental health 54.25, energy/vitality 36.71, pain 47.24, general health perception 45.65 and change in health 48.26. These data are shown in Table 3.2.

Table 3.2. Group scores on entry into the study (n = 110)

	Mean	Median	Standard Deviation	Range
BASMI	3.36	3.2	1.81	0.40 - 8.20
BASFI	4.63	4.65	2.63	0 - 9.74
BASDAI	5.0	5.35	2.24	0.20 – 9.04
Anxiety (HADS-A)	6.86	7.0	4.44	0 – 18
Depression (HADS-D)	5.41	5.0	4.22	0 – 19
Chance LOC	23.47	23.0	6.3	8 – 39
Powerful other LOC	26.37	26.0	6.30	15 – 47
Internal LOC	29.70	30.0	6.72	14 – 43
Physical functioning (SF 36)	56.25	55.0	30.8	0 – 100
Role limitation physical (SF 36)	34.0	32.50	26.76	0 – 80
Role limitation emotional (SF 36)	24.43	13.0	26.91	0 – 80
Social functioning (SF 36)	58.61	60.75	25.91	0 – 89
Mental health (SF 36)	54.25	56.0	18.70	12 – 92
Energy/vitality (SF 36)	36.71	40.0	19.04	0 – 80
Pain (SF 36)	47.24	44.0	25.41	0 – 100
General health perception (SF 36)	45.65	45.0	25.78	0 – 100
Change in health (SF 36)	48.26	50	14.86	0 – 100

3.1.2 Characteristics of participants who completed all 4 assessments

Eighty-nine (74 men, 15 women) of the 110 participants (80.9%) completed all 4 assessments. Reasons for non-completion were non-attendance (13), myocardial infarction (2), incomplete fulfillment of AS diagnostic criteria (3), and incomplete data recording (3). Among the 89 study completers, median age was 50 years, median age of reported disease onset 25 years, median duration of disease 18 years, and median age of diagnosis 35 years. Forty-eight participants worked full or part-time, 41 were unable to work or unemployed. Seventy participants were married, 4 divorced and 15 single, whilst 6 lived alone. Eight people had co-existent inflammatory bowel disease, 41 had previous iritis and 14 had psoriasis. Of these, 3 had both bowel and eye involvement, 2 had bowel and skin involvement and 4 had eye and skin involvement. Forty-one of 47 participants with iritis completed all assessments. These data are shown in Table 3.3.

Table 3.3. Characteristics of study participants who completed all 4 assessments (n = 89)

	Median	Interquartile Range (IQR)	Range
Age (years)	50	38.5 – 55.5	18- 77
Reported disease onset (years)	25	18 - 33	9 - 58
Risease duration (years)	18	13 - 27	2 - 50
Working fulltime/part time	48		
Unable to work/unemployed	41		
Married	77		
Divorced	4		
Single	15		
Living alone	6		
Inflammatory bowel disease	8		
Iritis	41		
Psoriasis	14		
3 had bowel and eye involvement **2 had bowel and skin involvement** **4 had eye and skin involvement**			

Characteristics of each individual participant, baseline scores for individual participants and initial SF36 scores for individual participants are shown in Appendix 7a, 7b and 7c.

3.1.3 Characteristics of participants who completed less than 4 assessments

Twenty one participants (12 men, 9 women) completed less than 4 assessments. Characteristics of this group were: median age 42 years, median age of reported disease onset 21 years, and median duration of disease 20 years. Ten of this group worked full or part-time, 6 were unable to work or unemployed (data for 5 participants was missing) Eleven participants were married, 3 divorced and 3 single, with 2 living alone (data for 3 participants was missing). No participants had co-existent inflammatory bowel disease; 6 had previous iritis and none had psoriasis. These data are shown in Table 3.4, and scores on entry to the study for these participants are shown in Table 3.5.

Table 3.4. Characteristics of participants who completed less than 4 assessments (n = 21)

	Median	Interquartile Range (IQR	Range
Age (years)	42	36 – 49.5	23-66
Reported disease onset (years)	21	15.5 - 28	11-46
Disease duration (years)	20	12.5 - 31	1- 42
Working fulltime/part time	10		
Unable to work/unemployed	6 (5 missing)		
Married	11		
Divorced	3		
Single	3		
Living alone	2 (3 missing)		
Inflammatory bowel disease	0		
Iritis	6		
Psoriasis	0		

Table 3.5 Scores on entry into the study for study non-completers (n = 21)

	Mean	Median	Standard Deviation	Range
BASMI	3.32	2.8	2.11	0.40 - 8.20
BASFI	5.36	6.20	2.68	0 – 8.89
BASDAI	5.57	6.20	2.17	0.72 – 8.64
Anxiety (HADS –A)	7.86	7.0	4.38	2 - 18
Depression (HADS-D)	4.57	4.0	3.88	0 - 10
Chance LOC	23.95	23.0	5.82	13 - 34
Powerful other LOC	24.81	24.0	5.44	18 - 39
Internal LOC	30.09	29.0	6.46	22 - 43
Physical functioning (SF 36)	63.80	70.0	29.15	5 - 100
Role limitation physical (SF 36)	26.19	25.0	24.44	0 - 80
Role limitation emotional (SF 36)	18.90	13.0	23.37	0 - 80
Social functioning (SF 36)	62.43	66.0	26.62	0 - 89
Mental health (SF 36)	53.52	60.0	21.11	16 - 80
Energy/vitality (SF 36)	41.10	50.0	19.03	0 - 65
Pain (SF 36)	48.81	55.0	24.56	0 - 88
General health perception (SF 36)	40.0	45.0	24.03	0 - 90
Change in health (SF 36)	46.43	50	8.96	25 - 50

Baseline disease status and psychological scores for the 21 participants who completed less than 4 assessments were not significantly different on any measure compared with those who did complete the study, although women were significantly more likely than men not to complete all assessments (P=0.017). Inclusion of these 21 individuals for the analysis of the first assessment data did not substantially alter any of the findings.

3.2. DISEASE, PSYCHOLOGICAL STATUS AND HEALTH STATUS FOR STUDY COMPLETERS DURING THE STUDY PERIOD

Mean (SD) scores for each measure for the 89 study completers are shown in Table 3.6. Overall the mean scores for disease and psychological parameters throughout the 18 month study period were relatively stable, although there was a significant (P=0.002) effect of time on anxiety score, due to disparity between the score at assessment 1 and scores at assessments 2-4, the latter of which were all very similar to each other. The overall significance of this finding is therefore unclear.

Table 3.6. Mean (SD) scores for each disease and psychological measure for participants who completed all assessments (n=89)

	ASSESSMENT				
	1	**2**	**3**	**4**	***P**
BASMI	3.37 (1.74)	3.49 (1.71)	3.41 (1.66)	3.45 (1.73)	0.43
BASFI	4.48 (2.61)	4.64 (2.71)	4.74 (2.75)	4.73 (2.81)	0.12
BASDAI	4.89 (2.25)	4.91 (2.40)	5.00 (2.36)	4.85 (2.40)	0.78
Anxiety (HADS-A)	6.76 (4.48)	7.69 (4.51)	7.51 (4.58)	7.57 (4.50)	0.002
Depression (HADS- D)	5.35 (4.32)	6.07 (4.93)	5.76 (4.31)	5.84 (4.56)	0.10
Internality (LOC)	30.13 (6.81)	29.42 (7.18)	28.90 (6.51)	29.43 (6.62)	0.15
Belief in chance (LOC)	23.49 (6.65)	23.84 (6.48)	24.15 (6.49)	24.85 (6.26)	0.13
Belief in Powerful others (LOC)	26.31 (6.49)	26.07 (6.58)	26.30 (6.11)	26.58 (5.51)	0.79

Table 3.6 shows mean (SD) scores for each measure of disease and psychological status at assessments 1, 2, 3 and 4. Differences in disease and psychological scores over time were tested using repeated measures ANOVA. P-values are shown (*) for each measurement tool.

Mean BASMI, BASDAI and BASFI scores for this group were very similar to those described by others in previous studies (Heuft-Dorenbsch, 2004, Auleley, 2002, Band, 1997, Sweeney, 2002, Robertson, 2004, Taylor, 1998, 8) but, as would be expected, were generally lower than in groups participating in clinical trials of anti-TNFα therapy (Braun, 2002, Brandt, 2003, Gorman, 2002, Maksymowch, 2002, 8). This suggests that the instruments behaved in the expected manner within this cohort. Similarly, normative data for anxiety and depression scores among 1792 healthy UK residents showed a mean (SD) score of 6.14 (3.76) for anxiety and 3.68 (3.07) for depression (Crawford, 2001), which are reasonably similar to scores of 6.74 (4.48) and 5.35 (4.32) respectively obtained within this cohort. Furthermore, the reported incidence of clinical anxiety in otherwise healthy people is 7%, rising to 33% of people with health complaints and 36% of people with back pain (Hermann, 1997), whilst clinical depression has been found in 5%, 13% and 29% respectively within these groups. In the present study, about 17% were clinically anxious and 8% clinically depressed suggesting that within the inherent limitations of comparing study groups, there was no particular bias in terms of psychological status.

Mean (SD) scores for the SF36 domains were stable throughout the study although the scores for physical functioning declined approximately linearly (P=0.017) from 57.58 (31.20) to 53.54 (32.06) by the end of the study (Table 3.7). Davies (2005) reported mean SF36 domain scores for an AS multinational sample (n = 277) which had taken part in a previous randomised controlled trial for biologic therapy (Davies, 2003). Overall, comparing the current study group to SF36 scores in the Davies cohort, mean scores were similar in all but four domains.

Table 3.7. Mean (SD) SF36 scores at each assessment for participants who completed all four assessments (n=89)

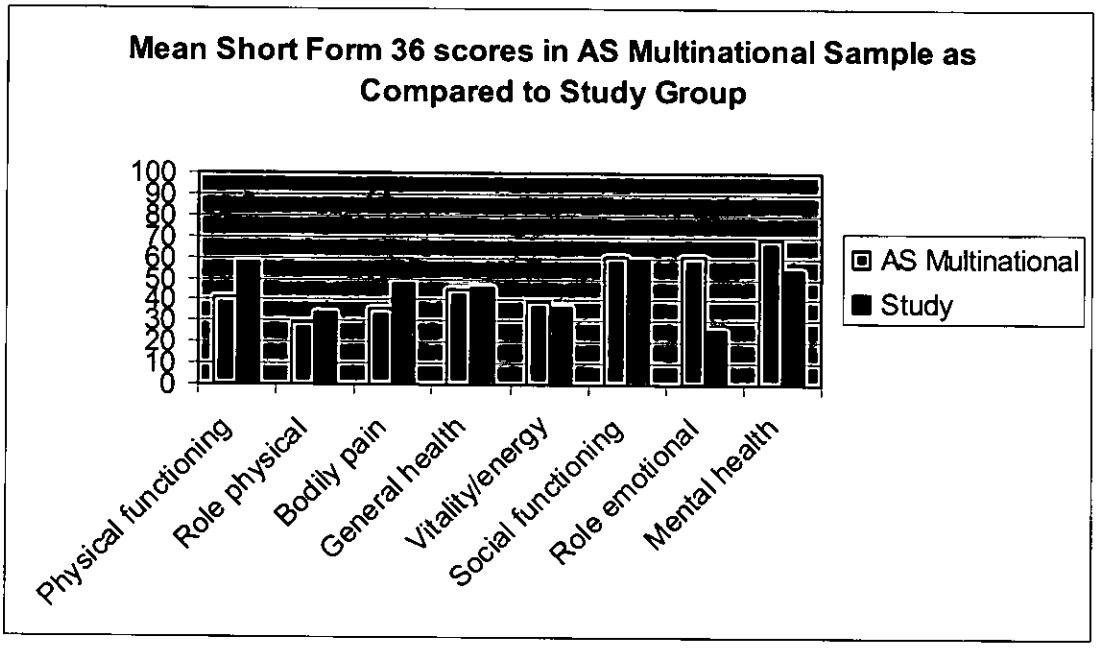
	ASSESSMENT			
	1	**2**	**3**	**4**
Physical Functioning	57.58 (31.20)	56.20 (31.93)	54.37 (32.87)	53.54 (32.06)
Role limitation due to physical function	34.39 (26.78)	36.52 (28.76)	37.08 (27.74)	36.92 (28.24)
Role limitation due to emotional problems	25.04 (27.73)	26.76 (26.86)	24.36 (24.56)	24.48 (25.09)
Social functioning	58.90 (26.16)	55.83 (26.86)	56.85 (25.81)	56.48 (26.23)
Mental health	54.54 (18.36)	53.38 (17.63)	52.90 (17.16)	54.49 (17.66)
Energy and vitality	36.40 (19.18)	33.10 (20.12)	33.70 (20.01)	33.04 (19.04)
Pain	47.19 (26.22)	49.20 (28.55)	49.55 (25.14)	48.84 (25.94)
General health perception	45.90 (26.20)	46.07 (25.90)	46.77 (23.20)	45.40 (23.42)
Change in health	47.89 (15.46)	48.88 (11.86)	50.28 (15.31)	49.16 (12.18)

Table 3.7 shows mean (SD) scores for each measure of the SF36 domains at assessments 1, 2, 3 and 4.

Chart 3.1 below illustrates comparisons between the Davies multinational cohort and the group in this study. Values are shown only for mean scores, since standard deviations were not reported for the multinational cohort. The four SF36 domain scores which appear to differ between the two groups include the physical functioning domain (multinational mean 41.5; study mean 57.6), which raises the possibility of better physical functioning within the current study cohort, whilst bodily pain scores raise the possibility of less bodily pain than the multinational cohort (multinational mean 36.2; study mean 47.2). Conversely, the role emotional domain scores (multinational mean

60.7; study mean 25.0) raise the possibility of a greater influence of role limitation due to emotional problems in the study group, whilst the mental health domain scores (multinational mean 68.6; study mean 54.5) raise the possibility that the current study group may experience more issues related to mental health than the multinational cohort.

Chart 3.1 Comparisons between the Davies multinational cohort and the group in this study



3.2.1 Associations between disease status and anxiety and depression during the study period

BASMI, BASFI and BASDAI scores correlated quite strongly with anxiety and depression scores at all assessment points, although for BASMI scores the levels of correlation were lower than for BASDAI and BASFI. Table 3.8 is given as an example for correlations between disease status and anxiety scores whilst similar correlations with depression are shown in table A.1 in the Appendix 9.

Table 3.8. Correlations between disease status and anxiety scores (HADS-A) (n = 89)

	ASSESSMENT			
	1	2	3	4
BASMI	$r_s = 0.43$**	$r_s = 0.33$**	$r_s = 0.46$**	$r_s = 0.38$**
BASFI	$r_s = 0.60$**	$r_s = 0.55$**	$r_s = 0.57$**	$r_s = 0.67$**
BASDAI	$r_s = 0.58$**	$r_s = 0.63$**	$r_s = 0.67$**	$r_s = 0.61$**

Table 3.7 shows correlations between these variables as assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Using HADS scores of 11 or more as a threshold, mean BASDAI and BASFI scores were significantly higher in both anxious and depressed subgroups. This finding was less strong and less consistent for BASMI scores. Table 3.9 is shows an example of disease scores in depressed and non-depressed subgroups whilst Table A.2 showing similar disease scores in anxious and non-anxious subgroups is in the Appendix 9.

Table 3.9. Disease scores in depressed and non-depressed subgroups (HADS-D)

ASSESSMENT							
1		2		3		4	
Non depress n= 82	Depress n =7	Non depress n= 74	Depress n =15	Non depress n= 78	Depress n =11	Non depress N= 77	Depress n =12
BASMI							
3.30 (1.73)	4.16 (1.82)	3.30 (1.71)	4.45 (1.33)	3.28 (1.69)	4.33 (1.37)	3.32 (1.72)	4.23 (1.60)
P = <0.216		P < 0.016		P < 0.050		P < 0.090	
BASFI							
4.25 (2.56)	7.01 (1.50)	4.17 (2.68)	6.96 (1.26)	4.45 (2.75)	6.81 (1.80)	4.31 (2.75)	7.41 (1.31)
P < 0.007		P <0.000		P < 0.007		P < 0.000	
BASDAI							
4.70 (2.25)	6.95 (0.75)	4.50 (2.33)	7.00 (1.51)	4.70 (2.32)	7.14 (1.40)	4.50 (2.37)	7.11 (0.91)
P < 0.010		P < 0.000		P < 0.001		P < 0.000	

Table 3.9 shows mean (SD) values for each measure of disease status in depressed and non-depressed subgroups, using HADS scores of 11 or above to identify clinical depression. Between-group differences were tested using independent-samples t-tests.

3.2.2 Effects of changing thresholds for defining clinical anxiety and depression

Hermann (1997) reported that the HADS does not incorporate a single, generally-accepted cut off score to identify anxiety or depression, although Zigmond (1983) suggested scores of 7/8 to denote possible anxiety or depression, 10/11 for probable and 14/15 for severe anxiety or depression. Using HADS scores of 11 or more as a threshold, subgroups with clinical anxiety and depression were created for analysis of subgroups. Further additional exploration of this concept was undertaken to assess possible implications of identifying the effects of altering this threshold.

Table 3.10 shows correlations between anxiety and disease scores at different thresholds created by reduced stepped groupings. As the thresholds were reduced the correlations gradually weakened until they were lost at an anxiety score of 5.

Table 3.10. Correlations between anxiety and disease scores at first assessment using different threshold scores for defining anxiety by reduced stepped groupings.

THRESHOLD	BASMI	BASFI	BASDAI
<11 (n= 74)	**r_s = 0.46****	**r_s = 0.58****	**r_s = 0.56****
>11 (n= 15)	r_s = 0.11	r_s = 0.21	r_s = 0.15
<10 (n= 71)	**r_s = 0.47****	**r_s = 0.58****	**r_s= 0.56****
>10 (n = 18)	r_s = - 0.07	r_s = 0.32	r_s= 0.26
<9 (n= 66)	**r_s = 0.48****	**r_s = 0.56****	**r_s = 0.49****
>9 (n = 23)	r_s = -0.01	r_s = 0.19	r_s = -0.15
<8 (n= 59)	**r_s = 0.39***	**r_s = 0.48****	**r_s= 0.49****
>8 (n = 30)	r_s = - 0.16	r_s = 0.04	r_s = 0.10
<7 (n= 52)	**r_s = 0.33***	**r_s = 0.42***	**r_s = 0.50****
>7 (n = 37)	r_s = -0.10	r_s = 0.03	r_s = 0.27
<6 (n= 45)	**r_s = 0.35***	**r_s = 0.47****	**r_s = 0.50****
>6 (n = 44)	r_s = 0.06	r_s = 0.18	r_s = 0.35*
<5 (n= 38)	**r_s = 0.16**	**r_s= 0.27**	**r_s = 0.47***
>5 (n = 51)	r_s = 0.04	r_s = 0.18	r_s = 0.37*

Table 3.10 shows correlations between each disease measure and anxiety scores within anxious and non-anxious subgroups at assessment 1, using different thresholds for clinical anxiety. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: *P < 0.05, ** P < 0.001.

Table 3.11 shows correlations between depression and disease scores at different thresholds created by reduced stepped groupings. As the thresholds were reduced the correlations gradually weakened until they were lost at a depression score of 6.

Table 3.11. Correlations between depression and disease scores at first assessment using different threshold scores for defining depression by reduced stepped groupings.

THRESHOLD	BASMI	BASFI	BASDAI
<11 (n=82)	**r_s = -0.41**	**r_s = 0.58****	**r_s = 0.59****
>11 (n = 7)	r_s = 0.44**	r_s = -0.07	r_s = 0.34
<10 (n= 78)	**r_s = 0.40 ****	**r_s = 0.56****	**r_s = 0.58****
>10 (n = 11)	r_s = 0.-0.45	r_s = 0.16	r_s = 0.22
<9 (n= 72)	**r_s = 0.32***	**r_s = 0.54****	**r_s = 0.54****
>9 (n = 17)	r_s = -0.18	r_s = 0.32	r_s = -0.18
<8 (n= 66)	**r_s = 0.34***	**r_s = 0.49****	**r_s = 0.49****
>8 (n = 23)	r_s = 0.03	r_s = 0.17	r_s = 0.24
<7 (n= 61)	**r_s = 0.30***	**r_s = 0.42****	**r_s = 0.47****
>7 (n = 28)	r_s = 0.18	r_s = 0.05	r_s = 0.29
<6 (n= 56)	**r_s = 0.24**	**r_s = 0.36***	**r_s = 0.53****
>6 (n = 37)	r_s = 0.31	r_s = 0.33*	r_s = 0.44*

Table 3.11 shows correlations between each disease measure and depression scores within depressed and non-depressed subgroups at assessment 1, using different thresholds for clinical depression. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

These observations raise the possibility that the presence of clinical anxiety or depression may somehow alter the relationship between these measurements. Anxiety and depression levels tended to change in parallel with disease scores up to the threshold score of clinical anxiety/depression, but above that threshold the relationship between disease and psychological scores as measured by these tools was distorted,

such that the correlations were much weaker. It is possible that this effect might be related to aspects of the psychometric properties of the psychological tools and/or the clinical tools, but this was not explored further in this study.

3.2.3 Associations between disease status and internality, belief in chance and belief in powerful others (LOC).

BASDAI scores consistently showed a negative, albeit relatively weak, correlation with internality and the same generally applied to BASFI and BASMI scores, showing that worse disease activity, function and movement were associated with lower levels of perceived control over health (Table 3.12).

Table 3.12. Correlations between disease status and internality score (LOC)

	ASSESSMENT			
	1	**2**	**3**	**4**
BASMI	r_s = - 0.25*	r_s = -0.23*	r_s = - 0.23*	r_s = - 0.13
BASFI	r_s =- 0.25*	r_s = - 0.25*	r_s = - 0.18	r_s = - 0.22*
BASDAI	r_s = - 0.35**	r_s = - 0.33**	r_s = - 0.26*	r_s = - 0.24*

Table 3.12 shows correlations between these variables as assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Using internality scores of 30 or more (i.e. the median score derived from all 4 assessments) as a threshold, mean BASDAI scores were generally higher for the low internality subgroup (n = 46) apart from at assessment 4, whilst BASMI scores were significantly worse for the low internality groups only at assessments 1 and 3. BASFI score was significantly worse for the low internality group at assessment 1 only. However mean anxiety and depression scores were significantly higher in the low internality subgroup throughout, except for the anxiety score on the second assessment (Table 3.13).

Table 3.13. Disease scores in high and low internality subgroups (LOC).

ASSESSMENT							
1		2		3		4	
High	**Low**	**High**	**Low**	**High**	**Low**	**High**	**Low**
			BASMI				
2.81 (1.68)	3.92 (1.64)	3.25 (1.65)	3.71 (1.74)	2.89 (1.52)	3.92 (1.65)	3.31 (1.74)	3.58 (1.73)
P < 0.002		P < 0.210		P < 0.003		P < 0.474	
			BASFI				
3.75 (2.52)	5.19 (2.53)	4.22 (2.72)	5.03 (2.68)	4.19 (2.87)	5.28 (2.55)	4.36 (2.64)	5.10 (2.95)
P < 0.009		P < 0.157		P < 0.062		P < 0.215	
			BASDAI				
4.06 (2.26)	5.67 (1.96)	4.32 (2.38)	5.46 (2.30)	4.42 (2.39)	5.57 (2.20)	4.44 (2.45)	5.26 (2.30)
P < 0.001		P < 0.025		P < 0.020		P < 0.108	
			ANXIETY (HADS-A)				
5.22 (4.11)	8.27 (4.35)	6.84 (4.35)	8.49 (4.56)	6.25 (4.54)	8.73 (4.34)	6.00 (3.99)	9.11 (4.47)
P < 0.001		P < 0.086		P < 0.008		P < 0.001	
			DEPRESSION (HADS-D)				
4.29 (3.94)	6.38 (4.46)	4.95 (4.07)	7.11 (5.45)	4.68 (4.21)	6.82 (4.19)	4.68 (4.05)	6.98 (4.79)
P < 0.022		P < 0.039		P < 0.018		P < 0.017	

Table 3.13 shows mean (SD) values for disease scores in subgroups defined according to whether participants had high or low internality, as measured by median internality scores over all four assessments. Between-group differences were analysed using independent-samples t-tests.

At each of the 4 assessments, internality scores showed significant but relatively weak correlations with anxiety and depression scores (Table 3.13).

Table 3.14. Correlations between internality (LOC), anxiety (HADS-A) and depression scores (HADS-D)

	ASSESSMENT			
	1	2	3	4
Anxiety (HADS-A)	$r_s = -0.37^{**}$	$r_s = -0.26^{*}$	$r_s = -0.27^{*}$	$r_s = -0.41^{**}$
Depression (HADS-D)	$r_s = -0.56^{*}$	$r_s = -0.30^{*}$	$r_s = -0.30^{*}$	$r_s = -0.33^{**}$

Table 3.14 shows correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

There were no consistent correlations between strengths of belief in powerful others or belief in chance and any of the disease status scores (Table A.3 Appendix 9).

However, there were consistently strong correlations between BASFI and BASDAI scores and anxiety scores (HADS-A) in subgroups with either high or low belief in chance. The strengths of these correlations were weaker and less significant for BASMI scores. An example of this data is shown in Table 3.15 for correlations between anxiety scores (HADS-A) and disease scores in subgroups with low or high belief in chance. Likewise for depression (HADS-D) there were consistently strong correlations between BASFI and BASDAI scores and depression scores in subgroups with either high or low belief in chance. However the strength of the correlation was weaker and less significant for BASMI scores in the subgroup with high belief in chance and was not significant at assessment 1 (Table A. 4 Appendix 9).

There were generally strong correlations between BASFI and BASDAI scores and anxiety scores in subgroups with either high or low belief in powerful others. However the strength of correlation was weaker and less significant for BASMI scores, and was

not statistically significant at assessment 1 for the subgroup with low belief in powerful others (Table A.5 Appendix 9). There were consistently strong correlations between BASFI and BASDAI scores and depression scores in subgroups with either high or low belief in powerful others. However the strength and significance of correlations was generally weaker for BASMI scores (Table A. 6 Appendix 9).

Table 3.15. Correlations between anxiety scores (HADS-A) and disease scores in subgroups with low or high belief in chance (LOC).

	ASSESSMENT			
	1	2	3	4
BASMI	*r_s = 0.53*** r_s = 0.34*	*r_s = 0.36** r_s = 0.29	*r_s = 0.49** r_s = 0.42*	*r_s = 0.45** r_s = 0.32*
BASFI	*r_s = 0.64*** r_s = 0.56**	*r_s = 0.59*** r_s = 0.50*	*r_s = 0.62*** r_s = 0.52**	*r_s = 0.57*** r_s = 0.58**
BASDAI	*r_s = 0.70*** r_s = 0.41*	*r_s = 0.60*** r_s = 0.63**	*r_s = 0.64*** r_s = 0.68**	*r_s = 0.56*** r_s = 0.63**
Low belief in chance	***n=45***	***n=46***	***n=46***	***n=43***
High belief in chance	**n=44**	**n=43**	**n=43**	**n=46**

Table 3.15 shows correlations between anxiety scores and disease scores in subgroups with high or low belief in chance. Subgroups were defined according to median scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

3.2.4 Associations between disease status and SF 36 generic health status

Scoring systems for the three disease status tools are such that increasing values indicate worsening status. Conversely for the SF 36 domains, lower scores indicate worsening status and more limitations. Throughout the study, BASMI, BASFI and BASDAI scores correlated strongly with all SF36 domain scores except change in health. Correlations were generally negative, except for 2 domains, namely role limitation due to physical function and role limitation due to emotional problems. An example of this data is shown in Table 3.16 whilst a similar table containing the BASDAI and BASFI data are shown as Tables A.7 (BASFI) and A.8 (BASDAI) respectively in the Appendix 9.

Table 3.16. Correlations between BASMI and SF36 domain scores.

	ASSESSMENT			
	1	**2**	**3**	**4**
Physical functioning	r_s = - 0.47**	r_s = - 0.51**	r_s = - 0.52**	r_s = - 0.45**
Role limitation due to physical function	r_s = 0.42**	r_s = 0.49**	r_s = 0.47**	r_s = 0.47**
Role limitation due to emotional problems	r_s = 0.42**	r_s = 0.42**	r_s = 0.52**	r_s = 0.41**
Social functioning	r_s = - 0.33*	r_s = - 0.46**	r_s = - 0.42**	r_s = - 0.27*
Mental health	r_s = - 0.32*	r_s = - 0.27*	r_s = - 0.42**	r_s = - 0.31*
Energy and vitality	r_s = - 0.38**	r_s = - 0.44**	r_s = - 0.39**	r_s = - 0.37**
Bodily pain	r_s = - 0.27*	r_s = - 0.47**	r_s = - 0.50**	r_s = - 0.27*
General health perception	r_s = - 0.41**	r_s = - 0.41**	r_s = - 0.42**	= r_s - 0.41**
Change in health	r_s = - 0.12	r_s = - 0.12	r_s = - 0.02	r_s = - 0.26*

Table 3.16 shows correlations between scores for BASMI and each SF36 domain at assessments 1, 2, 3, and 4. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

3.2.5 Associations between psychological status and SF36 generic health status

HADS anxiety and HADS depression scores have been reported to be significantly associated with SF36 summary scores. (Fossa, 2002). In the current study, the most significant correlations were found for associations between HADS and the mental health component of SF36, especially anxiety (Table 3.17). However, HADS depression scores were more strongly associated with the physical component of SF36 (Table 3. 18).

Table 3.17. Correlations between mental health and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = - 0.79**	r_s = -0.77**	r_s = - 0.80**	r_s = - 0.70**
DEPRESSION	r_s = - 0.73**	r_s = - 0.72**	r_s = - 0.76**	r_s = - 0.74**
INTERNALITY	r_s = 0.23*	r_s = 0.13	r_s = 0.21*	r_s = 0.26*

Table 3.17 shows correlations between mental health and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table 3.18. Correlations between physical functioning and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = - 0.50**	r_s = - 0.58**	r_s = - 0.59**	r_s = - 0.56**
DEPRESSION	r_s = - 0.60**	r_s = - 0.70**	r_s = - 0.68**	r_s = - 0.66**
INTERNALITY	r_s = 0.28*	r_s = 0.21	r_s = 0.18	r_s = 0.24*

Table 3.18 shows correlations between physical functioning and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Associations were negative between the SF 36 components with anxiety and depression and were positive with internality (Tables A.9, A.10, A.11, A.12 Appendix 9)

However for the role limitation due to physical problems and role limitation due to emotional problems, these associations were reversed with anxiety and depression correlations being positive and internality negative (Tables A12 and A.13 Appendix 9). There were no significant correlations between anxiety, depression, internality and change in health (Table A.14 Appendix 9).

The strength of correlations for both anxiety and depression scores were generally very similar, although the r_S values for depression and physical functioning were higher than for anxiety and physical functioning, which is consistent with the findings of Fossa (2002). In contrast, internality scores correlated consistently only with scores for general health perception, mental health and social functioning, and levels of correlation were weak.

3.3 EFFECTS OF CO-EXISTENT CONDITIONS: IRITIS

There were no significant differences in mean disease or in mean anxiety and depression scores between those with (n=41) or without (n=48) a history of iritis (Table 3.19).

Anxiety and depression scores correlated with BASMI, BASFI, and BASDAI scores for those with (n = 41) or without (n = 48) a history of iritis. However, strength of correlations were generally weaker for BASMI. Data are shown for anxiety in Table 3.20 and similar data for depression are shown in Table A. 15: Appendix 9.

Table 3.19. Disease and psychological scores (HADS) in subgroups with and without a history of iritis

ASSESSMENT							
1		2		3		4	
No iritis n= 48	**iritis n=41**	**No iritis n= 48**	**iritis n=41**	**No iritis n= 48**	**iritis n=41**	**No iritis n= 48**	**iritis n=41**
			BASMI				
3.22 (1.75)	3.55 (1.72)	3.40 (1.78)	3.58 (1.63)	3.23 (1.71)	3.62 (1.60)	3.40 (1.86)	3.50 (1.57)
P < 0.336		P < 0.634		P < 0.273		P < 0.782	
			BASFI				
4.58 (2.61)	4.34 (2.64)	4.83 (2.58)	4.42 (2.86)	4.78 (2.58)	4.70 (2.97)	5.01 (2.63)	4.41 (3.00)
P < 0.669		P < 0.474		P < 0.888		P < 0.323	
			BASDAI				
4.87 (2.25)	4.88 (2.27)	5.02 (2.20)	4.78 (2.63)	4.95 (2.26)	5.06 (2.49)	4.91 (2.38)	4.79 (2.44)
P < 0.972		P < 0.634		P < 0.824		P < 0.815	
			ANXIETY (HADS-A)				
6.58 (4.71)	6.97 (4.23)	7.56 (4.47)	7.83 (4.61)	7.23 (4.47)	7.83 (4.74)	7.60 (4.37)	7.53 (4.70)
P < 0.683		P <0.783		P < 0.541		P < 0.944	
			DEPRESSION (HADS-D)				
5.73 (4.67)	4.90 (3.88)	6.02 (5.27)	6.12 (6.12)	5.75 (4.53)	5.78 (4.11)	5.60 (4.61)	6.12 (4.56)
P < 0.371		P < 0.924		P <0.974		P < 0.597	

Table 3.19 shows mean (SD) values for disease and psychological scores in subgroups defined according to whether participants had a history of iritis. Between-group differences were analysed using independent-samples t-tests.

Table 3.20. Correlations between disease scores and anxiety in participants with and without a history of iritis.

	ASSESSMENT		
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.37**	*r_s = 0.40**	*r_s = 0.47**	*r_s = 0.39**
r_s =0.49**	r_s = 0.28	r_s = 0.45*	r_s = 0.34*
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.58***	*r_s = 0.59***	*r_s = 0.64***	*r_s = 0.66***
r_s = 0.62**	r_s = 0.49**	r_s = 0.48*	r_s = 0.52**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.62***	*r_s = 0.60***	*r_s = 0.63***	*r_s = 0.68***
r_s = 0.54**	r_s = 0.67**	r_s = 0.67**	r_s = 0.54**

Table 3.20 shows correlations between each disease measure and anxiety scores at each assessment in people with (shown in italics) and without a history of iritis. Correlations between variables were assessed using Spearman's rank correlations (r_s).
P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

3.4 EFFECTS OF CO-EXISTENT CONDITIONS: PSORIASIS

Although analysis of the effects of psoriasis was limited by the fact that the subgroups were numerically unequal (only 14 people had psoriasis), there were no significant differences in disease status between subgroups with or without psoriasis (Table 3.21). This contrasts with work by Brophy (2001), who found that both psoriasis and inflammatory bowel disease were associated with increased AS severity in terms of function and disease activity. Patients with axial psoriatic arthritis have also been found to have worse pain and function than those with peripheral psoriatic arthritis (Zink, 2006).

There were no significant differences in mean anxiety and depression scores between those with or without psoriasis (Table 3.21). To some extent, this contrasts with reports of patients with psoriasis having significantly higher levels of anxiety, depression and worry than their partners (Richards, 2004), whilst Kulkarni (2004) found that about one fifth of patients with psoriasis (n=63) had depressive symptoms.

Table 3.21. Disease and psychological scores (HADS) scores in subgroups with and without psoriasis

ASSESSMENT							
1		2		3		4	
No psoriasis n= 75	psoriasis n =14	No psoriasis n= 75	psoriasis n =14	No psoriasis n= 75	psoriasis n =14	No psoriasis n= 75	psoriasis n =14
BASMI							
3.37 (1.77)	3.37 (1.64)	3.47 (1.76)	3.57 (1.44)	3.45 (1.73)	3.18 (1.26)	3.45 (1.81)	3.40 (1.21)
P <0.999		P < 0.827		P < 0.587		P < 0.912	
BASFI							
4.39 (2.63)	4.88 (2.55)	4.58 (2.68)	4.95 (2.92)	4.79 (2.75)	4.49 (2.85)	4.76 (2.80)	4.61 (2.95)
P < 0.512		P < 0.643		P < 0.715		P < 0.857	
BASDAI							
4.87 (2.22)	4.95 (2.50)	4.89 (2.32)	5.01 (2.87)	4.99 (2.30)	5.06 (2.73)	4.99 (2.73)	5.14 (2.52)
P < 0.903		P < 0.864		P < 0.925		P < 0.625	
ANXIETY (HADS-A)							
6.63 (4.28)	7.50 (5.57)	7.60 (4.48)	8.14 (4.82)	7.61 (4.57)	6.93 (4.76)	7.68 (4.46)	7.00 (4.82)
P < 0.506		P < 0.700		P < 0.610		P < 0.606	
DEPRESSION (HADS-D)							
5.11 (3.94)	6.64 (5.97)	6.04 (4.92)	6.21 (5.15)	5.81 (4.29)	5.50 (4.62)	5.76 (4.45)	6.28 (5.30)
P < 0.224		P < 0.904		P < 0.805		P < 0.695	

Table 3.21 shows mean (SD) values for disease and psychological scores at each assessment in subgroups with or without psoriasis. Between-group differences were analysed using independent-samples t-tests.

There were no consistent correlations between anxiety and BASMI scores for the subgroup with psoriasis, although correlations with anxiety were found with BASFI and BASDAI scores, except for BASFI at assessment 3. This is in contrast to the subgroup without psoriasis for which moderate correlations between anxiety and all disease measures were found. Likewise, there were no strong correlations between depression and BASMI scores for the subgroup with psoriasis, but correlations between depression and BASFI and BASDAI were stronger. This is in contrast to the subgroup without psoriasis, for which strong correlations with all disease measures were found (Table 3.22). Similar data for anxiety are shown in Table A.17 Appendix 9.

Table 3.22. Correlations between disease scores and depression (HADS-D) in participants with and without psoriasis.

		ASSESSMENT	
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
r_s = 0.46	*r_s = 0.24*	*r_s = 0.19*	*r_s = 0.27*
r_s = 0.47**	r_s = 0.58**	r_s = 0.49**	r_s = 0.47**
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.76**	*r_s = 0.75**	*r_s = 0.70**	*r_s = 0.69**
r_s = 0.60**	r_s = 0.70**	r_s = 0.61**	r_s = 0.68**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.85***	*r_s = 0.82***	*r_s = 0.85***	*r_s = 0.57**
r_s = 0.58**	r_s = 0.61**	r_s = 0.62**	r_s = 0.67**

Table 3.22 shows correlations between each disease measure and depression (HADS-D) scores in subgroups with (shown in italics) and without a history of psoriasis. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

3.5 EFFECTS OF AGE

Two subgroups equal in size were defined according to participants being aged above or below 50 at the beginning of the study. Mean BASMI and BASFI scores were consistently and significantly higher in those aged 50 years and above (n = 45), indicating worse movement and function in this subgroup. However there were no significant differences between the subgroups in mean BASDAI, anxiety, depression and internality scores, except for assessment 4 with depression (Table 3.23).

Table 3.23. Comparison of disease and psychological (HADS-A, HADS-D and internality LOC) scores in subgroups older and younger than 50 years

ASSESSMENT							
1		2		3		4	
<50	>50	<50	>50	<50	>50	<50	>50
n= 44	n= 45	n= 44	n= 45	n= 44	n= 45	n= 44	n= 45
BASMI							
2.86	3.95	2.85	4.19	2.92	3.95	2.94	4.01
(1.81)	(1.48)	(1.74)	(1.36)	(1.76)	(1.38)	(1.87)	(1.38)
P < 0.003		P < 0.001		P < 0.003		P < 0.003	
BASFI							
3.81	5.21	4.01	5.34	3.95	5.62	4.00	5.61
(2.72)	(2.31)	(2.85)	(2.40)	(2.77)	(2.48)	(2.90)	(2.46)
P < 0.011		P < 0.020		P < 0.004		P < 0.007	
BASDAI							
4.71	5.13	4.50	5.37	4.61	5.45	4.48	5.28
(2.43)	(2.05)	(2.59)	(2.10)	(2.38)	(2.28)	(2.59)	(2.15)
P < 0.376		P < 0.086		P < 0.095		P < 0.121	
ANXIETY (HADS-A)							
6.49	7.07	7.38	8.02	6.98	8.09	7.17	7.88
(4.36)	(4.64)	(4.22)	(4.84)	(4.51)	(4.46)	(4.32)	(4.66)
P < 0.544		P < 0.507		P < 0.253		P < 0.462	
DEPRESSION (HADS-D)							
4.91	5.83	5.11	7.14	5.04	6.57	4.77	7.05
(4.03)	(4.62)	(4.87)	(4.82)	(4.17)	(4.38)	(4.24)	(4.66)
P < 0.319		P < 0.051		P < 0.095		P < 0.018	
INTERNALITY (LOC)							
30.23	30.02	30.36	28.36	29.46	28.26	30.49	28.24
(6.73)	(7.00)	(7.18)	(7.11)	(6.65)	(6.36)	(6.58)	(6.54)
P < 0.885		P < 0.190		P < 0.386		P < 0.110	

Table 3.23 shows mean (SD) values for disease and psychological scores at each assessment in subgroups defined according to whether participants were younger or older than 50 years at the beginning of the study. Between-group differences were analysed using independent-samples t-tests.

Anxiety (HADS-A) scores correlated strongly with BASMI, BASFI and BASDAI scores for both subgroups. However, the strength and significance of correlations with BASMI were generally lower than for the other disease scores, whilst correlations between anxiety scores and BASFI scores for those aged 50 and above were weaker than for the younger subgroup (Table 3.24). Similar data for depression (HADS-D) scores are shown in Table A.18 (Appendix 9) where depression scores correlated strongly with BASMI, BASFI and BASDAI scores for both subgroups. Interestingly the strength of all these correlations was lower for the subgroup aged 50 and above.

Table 3.24. Correlations between age and anxiety scores in subgroups younger than and older than 50 years

	ASSESSMENT		
1	**2**	**3**	**4**
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.51***	*r_s = 0.34**	*r_s = 0.46**	*r_s = 0.33**
r_s = 0.32*	r_s = 0.32*	r_s = 0.41*	r_s = 0.27
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.66***	*r_s = 0.61***	*r_s = 0.56***	*r_s = 0.52***
r_s = 0.55*	r_s = 0.42*	r_s = 0.46*	r_s = 0.56*
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.61***	*r_s = 0.51***	*r_s = 0.68***	*r_s = 0.68***
r_s = 0.53**	r_s = 0.69*	r_s = 0.63**	r_s = 0.60**

Table 3.24 shows correlations between each disease measure and anxiety scores in subgroups defined according to whether people were younger (shown in italics) or older than 50 years at the beginning of the study. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

3.5 EFFECTS OF DISEASE DURATION

Two approximately equal subgroups were defined according to participants with disease duration less than (n=49; mean = 14 years, range 2 – 19) and more than 20 years (n=40; mean = 29 years, range 20 – 50) at the beginning of the study. Mean BASFI scores were consistently and significantly higher in those with disease duration more than 20 years, indicating worse function in this subgroup. However there were no significant differences between the subgroups in mean BASMI and BASDAI scores. Additionally, there were no significant differences between the subgroups in mean anxiety and depression scores indicating no significant effect of disease duration (Table 3.25).

Table 3.25. Comparison of disease scores and psychological (HADS-A, HADS-D) in subgroups with disease duration less and more than 20 years.

ASSESSMENT							
1		2		3		4	
< 20	> 20	< 20	> 20	< 20	> 20	< 20	> 20
n = 49	n = 40	n = 49	n = 40	n = 49	n = 40	n = 49	n = 40
BASMI							
3.22 (1.82)	3.56 (1.65)	3.19 (1.74)	3.84 (1.60)	3.19 (1.74)	3.67 (1.54)	3.37 (1.89)	3.54 (1.52)
P < 0.354		P < 0.075		P < 0.175		P <0.650	
BASFI							
3.81 (2.72)	5.21 (2.31)	4.01 (2.85)	5.34 (2.40)	3.95 (2.77)	5.62 (2.48)	4.00 (2.90)	5.61 (2.46)
P < 0.011		P < 0.020		P < 0.004		P < 0.007	
BASDAI							
4.71 (2.43)	5.13 (2.05)	4.50 (2.59)	5.37 (2.10)	4.61 (2.38)	5.45 (2.28)	4.48 (2.59)	5.28 (2.15)
P < 0.380		P < 0.086		P < 0.095		P < 0.120	
ANXIETY (HADS-A)							
7.14 (4.68)	6.30 (4.23)	7.73 (4.12)	7.63 (4.45)	7.63 (4.45)	7.35 (4.78)	7.63 (4.41)	7.50 (4.65)
P <0.380		P < 0.910		P < 0.774		P < 0.891	
DEPRESSION (HADS-D)							
6.00 (4.75)	4.55 (3.63)	6.33 (5.12)	5.75 (4.73)	6.14 (4.48)	5.30 (4.11)	5.96 (4.56)	5.70 (4.62)
P <0.197		P < 0.586		P < 0.362		P < 0.792	

Table 3.25 shows mean (SD) values for disease and psychological scores at each assessment in subgroups defined according to whether participants had a disease duration of less than or more than 20 years at the beginning of the study. Between-group differences were analysed using independent-samples t-tests.

Anxiety (HADS-A) scores correlated strongly with BASMI, BASFI and BASDAI scores for both subgroups. However, correlations with BASMI were strong at assessments 2 and 3 only for those with disease duration of more than 20 years. Interestingly, strength of correlations between anxiety scores and both BASMI and BASDAI scores was higher for the subgroup with disease duration of more than 20 years. Depression scores (HADS-D) correlated with BASMI, BASFI and BASDAI scores for both subgroups. However, the correlation with BASMI score was not significant at assessment 1 and was generally weaker for the subgroup with disease duration of more than 20 years. Data for correlations between disease scores is shown for anxiety in Table 3.26 and for depression in Table A. 19 in Appendix 9.

Table 3.26. Correlations between disease scores and anxiety (HADS-A) scores in subgroups with disease duration less and more than 20 years.

	ASSESSMENT		
1	**2**	**3**	**4**
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.51***	*r_s = 0.31**	*r_s = 0.55***	*r_s = 0.55***
r_s = 0.31	r_s = 0.31*	r_s = 0.35*	r_s = 0.14
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.57***	*r_s = 0.51***	*r_s = 0.51***	*r_s = 0.52***
r_s = 0.62**	r_s = 0.58**	r_s = 0.66**	r_s = 0.68**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.54***	*r_s = 0.58***	*r_s = 0.67***	*r_s = 0.60***
r_s = 0.61**	r_s = 0.70**	r_s = 0.70**	r_s = 0.65**

Table 3.26 shows correlations between each disease measure and anxiety scores in subgroups defined according to whether participants had a disease duration of less (shown in italics) or more than 20 years at the beginning of the study. Correlations between variables were assessed using Spearman's rank correlations (r_s).
P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

3.6 EFFECTS OF GENDER

Interpretation of the analysis of possible gender effects on the results was constrained by the numerical inequality of male (n=74) and female (n=15) participants. However there were no consistently significant differences in any disease or psychological (HADS-A, HADS-D and internality LOC) scores for males compared to females (Table 3.27).

Table 3.27. Disease and psychological (HADS-A, HADS-D and internality LOC) scores in subgroups defined by gender.

ASSESSMENT							
1		2		3		4	
Male	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
			BASMI				
3.47 (1.79)	2.87 (1.40)	3.58 (1.74)	3.03 (1.44)	3.47 (1.69)	3.11 (1.54)	3.55 (1.77)	2.92 (1.40)
P < 0.220		P < 0.254		P < 0.444		P < 0.196	
			BASFI				
4.48 (2.60)	4.41 (2.76)	4.63 (2.70)	4.68 (2.86)	4.75 (2.75)	4.71 (2.84)	4.22 (2.81)	4.22 (2.82)
P < 0.924		P < 0.954		P <0.962		P < 0.445	
			BASDAI				
4.92 (2.17)	4.67 (2.71)	4.90 (2.41)	4.93 (2.42)	4.98 (2.26)	5.12 (2.89)	4.83 (2.38)	4.83 (2.58)
P < 0.704		P < 0.967		P < 0.835		P <0.970	
			ANXIETY (HADS-A)				
7.00 (4.52)	5.60 (4.22)	7.86 (4.66)	6.80 (3.71)	7.67 (4.54)	6.67 (4.84)	7.66 (4.32)	7.13 (5.42)
P = 0.272		P = 0.408		P = 0.440		P = 0.680	
			DEPRESSION (HADS-D)				
5.55 (4.36)	4.43 (4.08)	6.08 (4.86)	6.00 (5.41)	5.73 (4.11)	5.93 (5.38)	5.86 (4.44)	5.73 (5.27)
P = 0.321		P = 0.954		P = 0.869		P = 0.920	
			INTERNALITY (LOC)				
30.44 (6.38)	28.60 (8.73)	29.85 (6.92)	27.23 (8.26)	29.31 (6.00)	26.87 (8.56)	30.27 (5.82)	25.27 (8.64)
P = 0.342		P =0.205		P = 0.186		P = 0.007	

Table 3.27 shows mean (SD) values for disease and psychological scores for males and females. Between-group differences were analysed using independent-samples t-tests.

Anxiety scores generally correlated with BASMI, BASFI and BASDAI scores both for males and females, although the correlations with BASMI scores were much weaker for females and not significant at assessment 4. Overall, strength of correlations with BASFI and BASDAI were also weaker in females (Table A.20, Appendix 9). Similarly, data shown in Table 3.28 indicates that depression scores correlated strongly with BASMI, BASFI and BASDAI scores both for males and females. However, the strength of the correlation with BASMI was much weaker in females, and the strength of correlations with BASFI and BASDAI were also weaker in females although less than was found for anxiety.

Table 3.28. Correlations between disease scores and depression in subgroups defined by gender.

	ASSESSMENT		
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.65**	*r_s = 0.85***	*r_s = 0.86***	*r_s = 0.71**
r_s = 0.38*	r_s = 0.47**	r_s = 0.38*	r_s = 0.37*
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.54**	*r_s = 0.73**	*r_s = 0.63**	*r_s = 0.82***
r_s = 0.63**	r_s = 0.70**	r_s = 0.62**	r_s = 0.65**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.65**	*r_s = 0.71**	*r_s = 0.68**	*r_s = 0.77**
r_s = 0.60**	r_s = 0.61**	r_s = 0.63**	r_s = 0.65**

Table 3.28 shows correlations between each disease measure and depression scores in males (shown in italics) and females. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

3.7 EFFECTS OF HIP INVOLVEMENT

Two subgroups were defined according to whether participants had a median intermalleolar measurement of less (n=42) or more than (n=47) 99 centimetres, as an indicator of hip involvement. Data is shown in Table 3.29 for disease and psychological (HADS-A, HADS-D and internality LOC) scores in these subgroups.

Table 3.29. Disease and psychological (HADS-A, HADS-D and internality LOC) scores in subgroups defined in subgroups with and without hip involvement.

ASSESSMENT							
1		2		3		4	
With	Without	With	Without	With	Without	With	Without
			BASMI				
4.31 (1.36)	2.53 (1.62)	4.31 (1.29)	2.75 (1.70)	4.33 (1.29)	2.59 (1.53)	4.25 (1.43)	2.73 (1.66)
P < 0.000		P < 0.000		P < 0.000		P < 0.000	
			BASFI				
5.84 (2.09)	3.35 (2.44)	5.90 (2.36)	3.51 (2.52)	6.00 (2.32)	3.62 (2.64)	5.89 (2.43)	3.70 (2.74)
P < 0.000		P < 0.000		P < 0.000		P < 0.000	
			BASDAI				
5.56 (1.79)	4.27 (2.47)	5.96 (2.04)	3.98 (2.33)	6.04 (2.11)	4.07 (2.19)	5.72 (2.12)	4.08 (2.39)
P < 0.006		P < 0.000		P < 0.000		P <0.001	
			ANXIETY (HADS-A)				
9.02 (4.21)	4.74 (3.71)	9.62 (4.23)	5.96 (4.01)	9.57 (4.25)	5.66 (4.08)	9.74 (4.38)	5.64 (3.67)
P < 0.000		P <0.000		P < 0.000		P < 0.000	
			DEPRESSION (HADS-D)				
6.69 (4.32)	4.15 (4.00)	8.29 (4.66)	4.09 (4.31)	7.36 (4.00)	4.34 (4.15)	8.10 (4.50)	3.83 (3.64)
P < 0.005		P <0.000		P <0.001		P < 0.000	
			INTERNALITY (LOC)				
27.86 (6.60)	32.17 (6.40)	27.00 (7.10)	31.57 (6.60)	27.07 (6.43)	30.53 (6.20)	27.00 (6.63)	31.62 (5.86)
P < 0.002		P < 0.002		P < 0.011		P < 0.001	

Table 3.29 shows mean (SD) values for disease and psychological scores in subgroups defined according to a median intermalleolar distance over all 4 assessments of less or more than 99 centimetres. Between-group differences were analysed using independent-samples t-tests.

All disease scores were consistently and significantly higher in those with intermalleolar distance less than 99 centimetres, indicating worse movement, function and disease activity in this subgroup. There were also significant differences in mean anxiety, depression and internality scores between these subgroups, indicating that those with hip involvement have higher levels of both anxiety and depression. The subgroup with hip involvement had lower internality scores, indicating less ability to take control over situations.

4.1. SEQUENTIAL ASSESSMENT OF DISEASE ACTIVITY IN PEOPLE WITH ACTIVE DISEASE

To determine whether people with high disease scores showed evidence of spontaneous remission during the course of the study, BASDAI scores were analysed using the threshold of > 4 which is currently used in clinical practice to denote eligibility for treatment with anti-TNFα (current British Society of Rheumatology Guidelines for prescribing TNFα blockers in adults with AS, July 2004).

Out of a total 356 BASDAI evaluations in this study, 233 (65%) scored 4 or higher. Seventy of the 89 participants (78.7%) had at least 1 BASDAI score of 4 or higher, 54 (60.7%) participants scored 4 or higher on 3 of the 4 assessments, and 45 out of the 89 (50.6%) participants scored 4 or higher on all 4 assessments.

Out of the 54 participants with 3 out of 4 evaluations >4, only 2 had a result <3, which occurred on only 1 occasion, the values having returned to >4 at the next visit. There was therefore little evidence of spontaneous or sustained reduction in BASDAI scores below the threshold 4 level within the18 month study period. Table 3.30 shows the 4 BASDAI scores for each of the individuals (n=45) who consistently scored >4 throughout the study period.

Table 3.30. BASDAI scores consistently remaining >4

Identification Number	ASSESSMENT			
	1	2	3	4
1	5.1	6.8	8.4	8.2
4	7.4	6.8	6.7	6.3
7	5.3	5.4	5.2	4.3
15	6.3	6.3	5.9	5.4
21	6.3	5.2	5.3	4.1
22	7.4	8.1	7.4	7.0
23	7.3	8.4	8.4	8.3
25	4.8	7.4	4.4	7.7
26	7.6	7.3	6.7	6.2
27	7.5	7.6	5.4	7.6
28	5.6	4.7	5.8	7.6
29	5.3	6.7	6.4	6.9
31	6.6	6.8	6.4	6.6
34	4.1	4.4	5.5	4.8
37	5.3	6.3	6.3	7.1
40	5.9	6.1	7.5	6.1
42	5.5	5.5	6.3	4.3
45	7.0	7.7	6.3	8.8
47	7.2	5.3	6.8	6.3
48	5.0	7.2	6.5	7.7
50	8.8	7.7	7.1	8.1
51	9.0	8.5	8.3	8.2
54	6.6	8.2	8.1	8.4
58	5.9	6.8	6.9	6.8

Identification Number	ASSESSMENT			
	1	2	3	4
59	5.8	5.4	7.5	6.0
60	8.9	5.8	8.7	6.0
65	5.6	5.9	5.1	5.4
66	5.3	7.3	8.1	6.6
69	8.0	8.3	8.8	7.9
70	5.4	4.8	6.1	5.8
72	5.8	7.0	8.8	7.2
73	5.3	7.9	7.6	8.7
74	5.7	5.4	5.2	8.7
75	5.2	5.1	5.1	5.8
78	6.5	5.6	4.5	6.5
79	7.1	7.2	5.9	5.8
80	7.6	7.9	8.3	7.1
85	8.4	9.2	8.3	7.1
86	6.5	6.9	8.1	6.0
88	5.9	7.6	6.4	7.1
90	6.9	7.8	6.0	7.8
94	7.2	7.9	7.9	8.4
95	6.4	7.1	8.3	7.5
102	6.4	5.5	5.9	5.5
108	5.6	5.7	7.6	6.5

Table 3.30 shows the values for each individual's BASDAI score over all four assessments.

4.2. Analysis of BASDAI scores of 4 or higher

47 (53%) participants scored BASDAI 4 or higher on the first assessment, of whom 45 (51%) scored 4 or higher on all subsequent assessments. The distribution of BASDAI scores for this group shows that most were consistently between 5 and 7 (Table 3.31). There was no significant difference between this group and the remainder of the cohort in terms of their median age, age of reported disease onset or disease duration. In addition, 9 (10%) other participants scored 4 or higher on 3 assessments, whilst overall 70 (79%) participants had a BASDAI score of 4 or higher on at least one assessment during the 18 month period.

Table 3.31. Distribution of BASDAI scores for participants who scored 4 or higher on all assessments (n = 45)

Assess	BASDAI 4	BASDAI 5	BASDAI 6	BASDAI 7	BASDAI 8	BASDAI 9
1	2	19	9	10	4	1
2	3	13	9	14	5	1
3	2	11	13	8	11	0
4	4	5	14	13	9	0

4.3. BASMI and BASFI scores in participants with persistently active disease

To characterise further the disease status of the 45 participants with persistently high BASDAI scores, correlations with BASMI and BASFI scores for each assessment were analysed (Table 3.32). The results show consistently strong correlations between BASDAI and BASFI scores throughout the study, but comparatively weak correlations between BASDAI and BASMI scores.

Table 3.32. Correlation of BASDAI scores with BASMI and BASFI scores for participants who scored BASDAI 4 or higher on all assessments (n = 45)

Assess	BASMI	BASFI
1	$r_s = 0.297$ $p = 0.047$*	$r_s = 0.363$ $p = 0.014$*
2	$r_s = 0.355$ $p = 0.017$*	$r_s = 0.643$ $p < 0.001$**
3	$r_s = 0.265$ $p = 0.079$	$r_s = 0.427$ $p = 0.003$**
4	$r_s = 0.057$ $p = 0.711$	$r_s = 0.690$ $p < 0.001$**

Table 3.32 shows correlations between variables as assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

4.4. Disease outcome

BASDAI, BASMI and BASFI scores at assessments 1 and 4 were compared for the group who consistently scored BASDAI 4 or higher throughout. To enable the impact of persistently active disease on outcome to be assessed, these results were compared with those for the group who consistently scored BASDAI < 4 throughout (n = 19), indicating persistently quiescent disease (Table 3.33). Whilst there was no significant change in mean scores for any of the disease indices in the group with persistently quiescent disease, the group with persistently active disease showed a small but significant increase in mean BASFI score, suggesting deterioration in function during the course of the study. However, there was no significant change in either BASDAI or BASMI score during this time.

Table 3.33. Outcome of persistently active and persistently quiescent disease

Assess		BASMI	BASFI	BASDAI
1	Active (n = 45)	4.1 (1.6)	6.1 (1.8)	6.4 (1.2)
4	Active (n = 45)	4.2 (1.5)	6.6 (1.9)	6.8(1.2)
	P	0.514	0.022	0.074
1	Quiescent (n = 19)	2.0 (1.4)	1.1 (0.9)	1.6 (1.1)
4	Quiescent (n = 19)	2.1 (1.6)	1.2 (1.2)	1.7(0.9)
	P	0.434	0.706	0.652

Table 3.33 shows mean (SD) values for each measure of disease status at assessments 1 and 4 in the group who consistently scored BASDAI 4 or higher and the group who consistently scored BASDAI < 4. Within each group, significant differences in mean scores between assessment 1 and 4 were tested using Student's t-test.

4.5. Psychological status

Mean scores for anxiety and depression were significantly higher in the group with persistently active disease compared with the group with persistently quiescent disease (Table 3.34). However, neither anxiety nor depression scores increased significantly in the group with persistently active disease during the course of the study (Table 3.35), suggesting that persistent disease activity was not associated with deterioration in psychological status over this period. Mean anxiety score was higher at assessment 4 than assessment 1 for the group with persistently quiescent disease, although mean depression score was not different at each assessment.

Table 3.34 Outcomes of anxiety and depression scores in persistently active disease

Assess 1		Assess 4	
Active	**Quiescent**	**Active**	**Quiescent**
		Anxiety	
9.3 (3.4)	1.9 (2.0)	10.0 (4.0)	3.1 (2.6)
P < 0.001		P < 0.001	
		Depression	
7.7 (4.1)	1.3 (1.4)	8.4 (4.2)	1.4 (1.6)
P < 0.001		P < 0.001	

Table 3.35 Outcomes of anxiety and depression scores in persistently quiescent disease

Active		Quiescent	
Assess 1	**Assess 4**	**Assess 1**	**Assess 4**
		Anxiety	
9.3 (3.9)	10.0 (4.0)	1.9 (2.0)	3.1 (2.6)
P = 0.149		P = 0.006	
		Depression	
7.7 (4.2)	8.4 (4.3)	1.3 (1.4)	1.4 (1.6)
P = 0.191		P = 0.590	

Tables 3.34 and 3.35 shows mean (SD) values for anxiety and depression at assessments 1 and 4 for the group whose BASDAI scores were consistently 4 or higher (persistently active, n = 45) and the group whose BASDAI scores were consistently less than 4 throughout (persistently quiescent, n = 19). Between-group differences were analysed using independent-samples t-tests.

5. SUMMARY

Of 110 participants recruited to this study, 89 completed 4 six-monthly assessments of disease and psychological status over a period of 18 months. The results were analysed to explore associations between scores for disease and psychological status within the group, to determine the consistency of such associations over time, to identify components of the assessment toolkits, which showed the strongest and weakest associations, and to explore possible effects of other factors (co-existent conditions, age, disease duration, gender, hip involvement) on these associations. In addition, the data were analysed to provide an indicative comparison between the clinical and psychological status of this study group and other published cohorts.

The results showed that:

- BASMI, BASFI and BASDAI scores correlated well with anxiety and depression scores at all assessment points, although for BASMI scores the levels of correlation were lower than for BASFI and BASDAI.
- Mean BASFI and BASDAI, but not BASMI, scores were significantly higher in anxious and depressed subgroups.
- BASDAI scores showed negative and relatively weak correlations with internality and the same generally applied to BASFI and BASMI scores, showing that worse disease activity, function and movements were associated with lower internality.
- Subgroups with low internality had consistently higher BASMI, BASFI and BASDAI scores, as well as significantly higher anxiety and depression scores.
- There was no consistent correlation between strength of belief in chance or belief in powerful others and any of the disease status scores, nor with anxiety or depression scores.
- BASDAI, BASFI and BASMI scores correlated significantly with all SF-36 domain scores except change in health.
- All SF 36 domains demonstrated negative associations with anxiety and depression scores except for role limitation due to emotional problems and role limitation due to physical problems, for which the associations were positive.
- Conversely, correlations between internality and most SF 36 domains were positive, albeit weak and less consistent, but negative for the domains of role

limitation due to emotional problems and role limitation due to physical problems.

- There were no significant differences in disease or psychological scores associated with co-existent iritis or psoriasis.
- BASMI and BASFI scores were significantly higher in the over 50s, but differences in mean BASDAI, anxiety, depression and internality scores did not achieve statistical significance.
- There were no significant differences in disease or psychological status scores between subgroups whose disease duration at the beginning of the study was less or more than 20 years.
- There were no consistently significant differences between males and females in any disease status or psychological scores, whilst anxiety and depression scores consistently and significantly correlated with disease status scores in both sexes. Nevertheless, at each time point, relationships between BASMI and each of anxiety and depression scores appeared consistently stronger in females than in males.
- BASDAI scores remained consistently >4 in 50% of this cohort indicating that disease activity remained active throughout.

Table 3.36. Summary of the relative strengths of the key associations found within this analysis

Domain	BASDAI	BASFI	BASMI
Anxiety	Strong	Strong	Moderate
Depression	Strong	Strong	Moderate
Internality	Weak	Weak	Weak
Belief in chance	**Absent**	**Absent**	**Absent**
Belief in powerful others	**Absent**	**Absent**	**Absent**
SF 36	Strong	Strong	Strong
'Change in health' SF 36 domain	**Absent**	**Absent**	**Absent**
Anxiety in people without psoriasis	Strong	Strong	Strong
Anxiety in people with psoriasis	Strong	Strong	**Absent**
Depression in people without psoriasis	Strong	Strong	**Absent**
Depression in people with psoriasis	Strong	Strong	**Absent**
Anxiety and depression in men and women	Strong	Strong	Strong

CHAPTER 4

IDENTIFICATION OF INDIVIDUALS SHOWING CONCOMITANT CHANGE IN DISEASE AND PSYCHOLOGICAL STATUS

IDENTIFICATION OF INDIVIDUALS SHOWING CONCOMITANT CHANGE IN DISEASE AND PSYCHOLOGICAL STATUS

4.1. Rationale of approach used to identify participants with concomitant change in disease and psychological status.

The aim of this part of the study was to identify participants who demonstrated concomitant changes in both disease and psychological status during the 18-month study period. In principle, this would provide an opportunity to focus upon these participants to explore whether the associations between disease and psychological status found by analysing the group data could be identified at the individual level. Additionally an approach for investigating the underlying nature of the associations in more detail would be created.

Although mean scores over the 18-month study period for the group as a whole were quite stable, it is recognised clinically that individuals with AS commonly undergo periods of exacerbation and remission in disease severity. The approach therefore was to try to identify individuals whose disease and psychological scores changed in concert over at least two consecutive assessments and then to explore further with them the nature of this experience.

A key issue, which arises, however, is the question of how to identify clinically significant change in individuals' scores. To date, the only attempt to ascertain the minimum clinically important difference (MCID) for the Bath indices was published recently by Pavy et al (2005). The purpose of the study was to prospectively define MCID values according to patients' perspectives and in conjunction with the Bath indices. A 15-point global rating scale (validated by Jaesche and Juniper, 1994 and cited by Pavy, 2005) was used to examine separately the BASDAI, BASFI and BAS-G. Receiver operating characteristic (ROC) curves were plotted to determine the BAS change score that most accurately classified patients with respect to a clinically meaningful change. In terms of absolute value, it was determined that a change superior or equal to 7mm of BASFI corresponded to the smallest change, allowing the identification of a patient who experienced clinically important improvement (sensitivity = 0.60/specificity = 0.85). For BASDAI the MCID was 10mm or 22.5%, with sensitivity equal to 0.65 and specificity

equal to 0.82. For BAS-G the threshold value was 15mm or 27.5% change equal to 0.61 sensitivity and specificity equal to 0.74.

It remains extremely difficult, though, to establish if differences in MCID have a minor or important effect on the overall health of the patient. For the clinician, a 'clinically important' difference can be perceived as the smallest change that could lead to a therapeutic modification. However the clinician must also consider both the safety and the cost of the intervention modification. Therefore an improvement, which is classified as 'moderate', may not be considered as being 'clinically important' (Pavy, 2005). Pavy et al (2005) also noted that both the sensitivities and specificities obtained and the area under the ROC curves could be considered small. They considered this to be a result of therapeutic interventions and suggested that the values might be higher if other therapies had been given.

In the context of clinical trials, significant response to anti-TNFα treatment has been defined by the Ankylosing Working Group (ASAS) as reduction in the BASDAI score by 50% (BASDAI 50) or a fall of 2 units. They also recommended that response to treatment should be assessed according to a composite score, which included VAS scales reflecting spinal pain, inflammation (BASDAI), well-being and function (BASFI). Improvement in these domains by 20% or more constitutes an ASAS 20 response with 50% and 70% improvements constituting ASAS 50 and ASAS 70 responses respectively (Keat, 2005). Therefore this evaluation relies solely upon percentage change in each of the domains.

Regarding the definition of clinically significant change in the HADS, there is currently no available data, which defines how much change in the score is needed to be significant. However, the instrument has been shown to be sensitive to change. Herrmann (1997) in an extensive review cited studies of major depression and neurotic disorders using psychotropic drugs as well as cancer patients and heart disease patients who received psychosocial interventions or rehabilitation programmes. In all of these studies, HADS scores were significantly reduced as a consequence of the interventions. Some studies also demonstrated significant improvements in HADS scores when comparing treated with control groups. Methods to determine change in HADS scores vary. For example, Hopwood et al (2000) investigated change in depression over time in patients with lung cancer. Using a cut-off of 8-10 for 'borderline' and 11 or more for 'probable' cases of depression, the baseline HADS data was compared to that at first follow-up using

Wilcoxon's signed ranks test. However, there was no statistically significant change in depression rates identified by this study.

Sharpe et al (2003) attempted to determine whether statistically significant changes in HADS scores were of clinical significance when evaluating the long-term efficacy of a long-term cognitive behavioural treatment in RA. They re-analysed scores on the HADS anxiety and depression scales using cut-off scores conventionally taken to indicate a possible (>7) or probable (>10) clinical problem. The results of the HAQ were re-analysed according to the level of improvement shown in patients over time with 4 categories: *worse* – a deterioration in function greater than 25%, *un-changed* – a score within 25% of the original score in either direction; *somewhat improved* – an improvement in HAQ scores of between 25 and 49% and *much improved* – an improvement of 50% on the original HAQ score.

The paucity of published methodology or guidelines available at the time of this study led to the development and use of a novel methodology. This was created specifically for the purpose of independently analysing each participant's data to identify change in disease score and to identify when such change occurred in parallel with change in psychological status.

The following analyses were performed:

1. Pearson correlations between BASMI, BASDAI and BASFI scores and HADS anxiety and depression scores were calculated over all 4 assessment points for each of the 89 participants using Microsoft Excel.

2. Associations which were >0.5 were chosen. Each association of >0.5 was scrutinised to ascertain if there had been a substantial and simultaneous variation in both the disease and psychological status scores. For example, a correlation of r = 0.93 could be considered substantial but on investigation although the BASMI scores changed 2.91, 2.38, 1.29, 3.06 respectively, the anxiety scores remained unaltered at 8, 8, 7, 8 indicating that this was not a 'dynamically changing' association and was therefore unsuitable.

3. Having identified associations which met this criterion, the ranges of the scores were then reviewed for evidence of reasonably substantial changes. The highest

change between two consecutive scores was determined and the percentage of this change calculated.

4. To illustrate the dynamic nature of this association, charts were created for each individual identified by this methodology to have demonstrated concomitant changes in both disease and psychological status.

4.2. Scores in individual participants showing evidence of change over time.

27 individuals who demonstrated Pearson correlation values of $r > 0.5$ between at least one disease measure and either HADS anxiety or depression scores were identified (Table 61). Each participant is identified by their original study identification number and referred to by this number throughout this section. As is evident from Table 4.1, some individuals demonstrated such correlations only between one pair of variables, whilst others demonstrated several such bivariate associations.

The correlations which demonstrated significant change have been highlighted in Bold and those who went on to complete the study have been shaded. Those who would have met the criteria but did not go on to the further study have been formatted in italics.

Table 4.1. Associations between disease and psychological scores for individual participants

ID	Anxiety/ BASMI	Anxiety/ BASFI	Anxiety/ BASDAI	Depression/ BASMI	Depression BASFI	Depression BASDAI
4	r = 0.77		r = 0.57			
6		r = 0.96			r = 0.83	
12			r = 0.91	r = 0.51	r = 0.99	
18			r = 0.67		r = 0.52	
25	**r = 0.71**	**r = 0.66**				
26	r = 0.64	r = 0.59	r = 0.80	r = 0.50		r = 0.78
29	**r = 0.95**	**r = 0.80**	**r = 0.92**	**r = 0.75**	**r = 0.81**	**r = 0.67**
37	***r = 0.96***	***r = 0.99***	***r = 0.92***			***r = 0.56***
45		***r = 0.88***		***r = 0.79***	***r = 0.87***	***r = 0.69***
47			r = 0.98		r = 0.63	
48	***r = 0.95***	***r = 0.65***	***r = 0.80***	***r = 0.82***	***r = 0.57***	
51	**r = 0.97**			**r = 0.92**		
53	**r = 0.97**					
55	**r = 0.78**					
58		r = 0.98	r = 0.90	r = 0.75	r = 0.87	r = 0.98
60			***r = 0.67***		***r = 0.68***	***r = 0.74***
70		r = 0.77	r = 0.99	r = 0.94		
71	**r = 0.97**	**r = 0.94**		**r = 0.74**	**r = 0.69**	
73		**r = 0.97**				**r = 0.95**
74	**r = 0.92**	**r = 0.78**	**r = 0.57**			
81			**r = 0.93**			
85	**r = 0.67**	**r = 0.83**				
88						r = 0.57
91			**r = 0.65**	**r = 0.89**		
92			***r = 0.73***	***r = 0.94***		
95	r = 0.68		r = 0.79		r = 0.85	r = 0.51
107	r = 0.67			r = 0.92	r = 0.93	
27	**n = 14**	**n = 13**	**n = 16**	**n = 12**	**n = 12**	**n = 9**

Table 4.1 shows Pearson correlation values for disease measures and HADS anxiety and depression scores showing evidence of change over 4 assessments in individual participants.

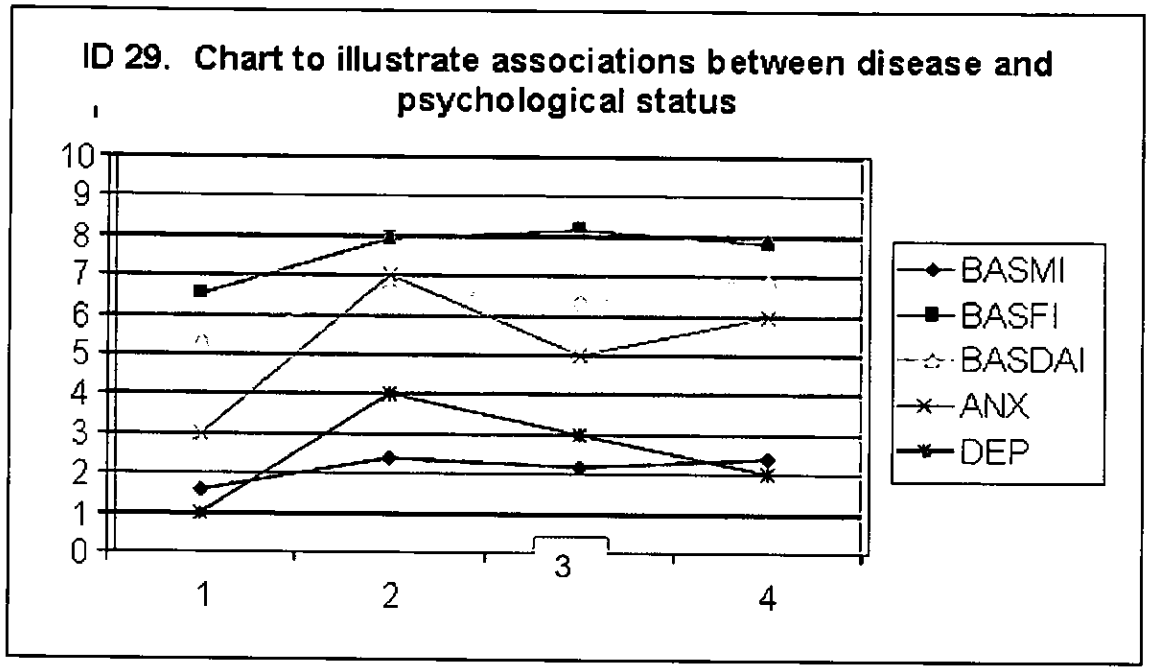
From this analysis, 16 (18%) of the 89 participants showed evidence of dynamic change in disease and psychological scores. Two of these participants were undergoing further investigations following the appointment of a new consultant rheumatologist to take over their care. It was therefore deemed as being insensitive to invite these participants to participate further with the study. On the basis of these findings however, 14 of the 16 were invited to participate in a qualitative study to explore relationships between dynamic change in disease and psychological status, which was undertaken as the final component of this project. Two of these participants failed to respond to the invitation and one participant, who did consent, withdrew due to complications following a hip replacement operation.

Data for Individual 29 are shown for illustrative purposes (Table 4.2 and Chart 4.1). Data for the 10 other participants are shown in Appendix 10. Each table shows strengths of correlations between disease and psychological scores. The highest change, which occurred for both the disease and psychological score are also shown, together with the percentage change, which this reflects. The range of scores for the individual recorded over the course of the study has also been included to demonstrate the extent of variation that occurred.

Table 4.2 Data for Individual 29

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
29	BASMI Anxiety r = 0.95	0.8 4	50% 133%	1.6 to 2.4 3 to 7
	BASFI Anxiety r = 0.80	1.4 4	22% 133%	6.5 to 8.2 3 to 7
	BASDAI Anxiety r = 0.92	1.4 4	26% 133%	5.3 to 6.9 3 to 7
	BASMI Depression r = 0.75	0.8 3	50% 300%	1.6 to 2.4 1 to 4
	BASFI Depression r = 0.81	1.4 3	22% 300%	6.5 to 8.2 1 to 4
	BASDAI Depression r = 0.67	1.4 3	26% 300%	5.3 to 6.9 1 to 4

Chart 4.1. Chart for Individual 29 illustrating associations between disease and psychological status



Data for 5 other participants who would, by these criteria, also have been suitable to participate in the qualitative study, are also shown in Appendix 11 together with summary data for the 11 other individuals who did not meet the full inclusion criteria for entry Appendix 12. For these, although the r values indicating strength of associations between disease and psychological status were > 0.5, levels of change in disease and psychological status scores were regarded as being too low to demonstrate dynamic and concurrent change in the relationship between the two scores.

The aim of this part of the study was to identify participants who demonstrated evidence of concomitant change in both disease and psychological status, as a basis for exploring further the underlying factors involved using an in-depth qualitative approach. In the absence of a well-defined and accepted methodology for identifying suitable participants, an approach was developed and utilised which appeared able to discriminate between dynamic and linear relationships. From this analysis, which also incorporated an element of clinical judgement combined with statistical analysis to discern clinically significant change, 16 of the 89 participants were identified as demonstrating evidence of concomitant and significant recent change in disease and psychological status. This subgroup was regarded as having the most potential, within

the overall study group, to provide insights into the nature of the relationships between disease and psychological status.

One could postulate that this analysis would identify those people who would have HADS scores in the middle banding of 'possible' anxiety and/or depression (7 – 11) as this range would potentially be more likely to fluctuate. Arguably, it is these people who would be the ones most likely to change rather than those who either had no anxiety and/or depression (range 0 – 7) or those with definite anxiety and/or depression (range 11- 21). An additional important consideration is that the items contained within the HADS instrument do not include somatic items therefore omitting the floor effect and thereby making the scales sensitive also in the ranges of mild forms of anxiety and depression (Herrmann, 1997). Undoubtedly however, chance effects had a significant influence upon this methodology. But if it were at all possible to identify a change sufficiently significant to identify those who had associations between their disease and psychological status, then this was a potentially suitable methodology to adopt. Interestingly, the individuals who went onto complete the qualitative study, did have a spread between the three HADS categories with the majority falling within the 'possible' anxiety and depression ranges (n = 6).

There are potential weaknesses attributable to this analysis as this has been a novel approach. Table 4.3 summarises potential strengths and weaknesses of this methodology.

Table 4.3. Strengths and weaknesses of the methodology.

Strengths	Weaknesses
The analysis allowed identification of concurrent changes, which occurred between the disease and psychological scores at the same time point.	This was a short set of observations (4) and therefore there were potentially a lot of correlations of <0.5 simply by chance. There is a possibility that 20% - 25% of correlation co-efficients would by greater than 0.5 even if there was no relationship.
Able to identify at which point the change had occurred and the degree (percentage) of the change to ensure that this was concurrent and clinically significant.	Utilisation of the repeatability coefficient ($=1.96\sqrt{2}s_w$ where s_w is the within-subject standard deviation), would give the largest plausible difference between two measurements (of the same quantity) thus informing whether a change was a 'real' one rather than just, potentially, random error.
ASAS clinical changes in the Bath indices also rely upon percentage change in the score and this was also utilised within this methodology.	Percentage change is overtly dependent on how low the lowest value is. This could have been standardised using a logic scale to measure the relative change more appropriately i.e. $\log_e$ [score/(max_score-score)]= $\log_e$ [score/(10-score) for the Bath indices.
For those in whom it was deemed that a 'change' had occurred in the BASDAI and BASFI domains, these scores exceeded the MCID scores suggested by Pavy (2005).	Extension of the time over which the observations occurred would determine if the pattern persists establishing if the relationships were less likely to have been simply by chance alone.

This was a novel methodology which enabled identification of a group of patients who went onto the qualitative phase of the study during which they completed a further

quantitative assessment within the context of the diaries they were asked to complete (Appendix 3). Responses to two questions within the diaries were indicated by a 10cm VAS line. The questions were:

- Please mark the line below with a cross to tell me how your AS has been today?
- Please mark the line below to tell me how much your AS has affected the way that you feel emotionally today?

Analysis of the responses to these questions (Table 4.4) revealed that 8 out of the 10 participants (one participant felt he was unable to complete his diary) had Pearson correlations > 0.5 between these 2 questions demonstrating a significant association between the responses. This would suggest that the methodology described above had been able to identify participants who were demonstrating concomitant change in both disease and psychological status.

Table 4.4 Correlations between self rated disease status and psychological status from diaries (participant 2 unable to complete)

Participant Number	Correlation
1	r = 0.72
3	r = 0.61
4	r = 0.83
5	r = 0.75
6	r = 0.58
7	r = 0.86
8	r = 0.44
9	r = 0.56
10	r = 0.81
11	r = 0.- 0.11

Table 4.4 shows Pearson correlation values for associations between the two responses for the questions asked within the diaries and made at the time of diary entry.

Furthermore, the psychological status of the participants identified fell into three sub groups for anxiety and depression scores as identified by their HADS scores throughout the quantitative study. Zigmond (1983) recommended cut off scores for the sub-scales which are 0 to 7 considered "non-case", 8 to 10 considered "possible case" and 11 to 21 considered "probable case". Table 4.5 shows the average HADS scores and range throughout the 18 month period of the longitudinal study for each participant.

Table 4.5 HADS scores throughout the longitudinal study

Participant	Average HADS Anxiety	Average HADS Depression
1	5.25 (range 3-7)	2.50 (range 1-4)
2	14.75 (range 12-20)	12.75 (range 8-19)
3	10.25 (range 9-14)	8.0 (range 7-9)
4	7.5 (range 4-10)	4.5 (range 4-6)
5	6.5 (range 5-9)	9.25 (range 7-12)
6	2.0 (range 0-6)	1.5 (range 1-3)
7	8.25 (range 7-10)	5.75 (range 5-7)
8	5.5 (range 3-9)	4.0 (range 3-5)
9	5.0 (range 3-9)	2.0 (range 0-4)
10	7.0 (range 3-9)	9.5 (range 4-11)
11	5.75 (range 4-8)	1.0 (range 0-2)

Table 4.5 shows the average HADS scores and range for each participant over an eighteen month period.

This cohort of participants thus can be subdivided into participants who were not anxious or depressed, participants who bordered on clinical anxiety (not depression), and participants with clinical depression (not anxiety). Each of these subgroups are shown in Tables 4.6, 4.7 and 4.8 respectively along with descriptions of associations identified and insights into personal or co-morbidity problems they described during the qualitative phase.

Table 4.6. Participants with no anxiety or depression identified by the analysis

Participant 1	Changing self-report measures identified associations both with anxiety and depression. Atrial fibrillation becoming a problem towards the end of the study.
Participant 6	Associations with anxiety and movement status only. Regarded iritis to be her main problem.
Participant 8	Associations for both anxiety and depression with disease activity and functional status. During study had bilateral knee replacements.

Table 4.6. Shows descriptions of associations identified in the quantitative study and additional insights into personal or co-morbidity problems for those who were not anxious or depressed throughout the study.

Table 4.7. Participants identified by the analysis who bordered on clinical anxiety (not depression).

Participant 4	Associations between anxiety, functional status and movement. Had considerable peripheral joint problems, hiatus hernia and peptic ulcer and described worrying a lot about his movement especially his neck.
Participant 7	Associations between anxiety and movement. Very late diagnosis. Retired.
Participant 9	Associations between anxiety and disease status and depression movement. Described having a very stressful job. Anxious about his future health and what others think of him. Mother's cause of death attributed to perforated ulcer associated with medication taken for her RA, influenced his views about not taking medication
Participant 10	Associations with both anxiety and depression with movement and functional status. Medically retired and bored with being at home. Described having little sense of achievement. Described previous history of alcohol abuse, kidney problems and diabetes Considerable variation in depression scores within the study, which border also on clinical depression at times.
Participant 11	Associations with anxiety and movement only. Very good scores overall but has more peripheral joint problems. Also has Crohns disease.

Table 4.7. Shows descriptions of associations identified in the quantitative study and additional insights into personal or co-morbidity problems for those who bordered on clinical anxiety (not depression).

Table 4.8. Participants identified by the analysis with clinical depression (not anxiety).

Participant 2	Associations between anxiety and depression and measurement score only. Consistently high reporting of disease status throughout. Death of son and wife and admitted to feeling depressed.
Participant 3	Associations between anxiety and movement and functional status. . Bereavement due to death of his father, one son suffering from autism, one son with ADH, mother in law schizophrenic. Has received counselling in the past and recognises depression.
Participant 5	Associations between anxiety and movement and function. Self-report measures high throughout the initial study. Has worsening function and worries caused by spinal stenosis (occurred during initial study and progressively worsened) and has been very traumatised by this. Main carer for wife who has RA Very angry that he has had no life since retirement.

Table 4.8. Shows descriptions of associations identified in the quantitative study and additional insights into personal or co-morbidity problems for those with clinical depression (not anxiety).

Therefore, this novel approach appears to have been reasonably successful in identifying participants showing concomitant changes in their disease and psychological status.. The participants who were identified demonstrated not only a spread of psychological status scores (HADS) but the analysis of the quantitative questions within the diary also confirmed that there were associations between disease activity and psychological status for this group which were explained further by the insights provided through the analysis of the qualitative data.

CHAPTER 5

INSIGHTS INTO ASSOCIATIONS BETWEEN DISEASE AND PSYCHOLOGICAL STATUS

INSIGHTS INTO ASSOCIATIONS BETWEEN DISEASE AND PSYCHOLOGICAL STATUS

5.1 INTRODUCTION

From the original 89 participants, 16 were identified as demonstrating concurrent changes between their disease and psychological status. At this point, two of the 16 participants were excluded as they were undergoing further investigations by a new consultant rheumatologist to clarify their diagnosis. Therefore, it was deemed to be insensitive to ask them to participate further with this study. Working with this group of 14 participants, the aim of this phase of the study was:

1. To understand individuals' perceptions of change in disease status and the associations, if any, of this with psychological status.
2. To add meaning and depth to descriptions of associations between disease and psychological status identified in the first phase.
3. To explore factors perceived by participants to influence disease and psychological status.

An information letter was sent to each person describing the qualitative study and 12 of the 14 people agreed to take part. One person was subsequently unable to be included, as he had recently undergone hip replacement surgery, which had been complicated by dislocation. Ten men and one woman completed the qualitative study. The demographics of this group are shown in Table 5.1. and concomitant disease status is shown in Table 5.2.

Table 5.1: Demographics of study participants

Average age	52 yrs range 30 -69yrs
Average disease duration	25 yrs range 8 – 47yrs
Average age of onset	25 yrs range 15- 42 yrs
Employment status	
Not working due to ill health	4
Retired	3
Working full time	3
Working part time	1
Social situation	
Living with others	9
Living alone	2

Table 5.2 Concomitant disease status

Concomitant disease	Number of participants
Psoriasis	3
Iritis	3
Inflammatory bowel disease	1

Descriptions of each participant have been provided (Appendix 13).

5.1.1. The efficacy of the diaries

The use of a diary was designed to enable people to record experiences and feelings as and when they wanted to and in as much detail as they wanted. Before they started to keep the diary time was spent with them explaining why they were being asked to complete it, as a method of recording how changes in their disease affected their mood. They were therefore sensitised to the kind of information required and the majority of the participants did provide information of these kinds of experiences.

The intention was that the information recorded could then be used to focus some of the discussion during the interview and provide context for some of the areas being explored. The majority of the participants, when given information about how to keep their diary, stated that they had not previously thought about such issues. The level of information recorded, as expected when using diaries, varied with some participants writing quite detailed accounts whist others wrote only brief statements. Examples of diary transcripts are provided in Appendix 14.

The diaries were collected prior to the interview taking place and enabled the researcher to prepare for the interview. The exploration of the issues raised within the diary during the interview enriched the process by focussing participant's discussion on events they had recorded. During the initial interviews the diary was discussed almost page by page however as the study progressed they provided a point of reference to illustrate and explore some of the issues being discussed and themes that were beginning to emerge.

This approach is consistent with the evolving nature of qualitative interviewing in which the schedule changes and is informed by insights obtained from participants. Examples of the development of the interview schedule are shown in Appendix 15 a (initial version) and 15b (version 4). But these were used to guide discussions and the order of the questions, way in which they were asked and supplementary questions varied from interview to interview.

During the interviews participants did comment on the process of keeping a diary as this was a new experience for all of them. One person decided to share his diary with his wife who, having read it, said that she had been unaware of how much pain and discomfort he had been hiding from her. Moreover, for the participant, this was the first time he had thought about the link between his disease and psychological status and he suggested that thinking about it seemed to make him feel worse. He also was suffering from atrial fibrillation, knee problems and a great deal of stress at work which were additional factors.

One participant felt unable to complete his diary. He had recently suffered bereavements of two friends and he felt too distressed to record his feelings. He asked for a further month to try complete it as in his own words, he 'did not wish to let the researcher down'. However the diary remained uncompleted. The subsequent interview proved to be more difficult to conduct as there was no prior insight into how he felt his psychological status may be affected by his disease status highlighting the contribution the diary made to framing and contextualising the discussion.

One participant asked for a copy of the diary to be used by his solicitor to help with his benefit claim. For another participant the content of his diary, which was extremely short, sensitise the researcher to the fact that he had just been diagnosed with prostate cancer and was undergoing additional tests and awaiting news of the prognosis.

5.1.2 Thematic analysis

All of the diary entries and transcripts from the interviews were included in the data analysis. The initial step was to read and re read all of the transcripts to obtain familiarisation with the data and look for potential codes using the participants own words. To bring order to the numerous codes generated (300) the codes were categorised initially into:

1. AS – physical impact of the condition
2. Psychological 'umbrella' issues

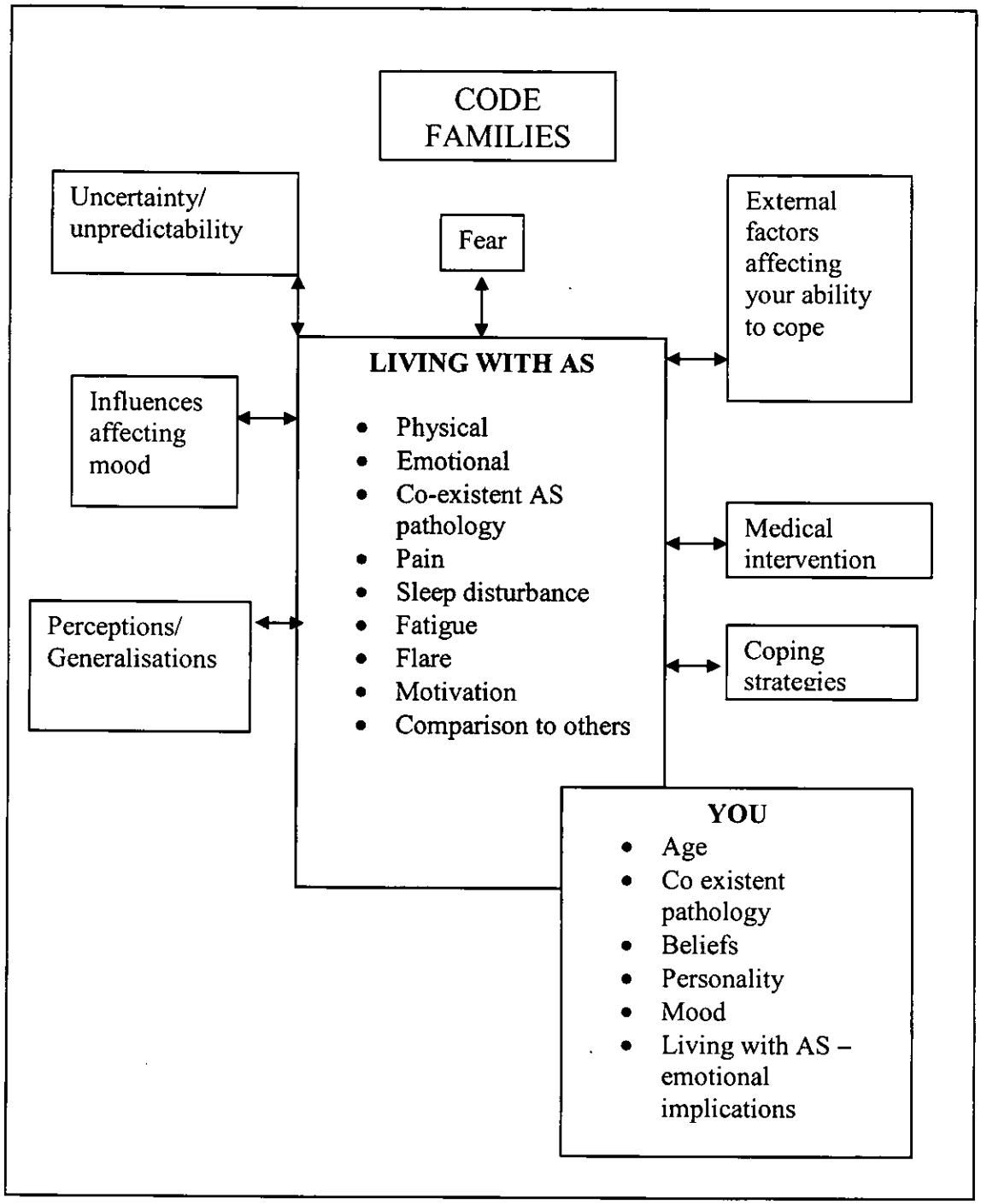
Each of these categories were read numerous time to identify potential themes (Table 5.3).

Table 5.3 Emergent families of themes

Physical	Psychological
Sleep disturbance	Personality
Peripheral joint involvement	Motivation
Unpredictability	Mood
Flare	Influence of mood
Co-existent pathology	Impact of focus on disease
Effects of other conditions	Hiding emotions
Living with AS	AS controlling/dictating
Pain	Control over mood
Ageing	Psychological baggage
Fatigue/tiredness	Sharing emotions with others
Mobility	Coping strategies
Inability to do physical work	Comparison to others with AS
Disease duration	Help from others
External influences on AS	Social implications

The data was then transferred into ATLAS. Ti V 5.0 which is a computer assisted qualitative data analysis software package which facilitates data management and analysis. Themes were subsequently checked, redefined and assigned meanings. These were then sorted creating 'families' of super codes (shown in Appendix 6) which linked related codes together. This was an extremely long and exhaustive process with data coding cross checked with a member of the supervisory team. Any discrepancies were explored and meanings explained and discussed until mutually agreed upon. Visualisation of the process was also found to be helpful Figure 5.1 illustrates one of the diagrams used during this process.

Figure 5.1 Visualisation of the interrelationship between the code families



The process of moving on from the initial data management to descriptive accounts identified elements and dimensions which gave rise to more detailed explanatory accounts. Examples of initial explanations of concepts were:

- The idiosyncratic person
- AS imposing physical effects
- Responses that AS gives rise to

These tentative themes were refined further to provide the final three key themes as:

1. Sometimes it doesn't bother you and sometimes it does.
2. Living individual lives
3. Ways of helping yourself

Each of these will be explored in detail.

5.2 THE KEY CONCEPTS FORM THE ANALYSIS

Participants generally perceived themselves to be coping well with their AS however they described periods when coping became more problematical and their AS was perceived to be harder to control. This was described as impacting upon their psychological status in terms of feeling irritable, frustrated, and impatient as well as being anxious or depressed.

> 'I have thought about it sometimes and it does, it really depresses you sometimes when it is bad. When it's not bad I try and live a normal life as much as possible.' [P10]

> 'I don't know it is strange and yet some times if I am ok and the sponds has not been bothering me I feel on top of the world. I feel great. If I am going anywhere I look forward to it then. And the next day, you are on a downer again because it is bothering you again.' [P8]

Participant's described personal characteristics which they felt influenced how they dealt with their AS:

> 'I am not the sort of person who gets down really, you know I don't let things bother me too much. I can cope with it you know and things no I never get down about things really. I mean obviously every body has their down times, I mean to be too cheerful would be you know wrong wouldn't it all the time but no I am a fairly level person so it doesn't affect me too much.' [P6]

> 'I don't tend to worry about a lot of things. My girlfriend, kids, wife get annoyed because I don't worry about certain things. When I am aware of whatever she is worried about but I don't react, I don't give her the right

signs, I am quiet aware of bills coming in but I don't worry about them. You only get to live once so.' [P4]

Having an optimistic outlook was described as being beneficial in helping some people to get on with their lives no matter what was thrown at them:

'I don't look back I always look forward and I think to myself well tomorrow will be better. You forget about yesterday. That's gone, that's finished it is tomorrow you should be looking at and that is me. I look towards tomorrow and I think I will be better tomorrow. You always think you are going to be better tomorrow.'[P8]

However, some people did described themselves as being worriers seeing this as a negative characteristic which made life harder to enjoy:

'I have always worried. Always. I didn't want to go down the pit. It was either that or go in the army. My dad died when I was 14 and so I was forced in to the pit really. It has always been problems, problems.'[P2]

Participant's descriptions of their approach to living with AS varied with some people perceiving themselves as having personality traits which enabled them to respond in a positive manner whilst others described being inherently anxious. However everyone identified times when their AS had a negative impact on their psychological status and these were often associated with deterioration in their condition and an increase in levels of pain and fatigue.

5.2.1 SOMETIMES IT DOESN'T BOTHER YOU AND SOMETIMES IT DOES.

This theme describes the experience of living with AS and how changes in disease status were perceived to influence psychological status. Within this theme four sub-categories were identified: symptoms, variability and uncertainty, 'well it affects your emotional state' and concomitant disease with AS. Each of these will be described and people's perceptions of the psychological consequences of these features will be explained.

Symptoms

The three main features of living with AS and which were described as influencing psychological status were pain, fatigue and sleep disturbance.

5.2.1.1. Pain

Pain was described as having a considerable influence on a person's life preventing movement, limiting activities and enjoyment and leading to feelings of frustration and depression. It was described as a constant and variable entity:

> 'What I do know is that my back at the bottom is aching and sore twenty-four seven. You don't get a day off for Christmas day. It is just there.' [P10]

> 'Sometimes you think to yourself I have had it all these years and I have never been without pain. It is always there; maybe between a degree between one and ten, sometimes it is only one.'[P8]

Participants described pain as having a negative impact on their mood, which limited their ability to enjoy themselves, and had the potential to wear a person down:

> 'Oh you felt so worn out all of the time probably due to the fact that you weren't sleeping properly and you had this constant bloody pain, pain, pain.'[P7]

The consequences of increasing and uncontrolled pain were described as impacting on the individual and other members of their families:

> 'There is no pleasure if you are in pain all the time. So what do you do? You sit at home all the time and you mope about which makes you depressed.' [P8]

> 'Well I get very bad tempered especially with them that think a lot about me. I do get a bit wound up; I'm not an easy bloke to live with at all. But I'm in pain most of the time and it's frustrating.'[P5]

For one person pain was associated with triggering panic attacks.

> 'Yes the pain wouldn't let me. I was thinking the pain, I can't move I couldn't do the big distance to actually get to the bus or anything so I felt

isolated then like I got panicky and all other stuff you know what I mean?' [P3]

Being in pain and the negative impact of pain on mood led to some people withdrawing from social situations and also to people withdrawing within their own homes:

'No because I found prior to diagnosis I just couldn't enjoy a drink. I would say no I don't want to go out for a drink. I didn't want to go out to the pub. I was an antisocial sod. But to stand at a bar in company with the pain, you are just a pain and they say who is that miserable sod? And so you tended to avoid that kind of thing.' [P7]

'Now and then I do get past that, I get tearful, then I just want to be alone then personally, stay away from people because usually whatever they say is going to wind me up anyway, not because of what they are saying, it's just my state of mind I suppose.'[P4]

Engaging in activities that may increase pain led to avoidance and participants expressed concern about overdoing things and pushing too far and 'paying for it later' with increased pain:

'Yes but it is hard for me to. I know that is when there is going to be a restriction again. Sometimes I can plough through it but I know what the consequences will be later.'[P9]

You try to but you know that if you do something it is going to make you worse than ever. So you have to give in to it and do nothing.'[P10]

Never being free from pain was described as impacting on participants not only in terms of what they could do but also on their psychological status and their ability to cope with and live their lives leading at times to feelings of depression, frustration and irritability.

5.2.1.2. Fatigue

Whilst much attention is paid clinically to pain management, AS participants highlighted the significant impact that fatigue had on their lives. Fatigue was described by participants as affecting their psychological status.

'Well yes, it is just getting on my nerves being tired all the time as if I have enough to put up with. Maybe it is making me tired I don't know but as if I've not got enough to put up with.'[P5]

For those participants in employment there was some uncertainty as to whether fatigue was a consequence of their AS or caused by their job. As with pain, levels of fatigue were described as variable, and this unpredictability was regarded as problematic:

'But you get the odd day when you feel absolutely knackered. You are knackered when you wake up. You are knackered when you go to bed. Then the following day you can be totally different.'[P7]

People described at times feeling so tired and drained that it became harder to motivate themselves to complete tasks:

'... it just sort of lowers you down a bit and you don't feel as enthusiastic to go out for a wander or push the pram around the block.' [P4]

Lack of motivation due to fatigue was regarded as being hard to overcome.

'Not that you don't want to do it, you are too bloody tired to do it. All that you want to do is to slump in the chair and become a couch potato because you are tired. You can't seem to motivate yourself enough to overcome that tiredness.'[P8]

Fatigue was described as being irritating, slowing people down and being unpredictable thus influencing mood and motivational levels.

5.2.1.3. Sleep Disturbance

People described being able to get to sleep but, after two or three hours, being woken by back pain and stiffness.

'In bed at night is one of my problems because I bet I get not much more that an hours sleep. You are wakened and then you are stiff. You can't get out of bed if you want to go to the toilet. That's if you have two hours if you have a good night.' [P2]

Pain was identified as a major factor in sleep disturbance. Some people had to adopt different sleeping positions and participants were also aware of the impact their

restlessness had on partners. Some people described having to get up and walk around in the middle of the night and then experiencing difficulty in getting back to sleep:

> 'When I have not had sleep, it can be 2 o'clock in the morning and I wake up in agony. Aches and pains I can't relax my spine and then I am tossing and turning all night. Just get yourself into a comfortable position and you just want to relax your body but you can't.'[P9]

> 'Sometimes you can't get to sleep because you can't get comfortable and you feel like beating the pillow because you are getting angry with yourself because you are just not sleeping and you are tired and you can't go off to sleep because you can't get comfortable.' [P8]

Feeling tired was associated with feeling 'a bit down' and becoming short tempered:

> 'When I don't get sleep of course, sleep deprivation makes you bad tempered, makes you how can I put it, you can't be bothered with anything because you haven't had the rest. Your mind has not been resting; your body has not been resting so therefore you become short tempered which I have never been a bad tempered person you know.'[P8]

For Participant 9 it was especially important that the consequences of sleep disturbance did not impact on his work as he felt this would jeopardise colleague's perceptions of him:

> 'So work wise if it is my emotions regarding having no sleep then I do try to keep them to myself. Not because I am embarrassed about it. It is just that I try to be the same person that I am 99% of the time.' [P9]

The discomfort created by AS was described as causing sleep disturbance which had a detrimental effect on mood by creating feelings of frustration, anger and irritability. Disturbed sleep was associated with increased fatigue during the day, frustration about not being able to achieve so much and with reduced levels of motivation.

5.2.1.4. Variability and uncertainty

All of the participants described the variable nature of AS. For some people a flare was associated with a short discrete time period whilst for others they were prolonged and had a significant impact on their lives.

> 'Only hours, not days. It is mainly through the night. After I had woken up for about three hours and then it would ease. There would be a little bit of pain throughout the day but again it is blocked out. But then it might start up again the following night. So although it is only an isolated spell it might be five or six days of mainly nights.' [P9]

> 'There are other times when I am having a bad flare up when there is nothing I can do. You get to a certain point where exercise doesn't make any difference then it is going to get worse and it gets worse no matter, you try to stay positive and stretch and do your exercises but it is so painful, it burns. There is nothing else like, I don't know how to convey it, it is not unless you have sciatica, or something like that you can't really image how it works with your body and it is there from the moment you wake up to the moment you close your eyes. It's an aching, frustrating because you have lost your movement but it burns almost like a stitch, it carries on and on its relentless and it will be some movement that you do that puts it back. I don't know how it happens.' [P4]

The unpredictable nature of flares was described by Participant 11 as contributing to a sense of losing the ability to control AS.

> 'Just totally that maybe tomorrow you will get something. You will worry about it then. You think that you are in control don't you and realise that you are not.'[P11]

Flares were described as 'coming out of the blue'. For some people there was uncertainty about how severe the flare might be:

> 'That is an immediate thought in your mind. You think is it flare up time and I wonder what this is going to be like' [P7]

Whereas others described warning signs which enabled them to judge the potential severity of the flare:

> 'When I get the feelings that it is going to happen, I can usually tell this is not going to be a good one, you get angry like, pissed off with it really to a degree, that's where the flood is. You start remembering what the pain is like. It's funny how your mind has blanked it of after. You forget you know. I suppose it's a bit like labour!' [P4]

Feeling that AS had resolved only to discover that it had the ability to reappear was also described:

> 'And so yes you have all that time when you think great it has gone and then it comes back and it's like a little poltergeist saying 'ha, ha, I'm still there!' [P9]

Participants made comparisons between flares, which could reassure them if they felt that their current flare was not as severe as those previously experienced.

It was also difficult for people to predict which areas of their body a flare may affect:

> 'It seems to move around all the time from legs to neck and any stages in-between. It seems to shoot out like a tree from there to different parts at different times. I never know when and where.'[P10]

Participants also described the psychological impact of having a flare:

> 'It is when you have a flare up and then you think bloody hell it is here again and then you can't do anything again and then you get aggravated.' [P2]

> 'Very short tempered, horrible to get on with much like when you get really angry at someone and you say something you don't mean, you are constantly aware that you are on the edge of loosing control if you like and you can't concentrate on what you are doing properly. It's like having an itch you can't scratch, it's constant, you know it's there but you can't get it and it's just frustrating.' [P4]

Participant 8 in particular described how positive he felt when his AS was quiescent as compared to his negativity when it is active. The unpredictability of symptomology could make people feel 'low' or even depressed:

> 'Yes because I feel I am doing so well. I have had no pain and then all of a sudden it starts and then the last spell maybe lasted a few days. As I say it is not constantly throughout the day. It is mainly evenings but I get so down I suppose because you have had such a long run of being in no pain what so ever and thinking that you can climb the world's highest mountains or do whatever.'[P9]

People also described having to push themselves harder to do tasks during a period of flare for example getting up earlier in the morning to accomplish usual routines or having to make an effort to be sociable:

> 'I think it takes a lot more effort. Naturally I think I am a nice bubbly person but when I have got to force it when I just want to go into my silent mode and just be quiet and I can't because I have got to keep to that standard. Then yes it is hard work, when you just want to sit there, say nothing and just get on with it. So it does become an effort.' [P9]

> 'It does get you frustrated. There is many a time when you don't want to even make a cup of tea. That's if you have a bad flare up like. It is not because you are lazy. You are just frightened about getting up. You do worry about that many a time.' [P2]

The unpredictable nature of AS led some people to be concerned about forward planning:

> 'You know you can't look forward to anything really because you don't know what you are going to be like that day this is the big thing.' [P8]

> 'I was going on holiday a few months ago and I was going on a cruise and I couldn't look forward to it because I thought to myself what will I be like when I am on it?'[P8]

However when a flare suddenly resolved, people described feelings of relief and happiness:

> 'I am surprised. I am very pleased. I wake up and I think 'yes'. When other days you think this bit, that bit and you think don't mention anything because you know they will think you are a walking disaster with all these different aches and pains. So yes that's great yes.'[P6]

Whilst participants described the impact of variability on their ability to plan from day to day they also described a degree of uncertainty and concern about the future:

> 'I worry about whether it is going to disappear or whether it is going to get worse, in the long run. If I am going to be like this for the rest of my life or whether it will get worse.'[P4]

Concerns were principally related to issues of loss of mobility and independence, especially the need to use a wheelchair or having to give up their homes to be cared for by others:

> 'It is like when I saw the guy in the car park. If I got like that would I be climbing ladders? Would I be doing this? I would find it extremely difficult if it stopped me and I would have to change my life completely. That is where the worries come and go sometimes.' [P9]

There were additional concerns associated with the potential development of spinal deformity; this was especially relevant for those who had experience of other peoples' deformity:

> 'I felt relief that I wasn't in that condition but I also thought what if that is me in 10 years time because I don't know whether it could be or not. And then there was the worry I suppose and the upset. I mean how he physically looked and people just staring and taking the mickey. I was worried that that could be me one of these days.'[P9]

The variability and unpredictability of living with AS appears to create an additional 'burden' upon people's lives. The impact of this is linked with influencing psychological status in that people are unable to predict how they will be from one day

to the next. Additionally, fears for the future were evident with AS creating additional worries concerning issues such as deformity and loss of independence.

5.2.1.5. 'Well it (AS) affects your emotional state'

Feelings of frustration, grumpiness, anger, unhappiness, annoyance, missing out on life, depression and being aggravated were all described by participants as being associated with living with AS. These feelings were described as a consequence of restricted physical activities, pain and having to weigh up the consequences of attempting things they knew could be challenging. AS was described as dictating what participants could do and limiting their freedom of choice for activities:

> 'It is very hard to explain it is just stopping you doing what you want to do. Frustration that you can't.'[P6]

Participant 2 loved playing darts and had excelled in this. As his AS worsened, he found it more difficult to pick his darts up off the floor. When other people began to help him, he felt ashamed and as a consequence stopped playing the only hobby he truly enjoyed and had been the centre of his social life. Participant 11 was an accomplished pianist and feared that his hand and wrist involvement could potentially stop him playing the piano in the future. Participant 10 supported Preston North End football team but no longer felt fit enough to travel to away games. Participant 7 had only been able to complete one year of an Open University history degree due to his pain and having to sit and read for prolonged periods. He had to give this up, as he was unable to enjoy his studies and found that his concentration levels were severely affected by having AS.

All of the participants described times when they found their AS more of a problem and this was linked with the variable nature of the condition. Increasing disease activity gave rise to additional problems such as the inability to predict from day to day, timing, extent, severity and location of pain, it impacts on sleep and leads to increased fatigue. Whilst participants emphasised the need to remain motivated and active they described the challenges of sustaining this during flares and how depression had the greatest detrimental influence upon motivation.

When people felt depressed, they described a lack of enthusiasm to do things. Although it was recognised that it would be beneficial emotionally if they could do something, it became very difficult to achieve this:

> 'Yes but it depresses you because you can't be bothered. You know it will cheer you but you can't get the enthusiasm up to do it whatever you want to do and you know it would have cheered you up at the back of your mind. It's difficult.'[P4]

Participant 2 described being scared to move due to fear of exacerbating his pain but also recognised that there was also an association with his motivational status:

> 'It does get you frustrated. There is many a time when you don't want to even make a cup of tea. That's if you have a bad flare up like. It is not because you are lazy. You are just frightened about getting up.'

5.2.1.6. Concomitant disease with AS

People with concomitant disease described difficulty in assessing the extent to which concomitant and AS disease activity were linked:

> 'I used to think that the serious part of it was when my eyes flared up, which was iritis so then I used to think something's happened for that to happen, where as I could never work out properly whether the iritis was following from something that had happened from the AS and whether the AS was coming from iritis you know because it was all one great big mish-mash.'[P1]

Iritis was described as particularly distressing by those who experienced it, as an additional burden and was perceived as being potentially more harmful than a flare of AS.

> 'I know that sounds daft when you've got iritis but it came into focus more and you were more conscious that something was wrong and that you had to manage it, where as when it's just normal, you can't do that kind of thing can you?' [P1]

> But yes there is a down side to having iritis, I don't like having it. I think that by the time you get it you are already a bit low anyway and then I sort of think 'Oh no I have got this now to put up with.' [P6]

The inconvenience of waiting in casualty and being unable to read and drive during an attack were described along with a fear of damaging eyesight in the long term. Foreign travel created additional anxiety due to concerns about not being able to communicate with medical staff and the potential delays this could lead to in treatment. Taking medication abroad 'just in case' was mentioned.

A distinction made between iritis and AS was that iritis was perceived as having a 'solution' and a 'resolution' which for Participant 6 was particularly important, as she feared the potential long term disability from her AS more than her iritis:

> 'Well I feel that the iritis always has a solution or a resolution to it. Whereas with the hips and the other joints they could perhaps deteriorate or never be able to recover.'

Concomitant pathology was described as an added burden perceived as being as unpredictable as AS. Iritis in particular created the most worry, as it is associated with fear of potentially damaging eyesight.

These data provide insights into the problems of remaining motivated especially when the disease is more active. This creates an additional burden, which results in every day life becoming more difficult and less, enjoyable. All of the participants described times when they found that their AS was more of a problem and this was linked with the unpredictable nature of the condition. Pain creates the most distress especially at times of flare, with the subsequent impact upon psychological status. People were aware of changes in their mood caused by their inability to do the things that they wanted to do and simply making it harder to live their normal everyday lives. Sleep disturbance and fatigue were also described as having a detrimental affect on mood with this being more problematic at times of flare. Further more for those with similarly unpredictable concomitant pathology, especially iritis, further challenges exist creating additional burdens.

Increasing disease activity gives rise to additional problems such as the inability to predict from day to day, timing, extent, severity and location of pain, impacts on sleep and leads to increased fatigue thus becoming a time when changes in psychological

status can occur. Additionally, being unable to predict how AS would go onto effect people in the future was described as creating fear and further distress. Whilst participants emphasised the need to remain motivated and active they described the challenges of sustaining this during flares and how depression had the greatest detrimental influence upon this aspect. The additional restrictions and constraints imposed by AS also affect emotional status creating feelings such as frustration, anger and unhappiness.

5.2.2 LIVING INDIVIDUAL LIVES

This theme describes the individuality of the participants lives and the ways in which factors such as up bringing, events occurring during childhood and adolescence and life circumstances were described as having a major effect on the way in which they not only came to terms with their AS but how they dealt with it on a daily basis. Within this theme three subcategories were identified, life circumstances, concurrent (non AS) pathologies and getting older. Taken together they illustrate the wider contexts of the participants' lives and the challenges with which they were contending.

5.2.2.1. Life Circumstances

Of the 11 participants 8 described key life events which they felt had influenced and impacted on their ability to cope with their AS. In some instances these were current life circumstance whilst in others they were past life events, which were still felt to be having an influence. These are summarised in Table 5.4.

Table 5.4: Key life events that affected individuals

Participant 1	Father had an above knee amputation and this significantly influenced how he perceived he should deal with his own illness. Occurred several years prior to the Group Study commencement
Participant 2	Forced to work down the pit as a young man. Bereavement of his son and one year later his wife. Both deaths occurred just before the Group Study commenced.
Participant 3	Bereavement of his father 10 years prior to the Group Study commencing. One son suffering from autism, one son ADH, mother in law schizophrenic
Participant 5	His father had AS and had been bedridden for 17 years Main carer for wife (RA) which commenced several years prior to the Group Study and continued throughout the study.
Participant 7	Delayed diagnosis of AS for 20 years. Only diagnosed approximately 2 years prior to the Group Study commencement. Had been divorced for several years prior to the Group Study as a result.
Participant 8	Divorced for many years prior to the commencement of the Group Study. His daughter had died in her early teens many years ago.
Participant 9	Mother had RA and died from a perforated ulcer approximately five years prior to the Group Study commencement. Medication blamed for her death.
Participant 10	Disabled father who had influenced his own perception of how he should address his own illness. Previous history of alcohol abuse. Had become tee total just prior to the commencement of the Group Study.

5.2.2.2. Current Life Circumstances

The challenges that some of the participants described living with were considerable, as illustrated by participant 3. One of his sons was autistic and he felt that the family had been stigmatised by his behaviour. They had to move home due to him being bullied, and the family didn't like their new home. His other son had Attention Deficit Disorder (ADD), which had also resulted in bullying particularly at school. His mother in law was schizophrenic and alcoholic and he and his wife were finding it increasingly difficult to ensure that she was taking her medication. Against this background he was aware that he was unable to adhere to his exercise regimes due to lack of time and increasing his emotional distress.

> 'When things are going particularly crappy in your life a lot like around my kids and you are doing things you don't have the time or the energy to keep up with your exercise and stuff like you should do and I mean I have said to you I think I should come back and I think I have neglected quite a bit recently and I have been doing half a dozen kind of things you know. I am

doing some stuff that does me good like but what I'm saying, I need re-educating, I've forgotten a lot of stuff but I don't feel it's because I have wanted to neglect or think I don't need it, it's because other things take over and you don't get the time to do stuff.'

Participant 5 was the main carer for his wife who had severe RA and had also recently undergone heart surgery. She needed a great deal of assistance from him and he was worried that his own declining health status would mean that he would no longer be able to help her:

'That's why I try to keep going. It's these that I am really bothered about. They are getting to me now these legs because if they go what is Sheila going to do for a start. She would be goosed without me, she really would.'

He was a proud man and having to ask his daughter for help distressed him. He was therefore extremely frustrated and frightened especially as he was facing the possibility of spinal surgery. Both of these participants were shouldering significant responsibilities within their lives which would be challenged by a deterioration in the status of their AS.

The two people living alone described their social isolation and the problems they had in keeping motivated and not getting depressed. Participant 2 did not do certain tasks for fear of falling and if his pain was too intense he slept in a chair rather than risk climbing the stairs. He relied heavily on friends and recognised their role in preventing his depression from worsening.

'It's a good job I have Tommy and Joe. Without them I don't know how I would have gone on really. Probably I would be depressed then.'

Participant 8 described having to force himself to complete even simple household chores and how just walking down the road to get his paper was an effort if he had more pain than usual. He also missed having company:

'It is someone to talk to. That's what you want, it is someone to talk to.'

For these two people being socially isolated was described as affecting their mood, they felt more vulnerable and less motivated to be active.

Within this cohort, 4 participants were either in full or part-time employment and described the pressures associated with working including work related stress and the need to ensure that their performance wasn't affected by their AS. Participant 9 felt he had too many responsibilities given to him by his manager, he also resented the fact that he kept going whilst other colleagues 'abused the system' by taking sickness leave with what he described as minor complaints. Being in a managerial position he described the importance of giving the correct example:

> 'I mean some days when I have been up all night or been experiencing sleeplessness, I get to work and I become awake and alert by 10 or 11 o'clock and then by 3 o'clock I look at the clock and I just wish that I could go home. And although we have a flexi system on some days I could go home early, I have to look at the rest of the office and I feel that I just can't be swanning off when I want to. And I feel I need to be there for the other staff.'

There were also financial concerns expressed related to needing to provide financial support for their families. Participant 2 described how, when advised that he would never work again by his 'work's doctor', he had gone home and cried being terrified that he would be unable to pay his mortgage and support his family.

One person, who was in the process of being made redundant, described choosing manual work as opposed to office work as he felt that being physically active would help to control his AS symptoms:

> 'Yes I am going to have to retrain because I have been in factory type work initially over the last 15 years I have always had it in my mind that I need to keep at it. If I was sat at a desk I would be worse because I would be sat still for hours at a time so while I hate working in factories it has kept me mobile in the respect that I can do a lot of bending and lifting and wearing those joints keeping them clean if you like, that's why I have stayed in factories and not moved into other jobs. It's daunting at my age.'[P4]

For other participants employment was seen as detrimental to their AS. Participant 1, a newspaper editor, spent his day working at a desk and recognised how this was detrimental to his AS:

'.....I just know that it's the job that I do, that's a job that I enjoy doing and the pain that I get for having to sit at a desk for 10 hours is just again something you have to grin and bear and live with.'

5.2.2.3. Past life events having an ongoing impact

Participant 2's son had died due to a drugs overdose approximately two years prior to the Group Study commencing and his wife had died a year later. He talked about being unable to come to terms with his loss thinking about this on a daily basis. He described his isolation and fears about falling. His inability to do house maintenance also worried him and he feared having to give up his home. His inability to move due to pain if he did certain tasks impacted on his emotional status. He also had many regrets about his life principally that he was 'forced down the pit' at a very early age in order to support the family as his father had died when he was only 14. He described feeling that he had never been given an opportunity to choose his own pathway to do the things he would have wished to do.

5.2.2.4. Experience of other family member's illness

Some participants described how their previous experience of living with another family member with impairment impacted on their anxiety about their own condition. Participant 5 described his father, who possibly had AS, as being almost bed-ridden for 17 years and the experience of watching a once physically honed man wasting away. Having been a keen weight lifter he was increasingly aware that his legs were loosing muscle bulk and, equating this with his father's experience intensified his anxiety:

'You think Christ almighty where is it all going to end you know are you going stop walking all together and I am dreading that. You have no life at all. It is a waste of bloody time being here, what's the bloody point?'

Participant 9's mother suffered with Rheumatoid Arthritis and died as a result of a perforated stomach ulcer attributed to medication. This led to him trying to avoid using medication, a decision that was challenged during exacerbations:

'That was a year last April and since then I haven't taken any tablets until July this year. I had a couple of big flare up and I didn't take the tablets and I think it was more pride really. It got to the stage where I thought that I am just really penalising myself here and so I started to take the tablets again.'

Furthermore, whenever new areas of involvement, especially hand and foot symptoms, occurred he became concerned that this might signal the onset of Rheumatoid Arthritis.

> 'I remember when I was little and her hands would swell and the pains and I just started to think about is this AS or is this the start of because I feel that I will end up getting arthritis in my hands etc. My granddad did, my mum has and if it goes through generations. And I have had it in my thumb but my mum's hands used to swell up initially so I kept looking to see if I had got swelling and there was no swelling.'

These data provide an insight into the complexity of these participants' lives and the wider social context within which their AS is being managed.

5.2.2.5. Concurrent (non AS) Pathologies.

Ten of the eleven participants, at the time of interview, had concurrent non AS related pathology which were often described as creating psychological distress and as being of greater concern than AS. These are summarised in Table 5.5. Some of these were commensurate with the first stage of data collection and some had been diagnosed after completion of the questionnaires but prior to qualitative data collection.

Table 5.5 Diversity of co-morbidities

	Co-morbidities occurring during completion of group study	Co-morbidities developed after completion of group study
Patient 1		Atrial Fibrillation
Patient 2	Osteoporosis, depression	Awaiting hernia operation, blood problems
Patient 3	Depression, panic attacks, claustrophobia	Impinged ulna nerve
Patient 4	RA, peptic ulcer, hiatus hernia	Abdominal hernia
Patient 5	Spinal stenosis - awaiting operation, high blood pressure.	
Patient 6	OA hands, Irritable bowel syndrome	
Patient 7		Heart condition, prostate cancer
Patient 8	OA, Bilateral knee replacements,	Spinal operation, prostate cancer suspected
Patient 9	Nil	Nil

Patient 10	Previous alcohol abuse, Kidney problems,	Diabetic

During the data collection for the Group Study other health issues had been concurrent. Participant 10 had been advised to stop drinking alcohol:

> 'I was told if I didn't stop drinking that I wouldn't see 50 and I got my first two grandchildren and so it is them or beer.'

Participant 4 had suffered from a peptic ulcer, which had a significant impact on his ability to sleep, and to achieve adequate postural positioning required for his AS:

> 'I will sit downstairs and dose and I will take some Gaviscon or something and it will ease off and then if you lie down you can feel it sort of burning again and so I prop myself up with 2 or 3 pillows and then I can't sleep because I am not flat.'

Participant 5 had deteriorated significantly due to his spinal stenosis, which had caused muscular weakness in his legs.

> 'I have managed pain all this time but what I can't manage is this. It is totally different. With pain you take painkillers, you can move, you can stand differently. With this you can't do anything, nothing at all. I can't do anything about this.' [P5]

The following examples are for those whose illness occurred between completion of the questionnaires and taking part in the interview. Participant 7 had developed angina and also diagnosed with prostate cancer and was trying to come to terms with this:

> 'Well this is it. If anything has got me down this past month it is that [prostate cancer] rather than the AS because the AS I can deal with it.'

Participant 2 was particularly worried about surviving a hernia operation due to a recently diagnosed blood problem:

> 'I am frightened to death about what is going to happen with this hernia here.'

Participant 1 was living with Atrial Fibrillation and the associated investigations and medications which for him had now become far more distressing than he perceived having AS had ever been:

'Yes, yes, the AF has. I just never, ever thought that I would've had something that it as debilitating because I've never looked on AS as being debilitating.'

These data highlight the range of impairments that participants were coping with 7 of the 10 participants dealing with other health issues during the period of the group study and this increasing to 9 out of 10 during the qualitative phase of the study.

5.2.2.6. Problems of attribution

People described the confusion they experienced trying to discern whether their AS or other impairments were responsible for the symptoms they were experiencing. Participant 1 in particular in trying to come to terms with his Atrial Fibrillation was extremely worried by the fact that his chest pains could be attributable to heart problems as he had no previous experience of chest wall involvement for AS:

'But only because I've been taking other medication and so all the things you told me about AF and your blood can clot in your heart and it like breaks free and you can have a blood clot and all that sort of stuff so I woke up the other night, a couple of weeks ago and I was in so much pain in my back and I thought "Oh stink! It's a blood clot!'

Two participants suggested that living with AS had played a role in the onset of other conditions. Participant 7 questioned whether the years of pain he had experienced contributed to the onset of his angina and participant 5 whether blood pressure problems were associated with his increasing back pain and disability. Participant 8 had recently had spinal surgery and after the operation found it difficult to tell which gave him the back pain, the operation or the AS. Participant 6 after developing abdominal pain described how this pain had made her more irritable as she was worried about the cause. Participant 7 had become so concerned by his rib pain that he had visited his doctor fearing that he had developed lung problems.

Increased psychological distress when symptoms appeared in new areas was also discussed. Attempts were described to differentiate new areas of pain from AS or other pathologies. Participant 9 was particularly concerned that he may be developing RA like his mother and so he was particularly concerned when he developed peripheral joint problems:

'Yes this is where the confusion starts because I have had pains in my big toes, at the side of my foot, my thumb and right at the back of my neck. At the back of my neck it makes me feel dizzy with the pain. I am thinking is this something else? This is where the confusion comes in.' [P9]

5.2.2.7. Psychological impact of co-morbidities

Some insights were given into the ways in which these co-morbidities were perceived to impact upon psychological status. Participant 5 was very frustrated by the fact that he was deteriorating to such an extent that spinal surgery may be his only option. He was frightened by the prospect of this and angry that he was in this situation:

'He said the only way is this decompression, you have got to have this decompression to relieve your nerves there is no other way and like I said I don't want the operation you know, I really don't and I don't want to be like this either so it's. What do you do?'

Anxiety and distress were evident for two participants awaiting hernia repairs. One person was distressed that a possible blood disorder would put him in danger of dying during surgery:

'I think I have had about three cigs since because I get worried about that. I have passed all my phone numbers out to all the relations if anything does happen with this. Peter's girlfriend said that she knew some to have had three hernias done at once. But I said they are not like me because my blood is that thick they don't know how my heart is pumping the blood round.'[P2]

Another person was concerned about his inability to exercise due to the hernia as he enjoyed exercise and felt the benefits. Not exercising caused him more pain, which in turn made him feel frustrated and 'grumpier'.

Participant 3 had been experiencing pain and weakness in his arm, attributed to a trapped ulna nerve. He described this as impacting on his life more than his AS:

'My life just recently has been mainly my arm. My arms and that they seem to have been bringing a lot of everything on because you feel desperate again to be honest you know.'

Participant 6 was developing Osteoarthritis in her hands and echoed the fact that upper limb function could be just as distressing as her AS especially the loss of flexibility in her fingers:

> 'Is this Osteo in my hands so that is separate? I get worried more if I would loose my hands, the flexibility in my fingers.'

The extent of co-morbidity in this group was marked both in terms of seriousness and severity. The seriousness of AS was judged within the context of the other impairments and in many instances described as less serious. Within the context of multiple co-morbidities people found it difficult to attribute symtomology. In some situations the co-morbidity actually prevented the use of coping strategies for AS raising the possibility of the linkage between their disease and psychological status within this concept. Table 5.6 combines the co-morbidities and life events, described previously, for these participants.

Table 5.6 Complexity of co-morbidities and life events

	Key life events which affected individuals	Co-morbidities during questionnaire completion of group study	Co-morbidities developed after questionnaire completion of Group Study
Patient 1	Father had an above knee amputation and this significantly influenced how he perceived he should deal with his own illness.		Atrial Fibrillation
Patient 2	Bereavement of his son and wife. Forced to work down the pit	Osteoporosis, depression	Awaiting hernia operation, blood problems
Patient 3	Bereavement of his father, one son suffering from autism, one son ADH, mother in law schizophrenic	Depression, panic attacks, claustrophobia	Trapped ulna nerve
Patient 4		RA, peptic ulcer, hiatus hernia	Abdominal hernia
Patient 5	Main carer for wife (RA), father had AS and was bedridden for 17 years	Spinal stenosis - awaiting operation, high blood pressure.	
Patient 6		OA hands, Irritable bowel syndrome	

Patient 7	Delayed diagnosis of AS for 20 years. Divorced as a result		Heart condition, prostate cancer
Patient 8	Divorced – daughter died in early teens	OA, Bilateral knee replacements,	Spinal operation, prostate cancer suspected
Patient 9	Mother had RA and died from a perforated ulcer. Blamed medication		
Patient 10	Disabled father who had influenced his own perception of how he should address his own illness	Previous alcohol abuse, Kidney problems,	Diabetic

This provides an insight into the complex circumstances of the lives of many of the people in this sub-group.

5.2.2.8. Getting older

A theme also highlighted as linked to a person's ability to cope with AS was the influence of age. Those within the younger spectrum felt that they were young enough to be able to cope with their AS even though there was a sense that there were certain aspects which were not as easy:

> 'Yes I think so yes because I am young enough just to get on with it. I think it has slowed me down just a little bit.' [P11]

One person described his most severe symptomology as occurring when he was younger and feeling that his age had been a positive factor enabling him to deal with this at the time:

> 'I don't think I'm as bad as I was when I was 24 or 26. I think that was my worst pain wise but I do think that physically you were a lot better at coping with it. You see so I could cope with the pain a lot more because of my age.'

However, the majority of participants were older and there was far more said relating to the detrimental aspects of aging and the impact of daily activities:

> 'No it is not the pain. It is the thought of not being able to do anything. I mean not being normal I mean you just want to be normal don't you? Doing things that you used to do when you were younger. I mean I can't do

that now. I can't play football or cricket with the grand kids like I used to. There is no chance when I am like this anyway.' [P10]

Participants also had difficulty in discriminating between the aging process and AS with regard to limiting physical abilities. Participant 6 described this as 'a mixture of the two.' Participants talked about how getting slower and less active made their AS symptoms harder to deal with:

'I think I'm slowing down but I think the AS is because I am getting older and slower that the AS is having a more marked effect whereas you used to grin and bear it more when you were younger.' [P1]

'But when you get old and you retire and you don't do that any more. You don't walk around like that any more and you could live with it better. I found out when I look back with hindsight I would do it again now and like I say I used to do a lot of walking and it wasn't as bad as it is now. It seems to have gone worse since I have retired without a doubt because I think one of the things is lack of exercise.' [P8]

Aging was also recognised as influencing mood in that people wanted to remain active but their body prohibited this:

'But you know yourself...that you never get older in your mind; you still think that you are 21 in every way. I look forward to things now as much as I did then. But you know deep inside that you can't do these things and that makes you feel a bit low. So age comes in to it as well I should imagine.'[P8]

Participants also described how much better they were at coping with their AS due to their experience:

'I think that I am coping better with it now with more experience and being used to it.'[P10]

5.2.2.9. The impact of retirement

People who had retired found themselves to be less active than they had hoped. They described how early retirement both voluntary or not by choice posed problems and distress. Participant 10 described not wishing to take medical retirement when it was offered but feeling that it became his only option. Since retirement he felt that his family were living on the bread line and felt that there could still be the possibility of working but as he said:

> 'I feel like I can go to work sometimes but I know what it will do to me. I would love to go out to work. I am bored to tears at home.'

Participant 5 also described the issue of redundancy. In his case however, he was experiencing hand involvement and he felt that he could not have carried on. He had anticipated being able to do the things that he and his wife had looked forward to. However, he had been extremely distressed as due to both his and his wife's failing health this was not the case making him very angry and frustrated. Two participants had reached normal retirement age and described the need to keep active during retirement:

> 'Since I have gone, I keep relatively busy and there are times when you can say I don't know how the hell I found time to work. But if you just retire and do nothing that is the worse thing that you can do. You just vegetate away and it doesn't matter what you have got. Whether you have AS or not, you are just going to go down the tubes at a rate of knots.' [P7]

One person's working life had been active and demanding giving him a sense of self-esteem. He recognised that the physical activity had been beneficial for his AS and that since retirement he found it difficult to motivate himself to exercise as his medical problems had intensified over recent years.

Getting older was perceived as adding an additional burden to coping with AS with problems associated with remaining physically active both in terms of ability and motivation. AS was also perceived as having a more marked effect than when participants were younger.

The individuality of the participants' lives was highlighted as complex with a range of factors described as influencing their ability to cope with AS. Concurrent (non AS) pathologies appeared to have had significant influence upon the participants lives creating additional confusion and impacting upon psychological status. The complexities surrounding social support and working status were also identified as being significant factors in how people coped with their AS. For some participants aging contributed to the difficulties people's experienced in coping with a condition which which remained as active as it was in their youth.

5.2.3. WAYS OF HELPING YOURSELF

A variety of practical strategies were described as being important in controlling symptoms and enabling participants to get on with their lives.

> 'Well I can manage, I can manage the pain and I can manage because I know exactly what to do.'[P5]

5.2.3.1. Medical intervention and advice

Medical intervention and advice was generally seen as being important in helping people to live from day to day and to control their AS and their pain. Positive feelings were ascribed to treatment with an awareness of its limitations:

> 'So from that point of view he has done a lot for me and as I say I have got my life back or 99% of it shall we say. It is the odd 1 or 2% that you can't ever get back that is the thing that winds you up from time to time.'[P7]

Participant 4's description of the impact of a treatment session illustrates the impact that treatment can have on mood:

> 'When I had those first sessions with Sue and she has massaged my neck then she has loosened off something that has been quite tight for a few months, it's euphoric, it's huge, and it's like an adrenaline rush feeling. You feel happier then.

Medication was regarded predominantly in positive terms.

> 'Once the anti inflammatories started to work I could move better. I wasn't in pain when I moved, I could turn over in bed, I could get a decent night

sleep and within 6 months of that, certainly within a week I felt the difference.'

Having understood the effectiveness of medication, some participants, only took it when they had 'a bad day' and this was described as being better than taking medication as 'a preventative measure'. There were some concerns identified relating to medication becoming ineffective and participants 'getting used to it'.
Not being without medication was important:

'I would get worried if I had forgotten them. Not worried but if you started to feel pain you think oh no I must get back home or you know I will do a u-turn 10 miles back if I need them' [P4]

Feelings of frustration were expressed when nothing was perceived to help relieve pain. Two participants became angry when they felt their doctor had changed their medication for 'cheaper versions' or because they had taken a medication for longer than their doctor felt was appropriate. In some instances, 'newer' medication was not perceived to be as effective leading to feelings of more frustration and disillusionment.

One person felt that his mother's medication could have contributed to her early death, and he became very wary of taking his own medication describing living without it as an achievement.

When they occurred, negative experiences with healthcare professionals appeared to be detrimental to future care and perceptions. Participant 2 had felt very much worse after physiotherapy and had told his doctor who had replied that he would 'just have to go away and live with it.' Participant 5 described being extremely frustrated and angry by being prescribed what he perceived as medication, which did not address his pain resulting in him becoming reticent about seeking help in the future:

'It was getting really bad and I was getting really annoyed. So I had to go to the doctor's and it was a locum doctor and he said 'you will be all right', he put me on bloody Prozac didn't he. I might as well have been a bloody vegetable so I just scrapped them and never bothered again after that.'

Participant 4, who had a restricted and fused cervical spine, insisted on riding his motorbike not only on the road but also on the racetrack. He was aware that he was

going against medical advice but he felt that concentrating on riding allowed him to move his neck further giving long term benefits which he would have been unable to achieve with conventional treatments.

These data highlight the positive and negative perceptions of medical interventions and how people located their experience of these interventions within their own life contexts and belief systems, which was sometimes contrary to medical advice. There was also a sense that participants were able to identify and understand the limitations of medical interventions and that participants could highlight the positive impact of medical interventions on mood when an intervention was perceived as being effective. Negative feelings such as frustration and anger occurred when medical interventions were ineffective.

5.2.3.2. Exercise and Activity

Exercise was perceived as being especially beneficial but participants adopted a broad definition of exercise, which included activities such as walking:

> 'I am doing a lot more walking lately and it seems to be doing me a lot of good. The more I walk the better I feel.'[P10]

> 'Certainly when you come back from walking, you can feel quite high.'[P7]

'Pure' exercise was also described as helping in physical ways:

> 'Because at one stage it was when you have a flare up you shouldn't do anything and relax and then somebody else told me no pain no gain so it was only when I came here that I was told that the more pain I have got and the more I do the better I will feel. And it does work.'[P9]

Getting out of the house was highlighted as a distraction from pain and feeling low and regarded as being beneficial with the additional social consequence of meeting others. Wintertime was found to be difficult as adverse weather conditions limited the extent to which some people could get out.

By exercising there was also the sense that participants had some control over their AS:

> 'With AS you have got a little bit of control in the respect that if you exercise and stretch it gets better rather than worse.'[P4]

Being active at work was also seen as a positive coping strategy. Participant 8 in particular had a very active job and since retirement he perceived that being less active was detrimental to his ability to live with his AS. Remaining active was a particular concern for Participant 4 who was facing redundancy and perhaps a career change. He had chosen a physical job due to his recognition of the positive benefits of remaining active in controlling his AS:

> 'If I was sat at a desk I would be worse because I would be sat still for hours at a time so while I hate working in factories it has kept me mobile in the respect that I can do a lot of bending and lifting and wearing those joints keeping them clean if you like, that's why I have stayed in factories and not moved into other jobs.'

Getting up and moving around relieved pain and stiffness.. However the need to be changing positions meant that participants also found it difficult to relax:

> 'Yes but I can't sit for long, I have to keep getting up.'[P5]

Difficulty getting comfortable was described embarrassing especially when it distracted others:

> 'If I take my older daughter to the pictures and I am feeling bad, I will be moving and shuffling in my seat all night. It's like when you can't sleep in bed, you are constantly moving about and every time you shut your eyes you can't go off. You don't enjoy the film; you just sit there shuffling about. You go to the loo to have a walk and your hips are grinding and aching. You get agitated in a way that you feel that everything is against you not from that sort of paranoia sort of thing, it's not that sort of thing, it's more of a now and then you feel 'God why has this got to happen now'. You get annoyed inside especially when it is something like a birthday party and then you are there in front of people.' [P4]

The need to be constantly moving also impacted on work with difficulties in sitting at workstations making prolonged periods of concentration difficult to achieve. Having to get up and walk around the office was seen as essential but having to stretch in front of others was embarrassing and led to concerns about being labelled the 'bad back'.

5.2.3.3. Distraction

Pain was the principal symptom described as being controlled by distraction 'techniques'. Distractions such as taking part in conversations, being busy and involved with others was described as a method of coping with pain as illustrated by participant 9's description of how talking about a DIY project with his friend enabled him to complete the task.

> 'But I think that night even though I got up at 5 o'clock and I was in pain, she was talking about she was excited and it lifted my spirits and so it kind of blocked the pain and we had a good laugh. [P9]

Participant 8 described being on a family outing:

> 'By the time I got there I was absolutely wiped out. I sat down for two or three minutes and I thought I have bloody done it so I went to look round the fort and you are looking at things of interest and you forget about the pain.'

People described many and varied ways in which they perceived they could gain a degree of control over their AS. Medication was regarded in a particularly positive light with people describing how their mood could be enhanced when they perceived that medical interventions were being effective. Conversely frustration and anger occurred when medical interventions were perceived to be ineffective. Exercise and activity were also regarded as being helpful in controlling symptoms. Whilst the need to be constantly moving relieved symptoms it was also described, in some situations, as causing embarrassment. Distraction was described as helping to control pain with resultant positive psychological responses. Participants talked about the sense of control they achieved over their AS by using such strategies which was particularly emphasised and valued.

SUMMARY

The aim of this study was to gain insights into the associations that people made between their disease and psychological status. Whilst participants generally perceived themselves to be coping with their AS, they were aware of the psychological impact of their condition. Periods were described when AS was perceived to influence psychological status and these were often linked to deterioration in the condition and a corresponding increase in symptoms such as pain, fatigue and sleep disturbance.

As well as the physical symptoms, the unpredictable nature of the condition was also associated with influencing psychological status. The variability and unpredictability of living with AS meant that they were unable to predict how they would be from one day to the next affecting their ability to forward plan. Insights were also provided into the problems of remaining motivated especially when the disease is more active. As people got older, they described finding it much harder to deal with their condition feeling that they were becoming less active, less able to participate in activities and less able to control their symptoms.

Participant's descriptions of their approach to living with AS varied with some people perceiving themselves as having personality traits which enabled them to respond in a positive manner whilst others described being inherently anxious. A variety of ways in which people perceived they could gain a degree of control over their AS were described including medical interventions, exercise and distraction.

A significant finding of this qualitative phase of data collection was the complex nature of the participants' lives and the range of health and social factors with which people had to contend. Previous life events such as bereavement and the experience of other family member's illness were described as having an ongoing impact on people's lives and were perceived to continue to influence their ability to live with their condition. Current life events such as caring for other family members and employment pressures were also identified as creating an additional burden. A number of additional pathologies were also identified as having a negative impact on people's ability to live with their AS and, in some instances were described as being of greater concern than the person's AS.

Insights from this phase of data collection have identified a range of factors which may explain the links between psychological and disease status in this cohort of patients. Whilst a deterioration of their AS was described as having a negative psychological impact other aspects of people's lives were also identified which would be affected by a change in AS. The majority of these patients were contending with a range of other health and social issues highlighting the need to locate the management of AS within the wider contexts of people's lives.

The strong associations found in the quantitative data with disease status and anxiety, depression and the SF36 domains could potentially be explained by the 'sometimes it bothers you' theme. This theme emphasises the physical implications imposed by the disease activity of AS and echoes the focus of the items within of the disease activity outcome measures. It should also be emphasised that the data from this subgroup suggested that AS, on a day to day basis, did not for the majority of participants appear to cause undue distress, they had adjusted their lives to accommodate it. It was periods of increased disease activity which were described as leading to problems with coping with everyday demands of their lives which then affected their psychological status. These changes appeared to be compounded by the social contexts of the participants' lives and the number of co-morbidities with which they were contending. They were managing to cope with the complexities of their lives but if the status of their AS changed as well this imposed an additional burden upon them providing, for this subgroup, insights into the associations identified in the quantitative data.

CHAPTER 6

DISCUSSION

DISCUSSION

This study aimed to investigate associations between disease and psychological status in AS. In the first phase, three AS-specific measurements of disease status, together with tools for measuring psychological and generic health status were used to sequentially assess 89 AS patients on four occasions over an 18 month period. The second phase utilised qualitative methodology to provide insights into individuals' perceptions of the links between disease and psychological status with patients whose scores over the 18 month period of the study indicated concomitant change in disease and psychological status. The combination of quantitative and qualitative techniques not only identified key associations but also provided insights into the underlying reasons, other contributory factors, and implications for clinical practice.

6.1. ASSOCIATIONS BETWEEN DISEASE STATUS AND PSYCHOLOGICAL STATUS

6.1.1. Associations between disease status and anxiety and depression

Extensive literature describes the influence that anxiety and depression have over disease status and outcomes in other impairments, however this is the first study to identify such associations in AS. This study identified that anxiety and depression scores are associated with each of the AS disease status measures and that people with clinical anxiety and depression report worse disease status. These findings are consistent with previous work showing that both anxiety and depression influence pain experience both experimentally (James and Hardardottir, 2002, Willoughby, 2002) and in postoperative settings (Carr, 2005). It has been shown that people who are more anxious and depressed report greater levels of pain even to the extent that an induced depressed mood can be associated with alterations in response to pain (Willoughby, 2002 as cited by Williams, 2006). People with chronic pain who are anxious report more pain and accept it less than those who are not (McCracken, 1999). It has also been shown that the experience of pain can be intensified by depression both by reducing pain thresholds and also pain tolerance (Williams, 2006). Depressed patients with chronic back pain experience greater pain intensity, greater interference with activities such as social, outdoor and housework due to pain and demonstrate increased pain behaviours (Haythornthwaite, 1991). Untreated depression in people with chronic pain has also been associated with poor response to pain treatment (Doan, 1989). Ward

(2002) identified associations between subjective assessments of disease activity and anxiety and depression scores in SLE, with anxiety and depression scores running in parallel with changes in disease activity. Anxiety and depression have also been attributed to influencing outcomes both in low back pain (Hasenbring, 1994, Pincus, 2002), chronic pain (Doan, 1989) and psoriasis (Kulkarni, 2004).

This study therefore identified findings that are consistent with the literature in several other long-term conditions. This could have implications in that AS patients who have anxiety and/or depression may have additional difficulties with their experience of pain. The possibility also exists that such people may have a more negative response to treatment interventions and be less adherent to regimes. Potentially these people would have poorer outcomes and a worse prognosis than those who are not anxious or depressed.

6.1.2. Association between disease status and locus of control

Results from this study showed that BASDAI scores consistently showed a negative, albeit relatively weak correlation with internality and the same generally applied to BASFI and BASMI, suggesting that worse disease activity, function and movement were associated with lower levels of perceived control over health. These findings demonstrate an association with internality and disease outcome measures, consistent with other studies in the literature. Harkapaa, (1991) found that patients suffering with chronic low back pain but who demonstrated stronger internal control beliefs gained more from treatment. These patients learned their exercises and undertook them more frequently compared with those who believed in the control of powerful others or chance factors. Distress and internal locus of control have been found to be related to disability in back pain patients. Those with a high belief in their own control had less disability and less distress than those with weaker beliefs in internality who had greater levels of distress and high levels of disability. Patients with strong internal beliefs reported less intense pain and demonstrated less pain related behaviours than those with weaker internal beliefs (Harkapaa, 1996). Therefore there is a possibility that the association between the Bath Indices and internality, whilst not as strong as that between anxiety and depression, could be an important factor in the identification of those who may respond to treatment interventions.

In contrast there were no significant correlations between disease status and levels of belief in chance or powerful others. This is to some extent surprising as it might be expected that those with a belief that health is controlled by chance factors may have poor motivation to engage in preventative or protective health behaviours and would therefore have poorer health outcomes. This was demonstrated by Murray and McMillan (1993), who found that people with a high belief in the control of chance factors were less likely to attend for cervical screening and those with a high belief in the control of powerful others were less adherent to breast self examination.

Unfortunately, there has been little work applying this concept in AS, although Barlow (1993) utilised Locus of Control when working with self help groups. This study identified that members of a self help group were distinguished by a combination of factors which included low reliance on powerful others health locus of control beliefs, greater satisfaction with available support and increased frequency of exercise. This difference in 'powerful others' beliefs between self help members and non-members was unaffected by health status and as Barlow (1993) stated this was in accordance with research on rheumatoid arthritis patients, where the relationship between health locus of control beliefs and compliance were found to be independent of the degree of arthritis activity (Roskam, 1986). Reid (1984 cited by Barlow) also suggested that people might learn to accept the reality of their disease and adjust their beliefs accordingly. Therefore it might be postulated that people with a chronic disease such as AS, adjust their beliefs by lowering their expectations of their personal control over their health.

Potentially, this could be a reason why there were no associations within our study for beliefs in chance or powerful others. It could also be that the locus of control construct may only give 'some clues to help to unravel the mystery of health perceptions' which would indicate that this measure as a construct could have inherent flaws and weaknesses (Wallston, 1992). This is an important consideration as a debate exists as to whether the belief in internal and external control is a relatively stable personality characteristic carried from one situation to the next (Wallston, 1992) or whether it is dependent upon a particular situation with people not fixed at one point along the continuum as 'internals' or 'externals'. It is suggested that individuals may perceive themselves as being in control of some aspects of life such as personal finances, whereas they may not perceive themselves as being in control of other aspects, such as health (Smith 1970).

Internality showed similarly significant, but relatively weak correlations with anxiety and depression. This is consistent with the theory that anxiety is based on uncertainty and lack of control and predicts that those with a belief in their own control (internals) would be less anxious than those with a belief in the control of powerful others or chance factors (externals) (Phares, 1976). There is evidence that those with a belief in the control of powerful others or chance factors is also linked with anxiety and depression (Crisson, 1998). A linear relationship between externality and anxiety and adjustment has been described with extreme externals and internals potentially being more maladjusted and anxious (Phares 1976). It is therefore somewhat surprising that in this cohort those with high scores in beliefs in the control of chance factors did not show high levels of anxiety or depression. Although men have been shown to indicate a belief in the greater influence of powerful others and chance factors compared to women (Roberts, 2002), it seems unlikely that the small number of females in this cohort would not fully account for this lack of association. Perhaps this may be due to the possibility that the locus of control construct may form only a relatively small portion of the larger and more important construct, involving perceived control over health (Wallston, 1992).

6.1.3. The influence of psychological status on responses to self-complete questionnaires

The Bath measures of disease status differed markedly in the extent to which they showed linkage with measures of psychological status. BASMI scores correlated least strongly with psychological status and by identifying sub groups for those with clinical anxiety and depression, consistently worse BASDAI and BASFI scores were found for those with clinical anxiety and depression. However, in the non-anxious and depressed sub groups, BASMI scores were not significantly different. A potential explanation of this finding is that BASMI scores are derived from an objective assessment by a trained metrologist whereas BASDAI and BASFI scores are derived from self-completed questionnaires. It may be that the subjective element of self reported disease status measures that make them more sensitive to such effects compared to objective measures. This is therefore a potentially important phenomenon in both clinical and research settings. For example, clinicians may need to be aware of the impact that psychological status may have on self-reported instruments particularly in the context of the BASDAI which influences patient selection for and responses to biologic interventions.

For such issues to be taken into consideration the adoption of a biopsychological approach to assessment would be essential. It is clear that if there is an understanding of where the individual is 'situated' at the time of their assessment, then issues other than the biomedical status of their AS may be identified as influencing their ability to live with the symptoms of their condition at that time. The conventional approach to assessment, focusing predominantly on biomedical factors, could lead to individuals being offered biologic interventions to which they may not respond because their subjective assessment of their disease status has been influenced by factors other than their AS.

The results from this study indicate that BASMI scores may be less susceptible to psychological effects, and it could be argued that this method of assessment may provide a more independent indicator of clinical disease status than BASDAI or BASFI scores. The potential for patients' psychological status to impact on the completion of a self-reported questionnaire has been highlighted by (Kennedy, 2003). This study warned that self reported disease activity is subjective in nature and demonstrates a state of mind as well as a level of clinical activity. Furthermore, Hidding (2004) found that self reported health status was more strongly related to personality traits such as neuroticism, social inadequacy, self-esteem and health locus of control than to the degree of disability in AS and suggested that when assessing health status in AS by self-report, these should be taken into account. However should a biopsychosocial approach be adopted this would alert healthcare professionals to the existence of factors other than disease status which have the potential to influence self-reported disease activity scores and the scores could be interpreted with this in mind. A short coming of the current approach is that the focus tends to be solely on clinical data isolated from the wider psychsocial aspects of patient's lives.

Disease activity measures as well as psychological factors have also been shown to have a role in explaining variance in self-report measures of functional capacity in RA (Van der Heide, 1994). In addition, Groarke (2004) found that disease status added to the prediction of variability in self-reported functional status in RA. It was suggested that an assessment of disease status was useful when considering reports of physical disability but it was also important to incorporate psychological issues such as the measurement of illness perceptions which were found to account for a greater proportion of the variance in pain scores. In this study, disease activity was associated

with poor physical functioning, but illness perceptions, such as endorsing serious illness consequences and low illness control, were more closely associated than the objective disease measures with high pain reports. This study suggested that it might be important not to assume that reports of pain always reflect increased disease activity.

The limited extent to which patient-reported measures may capture overall disease status in AS has been raised (Haywood, 2005). A major consideration was that the single item visual analogue scales which make up the BASFI and BASDAI may only provide a limited reflection of the domains, which are represented. There was an additional argument that patients may experience difficulty in completing VAS scales making it easier for those scoring in the middle of a scale to register change rather than being clustered at the end of the scale (Liang, 2002). This may indicate that BASMI scores would be less susceptible to such effects, and may therefore provide a more independent indicator of clinical disease status than BASDAI or BASFI scores.

Recent work by Haywood (2004) advocated that health related quality of life assessment should be promoted for AS patients. Patient-assessed health instruments could provide a more accurate assessment of disease impact on health care from the patient's perspective and should be considered as a core assessment domain. Haywood indeed published the Patient Generated Index (Haywood, 2003), which was the first AS-specific individualised measure of health related quality of life. Currently evaluation is being undertaken of a new patient-reported measure of health related quality of life at Staffordshire Rheumatology Centre and the RCN Institute in Oxford. This would allow patients to identify key issues, which are specific to their quality of life whilst taking into account psychological issues, thus enabling identification of potential influences of psychological status.

6.1.4. Associations between disease status and health status

All disease status measures correlated significantly with each of the SF36 domains except change in health throughout the study. The SF36 data were consistent with the other associations found in this study namely those within specific domains of pain, physical functioning, social functioning, mental health, energy and vitality and general health perception. The SF36 was therefore useful as a generic measure alongside disease specific measures in that it allowed for a degree of reinforcement of the findings from the disease specific measures. The SF36 was chosen as it is the most widely used

generic health profile in studies with AS and is the only generic instrument with evidence of responsiveness following drug treatment and physiotherapy in AS. The use of the SF36 enabled this cohort to be compared to others. Comparisons between the Davies Multinational AS cohort (Davies, 2005) and this cohort revealed differences in four SF36 domains. These were physical functioning (multinational cohort mean 41.5; this cohort mean 57.6), raising the possibility of better physical functioning within the current study cohort and bodily pain scores raise the possibility of less bodily pain than the multinational cohort (multinational cohort mean 36.2; this cohort mean 47.2). Conversely, the role emotional scores (multinational cohort mean 60.7; this cohort mean 25.0) raise the possibility of a greater influence of role limitation due to emotional problems in the study group, whilst the mental health scores (multinational cohort mean 68.6; this cohort mean 54.5) raise the possibility that the current study group may experience more issues related to mental health than the multinational cohort. However conclusions drawn from these comparisons are tenuous because the Davies cohort is multi national and raises issues such as differences in culture, treatment regimes, gender and disease severity. In contrast, this cohort was hospital-based from a small geographical location.

It has been highlighted that SF36 for elderly patients (sixty-five years of age) can be more difficult to complete (Jenkinson, 1996). This study cohort had only three participants over this age at the start of the study and three between 60-65 years. Therefore this was not taken this into account when analysing SF36 data. There were no reports from participants when completing their questionnaires that they were experiencing difficulties.

Associations between both anxiety and depression and the generic health measure were investigated. The most significant correlations were found for associations between HADS scores and the mental health component of SF36, especially with anxiety. However, HADS depression scores were more strongly associated with the physical component of SF36. This is consistent to a certain extent with Fossa (2002) who reported HADS anxiety and HADS depression scores to be significantly associated with SF36 summary scores. Each component of the SF36 was analysed individually not using the summary scales as it was felt that more detail of the data would be extracted. Fossa (2002) also suggested that because significant correlations between HADS anxiety and the mental health component were identified that both anxiety and

depression should be assessed additionally if the SF36 is used as an assessment of quality of life in clinical practice. The suggestion that associations between anxiety and depression and the SF 36 specific domains were similar to those with the specific disease status measures is also supported by the findings of this study.

In contrast however, internality scores correlated consistently only with scores for general health perception, mental health and social functioning, and levels of correlation were weak. This was not unexpected in view of consistently negative, albeit relatively weak correlation between internality and the AS disease status measures. This might be related to the inherent limitations of the locus of control construct (Wallstron, 1992) and therefore strong associations with generic components of the SF36 were less likely than with a disease specific measure.

6.1.5. The impact of co-existent conditions

No effects of co-existent iritis or psoriasis on either disease or psychological status were demonstrated in the first phase of this study, which is inconsistent with other literature which suggests that those with co-existent psoriasis were more functionally impaired, (Robertson and Davies 2004) and also more likely to be depressed (Kulkarni, 2004, Richards, 2004). One reason why this was not demonstrated in this cohort could be that although there were 14 participants who had psoriasis, only 5 people had significant peripheral joint involvement.

However data derived from the qualitative work suggested that in this cohort co-existent conditions might be linked with psychological status. Within this cohort iritis and especially a flare of this condition was described as particularly distressing and perceived as being more harmful than a flare of AS due to concerns about fear of losing eyesight and the inconvenience caused. Unfortunately, data on flares of iritis were not collected as part of the quantitative phase of this study, but this potentially may have provided a means of enriching the data to explore the impact of this co-morbidity. It could be that changes in psychological status may have been influenced by a flare of iritis alone rather than by AS.

6.1.6. The influence of age, disease duration and gender on disease status measures

BASMI and BASFI (but not BASDAI) scores were significantly related to age, having controlled for disease duration, whereas no relationship was found between these disease status measures and disease duration itself. This suggests that age rather than disease duration may influence disease status measures. BASMI and BASFI scores may also increase with age alone irrespective of disease and even though these tools are AS specific. It would therefore be important to determine the range of these scores in otherwise healthy older people to explain this. It may be helpful to develop age-differentiated mean scores for AS patients in the BASMI and BASFI domains.

Taylor et al (1998), using data from RNHRD, suggested that AS may remain active after 40 years and although they found no correlation between BASDAI and age, they also reported that BASDAI was weakly correlated with disease duration. Disease duration was more strongly associated with BASFI and BASMI and they considered that duration of disease would be of more clinical relevance than age in AS. They produced reference centile charts for the Bath indices based on disease duration. However disease duration is difficult to assess, relying heavily upon patient recall of the onset of initial symptoms with the added complication that considerable delays could occur before diagnosis is confirmed. Gran (1997) illustrated this whereby the average duration from onset of symptoms to diagnosis was 8.6 years between 1961-1969, 7.2 years between 1971-1980 and 3.7 years between 1981 and 1990. Gran (1997) reported that 80% of patients with disease duration longer than 20 years still had daily pain and stiffness and that loss of function occurs during the first 10 years of disease, correlating with the occurrence of peripheral arthritis and x-ray changes. This highlights that AS persists throughout the life course. Kennedy (1993) on the other hand used a tool, which was the precursor to the BASDAI and reported that disease status was independent of disease duration. Interestingly, the patient group who had scored highest on the disease activity scale was significantly older than the group with the lowest scores. They therefore postulated that older people were not as active thus finding it harder to keep their disease under control. They also noted that those with the longest disease duration also had significantly higher scores. However the disease duration of the two extremes, i.e. those with mild and those with severe disease, was not significantly different from each other and this indicated that activity was unrelated to the length of time that people had their AS.

Further insights linking age with psychological status were identified in the secondary phase of the study. Participants described feeling vulnerable and distressed as they recognised that AS disease activity did not subside, as they got older. Older participants found it more difficult to cope on a physical level and had fears concerning further loss of independence or even being confined to wheelchairs. It was this fear of continuing to worsen and the knowledge that their AS was still active that was attributed to causing psychological distress. Whilst people thought that they would have more time to 'look after themselves' when they retired they described finding it harder to exercise and they were less active and therefore they felt that they had less control over their AS. Additionally, younger people perceived that they coped better with their AS because they were young enough and fit enough to remain active. These findings correspond with Kennedy (1993) who reported that disease status in AS was independent of disease duration. They also postulated that because older people are not as active, they found it harder to keep their disease under control.

There was no effect of gender on disease status in this cohort. This finding appears to contradict the literature on the effect of gender in AS, although this cohort included only a small number of women (15) who completed the study, despite initial recruitment at a 3:1 male: female ratio. Gender differences in AS severity and functional disability have previously been described. Taylor (1999) found that females had more disease activity and more functional impairment than males despite better disease scores. Falkenbach (2003) in a study based in Holland found that males had more progressive disease but women reported more functional disability. This was a large cross-sectional study, which analysed data from 1193 men, and 345 women. Similarly, Jimenez-Balderas (1993) found that women had less frequency of 'bamboo spine' and less restriction of spinal extension. The clinical picture in women was also reported to be better with shorter duration of iritis attacks and fewer hip replacements. This was a retrospective review of 'charts' in Mexico and great care was taken to match 41 male and 41 female patients for age of onset and disease duration. Will (1990) also reported that men had worse lumbar spine involvement. This was a large study of 1202 men and 498 women. In a parallel study of 100 men and 50 females, x-rays showed similar radiographic changes in the sacroiliac, cervical spine and hips. However there was worse radiographic change in males in the lumbar spine. In contrast however, Kidd (1988) in a British hospital cohort comprising 70 males and 35 females found no gender differences in spinal symptoms, chest expansion, peripheral arthritis, extra-articular features or

functional outcome. Axial disease was more severe in men but the overall pattern of clinical disease was very similar for both sexes.

Other studies have acknowledged the difficulties associated with identifying gender biases. Will (1990) highlighted the fact that women may have mild disease or minimal symptoms and may remain undiagnosed. AS prevalence in the community is uncertain as all published data has been ascertained from hospital cohort or self-help group cohorts. Two of the larger studies reporting on gender effects (Will, 1990 and Falkenbach, 2003) have been questionnaire-based studies which may lead to an over representation bias with those with higher educational levels, social and economic status being more likely to respond.

6.1.7. The influence of hip involvement on disease status measures

Patients with hip involvement had significantly higher BASMI, BASFI and BASDAI scores. This was a consistent finding with the findings of Robertson (2004) who found that those with hip disease had significantly higher BASMI scores, and Amor (1994) who found that those with no hip involvement had a less severe outcome. Sweeney (2001) also reported that patients with a total hip replacement had higher BASFI scores. It would therefore appear that as hip involvement becomes more apparent the effects on function are clearer as identified by the BASFI. The BASFI is probably responsive to hip involvement as items rely upon hip function such as 'bending to pick a pen up from the floor', 'climbing stairs' and 'getting up from a chair'.

Further insights into the associations between disease and psychological status

Additional descriptions of insights into the associations between disease and psychological status were ascertained from the qualitative study. These data were derived from a sub group who demonstrated concomitant changes in disease and psychological status and are therefore not generalisable to the whole cohort. However this additional study did help to increase our understanding of the complexity of individual's lives which were not identified in the quantitative phase of the study

The strongest associations identified in the quantitative study were those between disease status (both disease specific and generic measures) and anxiety and depression. Within the qualitative data the changes in the symptoms of AS were strongly associated

with anxiety and/or depression. The continual presence of pain and its increase during periods of exacerbation were associated with a negative impact on psychological status especially when people perceived themselves as never being free from it. The additional effects of both sleep disturbance and fatigue were also described as influencing psychological status especially during flare. People knew that they were more difficult to live with and used terms such as 'depression' to describe the influence of symptoms on their mood during these periods. Whilst clinical attention may focus on pain, fatigue was regarded as being as distressing as pain and was also associated with a negative impact on psychological status. Hewlett (2005) has recently highlighted that fatigue in RA is a major concern for patients but that health care professionals have been less focused on this symptom.

Moreover this study also suggested that the unpredictability of disease status was associated with a lack of control a person felt they had over their AS. This was regarded as increasing distress when AS symptoms were exacerbated. Insights into the ways in which individuals were able to help themselves were given in the study. This emphasised the value of having some control over the condition which was regarded having a positive effect on psychological status. However the level of control a person felt they had was challenged when the experienced an exacerbation of their condition and acted as a reminder that perhaps they did not have the degree of control they thought. This concurs with the literature as the impact of uncertainty of outcome in other chronic illnesses has been described (Weiner, 1975). RA patients were found to suffer from a varying loss of control over their disease and this was associated with the unpredictability of acute exacerbations of disease activity. Therefore the insights from the qualitative data highlight the challenges that patients face when never knowing from day to day how they are likely to feel or function and whilst feeling in control of their AS experiencing times of exacerbation which challenged their sense of control.

Arguably the most significant factor to have been identified as influencing how this cohort of individuals were able to manage their AS was their life circumstances. This does not fully explain the linkage with the associations identified quantitatively but highlights previously unidentified factors withn the context of AS, with the potential to hinder or even preventing individuals from managing their AS. The considerable comorbidity within this cohort was surprising and the effect that this had on psychological status was described by participants as being significant. Psychological

issues were also described as being influenced by social aspects of this participant's lives which again were described as contributing to how they managed their AS. In some instances these issues were perceived as being of greater concern than AS. Therefore it can be seen that as clinicians we need to be aware of the impact of additional factors within a person's life be these social circumstances, co morbity or psychological complexities, that the links between disease and psychological status potentially more complex than may have been anticipated.

6.2. IDENTIFICATION OF SUSTAINED DISEASE ACTIVITY

This is the first prospective study to investigate the outcome of active disease in AS using validated markers of disease severity and using a definition of active disease, which is currently used in the UK to guide commencement of anti-TNFα treatment. Of 47 participants who scored BASDAI 4 or higher on their first assessment, 45 showed persistently active disease over the subsequent 18 months. These findings show that the widely-perceived model of disease relapse and spontaneous remission in AS does not apply across the entire spectrum of disease activity, and suggest that patients with active disease may commonly continue to experience high levels of disease activity over the longer term. These results have important implications for care planning in clinical practice, not only in terms of commencing anti-TNFα treatment but also for tailoring exercise programmes and providing appropriate and timely advice and support to take account of persistent disease activity.

The BASDAI has rapidly become a standard tool for measuring disease activity and continues to be widely used in large clinical trials of pharmaceutical and other interventions in AS, including randomised controlled trials of anti-TNFα (Maksymowych, 2002, Brandt, 2003, Gorman, 2003, Davies, 2003). The recent BSR guidelines for prescribing anti-TNFα therapy in adults with AS used BASDAI scores to define criteria for eligibility (Keat, 2005), and recommended that a threshold score of 4 should be used for this purpose. It may be tenuous to routinely apply the same threshold score to define disease activity across all patient groups and in all clinical settings and locations. Therefore, to take account of the possibility that such effects might influence the conclusions, data were analysed using a BASDAI threshold score not only of 4 but also of 5 and 6. Despite raising the BASDAI threshold score to

these levels, a substantial proportion of this cohort continued to be categorised as having persistently active disease, such that 38 (43%) participants scored 5 or higher on all 4 assessments whilst 16 (18%) scored 6 or higher throughout. These findings demonstrate that the overall conclusions are not heavily dependent on the inherent psychometric properties of BASDAI scoring.

To investigate the impact of persistently active disease on clinical outcome a smaller group (n = 19) were identified within the cohort, which consistently showed BASDAI scores less than 4. This enabled comparison of results within a subgroup that clearly had persistently active disease with results within a subgroup, which had persistently quiescent disease over 18 months. The remainder of the cohort (n = 25) were not included within this analysis because all participants in this category demonstrated an intermediate and often variable level of disease activity over the study period, which did not allow a sufficiently robust classification for the purposes of comparison. For the participants with persistently active disease (n = 45) there was no significant deterioration in either mean BASDAI or mean BASMI score during the 18 month study period, although mean BASFI score increased significantly from 6.0 to 6.5 over this time, suggesting some deterioration in function. In contrast, for the 19 participants with persistently quiescent disease there was no significant change in BASDAI, BASFI or BASMI score between the first and fourth assessment. These results are consistent with previous work demonstrating poor outcome of persistently active disease (Kennedy, 1993), and support the case for early clinical interventions aimed at reducing active disease.

The possibility that anxiety and depression levels would remain stable was also explored, since although mean BASDAI scores were consistently high they did not increase over time within this group. Another possibility was that prolonged disease activity, albeit not worsening in severity, might lead to deteriorating psychological status. Scores for both anxiety and depression were significantly and consistently higher in the group with persistently active disease compared with the group with persistently quiescent disease. For the latter group, there was a small increase in mean anxiety score at assessment 4 compared with assessment 1, the clinical significance of which is uncertain. However, there was no evidence that either anxiety or depression levels increased during the course of the study in the group with persistently active disease. Further monitoring would be needed to determine whether this continues to be the case

over the longer term, and also to characterise change in anxiety and depression status following spontaneous remission or successful treatment with anti-TNFα in this group.

These findings support the validity of using BASDAI scores of 4 as a marker for eligibility for anti-TNFα treatment, since within this group there was evidence of functional deterioration but no evidence of spontaneous remission over 18 months. These findings also have important implications for care planning, since they show that active disease is unlikely to spontaneously remit over this period. There is therefore no rationale for delaying the introduction of anti-TNFα treatment for patients who demonstrate such levels of disease activity. However unless anti-TNFα treatments are readily available locally, practitioners' advice and support for patients with active disease is paramount. It is important that patients should receive support with rehabilitation not only with exercise regimes but ideally with intensive courses of physiotherapy. Support with both conventional medical interventions and self management regimes is also important. Moreover there is the possibility that patients may not wish to receive anti-TNFα treatments or that this may be a contraindicated intervention. In this scenario access to continuing rehabilitation is therefore essential.

6.3. BIOPSYCHOSOCIAL APPROACH TO ASSESSMENT

The identification of a cohort of patients showing concomitant changes in measures of psychological and disease status provided an opportunity to explore within this group possible explanations for these associations. Whilst the quantitative data highlighted the association the qualitative data highlighted two potential reasons for why participants' levels of anxiety and depression changed in line with changes in disease activity.

6.3.1. Life circumstances

Within this cohort a range of current and past life circumstances were identified which were described as posing challenges for the participants and having an impact on their ability to cope with their AS, especially when it changed. These included the burden of providing care and support for other family members, concerns about maintaining employment, or fear of being ill and living alone.

There has been little exploration of these factors in AS. Sirmali (2003), in a case report, highlighted psychosocial concerns regarding employment, psychiatric problems and alcohol addiction in a thirty year old waiter with severe AS. Dagfinrud (2005) explored difficulties in everyday activities related to functional impairment in patients with AS using the International Classification of Functional Disability and Health framework (ICF). This study also examined the relationship between measures for personal characteristics, impairment and activity/participation levels. It suggested that further research is needed to identify social, structural and attitudinal barriers which influence participation in patients with AS but unfortunately psychological factors were not integrated into the study.

There is some concurrence with this study in findings revealing that life circumstances created barriers, which prevented participation in treatment regimes. For example, the demands placed upon participants by their social/life circumstances meant that they had very little time to exercise and adhere to their treatment protocols.

Keefe (2002) in an overview of the emerging literature on biopsychosocial assessment and treatment in OA and RA, emphasised the importance of understanding social factors such as support and socioeconomic status in understanding arthritis pain and disability. Studies have suggested that low socioeconomic status is related to higher functional disability, depressive symptoms and mal-adaptive coping styles (Berkanovic, 1996, Downe-Wamboldt, 1995, cited by Keefe, 2002). RA sufferers who have higher daily support have also been identified to experience much higher levels of psychological well being and to be less depressed than those without support (Doeglas, 1994, cited by Keefe, 2002).

6.3.2. Co-morbidity

Although the effects of coexistent conditions were not demonstrable from the quantitative data, a significant finding in the qualitative data was that within this subgroup, co-morbidity appeared to have a substantial influence on a person's ability to live with AS. Within this smaller cohort the amount of co morbidity was striking and not only did people describe the impact of the co-morbidity on their ability to manage their AS but also how the level of worry which the co-morbidity elicited often became a major influential factor on psychological status. It was apparent that the participants within this cohort had very complex lives and were dealing with more than one

impairment. People described feelings of confusion as they tried to discern whether it was their AS or other impairments that were responsible for the symptoms they were experiencing. The seriousness of AS was also judged against other impairments and in many instances described as being less serious. In some situations the co morbidity prevented the use of coping strategies for AS. This therefore influenced perceived levels of control that people had over their AS. This raises the possibility that co morbidity had an important influence on the associations identified and that clinicians need to be aware of this concept. This is consistent with the literature in that co morbidity has been identified as influencing outcome in people with other long-term health conditions. For example, Treharne (2005) identified that RA patients with co-morbid CVD had significantly higher depression levels and advocated the potential benefits of identification of those who are depressed by systematic screening. The presence of co existent chronic conditions, particularly heart disease, pulmonary disease and obesity has also been shown to increase the likelihood of subsequent disability in knee OA (Ettinger, 1994).

The data from this qualitative work provide insights into the potential links between biological, psychological and social factors and the influence these have on how people were able to deal with their AS. A need to utilise a biopsychosocial approach to the management of other conditions has been advocated. Parker (1991) suggested that that the biopsychosocial perceptive was useful in estimating RA disease activity. Schoenfeld-Smith (1996) identified that key biopsychosocial variables such as pain and helplessness may affect the development of disability in RA and are significant mediators of the relationship between disease activity and future disability. Covic (2003) advocated a biopsychosocial approach in RA which acknowledged that the physical aspect of the condition may dominate but that it is mediated by psychological factors, which can be targeted with an appropriate interventions. Moreover, Dekkers (2001) identified that life events were correlated with psychological distress but not with disease activity in RA. More recently, Hunt (2008) recently advocated a biopsychosocial framework by which to manage OA of the knee suggesting that concentration on the traditional biomedical aspects prevents complete representation of the health condition and therefore limits treatment effectiveness.

The findings from this study suggest that current assessment domains for AS will be unlikely to identify such complexities within a person's life. Standardised measures

certainly do identify disease status but are limited to disease status. Equally, psychological status can be assessed by utilising appropriate instruments. What this study has identified is that there are limitations to these approaches and that only by adopting an approach which includes physical, psychological and social elements can a true picture be drawn that encompasses the whole health spectrum of the individual. For this to be achieved, a biopsychosocial approach to the assessment of AS seems appropriate. Such a format would not only integrate not only the impact of AS on a person's physical status but would also enhance understanding of psychological influences and take into account the impact that life complexities are creating.

Potentially this study has highlighted that it is the complexity of people's lives, which may explain why deterioration in their disease status could be leading to an increase in anxiety and/or depression. Additional pressures such as changes in demands placed upon them in the social setting or changes in co-morbidity status appear to create additional pressures. The impact therefore of an unpredictable increase in AS disease activity would make it harder for them to provide the levels of support for those dependent on them. Within this small cohort people who physically had to provide care for family members and others who had demanding jobs were identified. Additionally, the extent of the severity of the co morbidity for some participants actually meant that they were unable to remain as active as they needed to be. This suggests implications for the current management of AS, which may require interventions to address patients' needs in a fully holistic sense encompassing not only timely medical but psychological interventions.

6.4. METHODOLOGICAL ISSUES

6.4.1. The significance of the clinical setting

A significant strength of this study was that data collection was situated within a clinical setting as part of participants' routine care. This factor reduced the burden of participation and alleviated potential distress created by unfamiliar settings. As a result of this attrition rates were minimised. A further important strength was that this cohort was recruited from an established cohort of AS patients who as part of their clinical care received regular assessments. Not only did this facilitate recruitment in that all patients had confirmed diagnosis but routine review appointments had also been pre booked. This meant that a large number of participants (110) were recruited within a very short

time scale (three months). The researcher also had an established rapport with all patients, which enhanced explanation of the study and potentially influenced compliance throughout the study. Patients were also familiar with the assessment procedures. Psychological status was routinely assessed in clinical practice using the Hospital Anxiety and Depression Scale (HADS). Therefore this alleviated the potential for distress when focusing on psychological issues.

All questionnaires were presented within a booklet. It was hoped that because patients had prior knowledge of the format of the majority of questionnaires in a clinical setting, that being part of a study would not necessarily bias their answers. The booklet was also printed and not photocopied so that all VAS lines were exactly 10 centimetres long and was designed with thought given to the order of the outcome measures and the time it would take to complete. The researcher also made sure that all questions had been answered at each assessment thus enhancing quality of data and minimised non-completion. The researcher also had an established rapport with all participants and was available to answer any questions or concerns. Every care was taken to ensure that nothing was said that could sway peoples responses and all aspects of the questionnaires were explained in the same manner to each participant ensuring that although they were familiar with most of the instruments that they felt that it was a true account of how they felt at that particular assessment point.

This study also benefited from the fact that the same person was almost entirely responsible for all the metrology assessments throughout the study, therefore minimising inter-operator inconsistencies within the objective assessment procedure. Should the researcher not be available then only one other trained physiotherapist carried out the BASMI assessment. The researcher made all calculations, anonymised all data and inputted all data to a password-protected database. Moreover, the assessments were made at approximately the same time of day, i.e. mid-afternoon during the designated clinical time for the AS monitoring service. The researcher was also the only person to calculate and input the data. This was completed weekly and diligently, ensuring enhanced consistency of data with less error.

6.4.2. Mixed methods

As the study evolved, it became clear that a combination of methodologies was needed to explore in depth some of the associations between disease and psychological status,

which were identified. Whilst statistical associations have the potential to identify associations they do not provide explanations.

Mixed methods research is now becoming an established and recognised approach, and in this study the combination of these methods helped to address the questions posed. There has been an increasing challenge to the divide in research methodologies with an increasing number of researchers utilising mixed methods research. Cresswell (2007) advocated that adopting a mixed methods approach allows the researcher to provide a better understanding of the problem than if either a quantitative or a qualitative approach were used alone. Indeed Robson (1993) suggested that multiple methods can rule out error due to the methods utilised in that different complementary questions within a study also assess the plausibility of threats to validity of the primary technique used. A mixed method encourages multiple paradigms rather than the typical association of certain paradigms for qualitative researchers and others for qualitative researchers. In this study, without the addition of a qualitative component it would not have been possible to develop an understanding of the associations that the quantitative method had identified. Moreover, this combination of methodologies has allowed for a clear separation in the presentation of the results. Indeed this separation emphasises the understanding that the qualitative study was attempting to further explain the associations.

The mixed method approach identified that there is far more complexity with these associations than may have been anticipated. For example, the results suggest that factors such as life circumstances and co morbidities have an important influence on how people are able to manage their condition. The associations between disease and psychological status within this cohort can therefore be better understood. However without the initial quantitative data, which identified these associations, the foundations on which to progress this study would not have been in place.

6.4.3. Limitations of this study

There is the possibility that the characteristics of this cohort may be substantially different from other cohorts with AS, limiting the generalisability of these results. As a hospital cohort these patients may have more aggressive disease than those who remain in primary care (for whom there is no available data) leading to limitations for the generalisability of the findings. However this cohort appears very similar to the British

hospital cohort described by Robertson (2004) suggesting that the people in the cohort were broadly similar to other AS patients who are receiving secondary care.

At recruitment there was a potential for bias as the researcher knew the characteristics of all potential participants. Participants also knew the researcher and may have felt an obligation to consent to participate. It was therefore imperative that as a researcher, awareness of this potential to bias the recruitment selection could occur and therefore each participant was approached in the same way and adherence was maintained with the appointment scheduling as for routine clinical care.

Eighteen months was a relatively short period for a longitudinal study. Extension over a longer time period would have been preferable as there would have been more evidence for the confirmation of findings. Unfortunately, the longitudinal study had been designed to fit within a programme of studies for a research degree therefore meaning that all data collection was limited to just four time points. There will always be the caveat that if there were more data available then the analysis would be more secure, but there was no opportunity within the context of this fixed time frame to continue with the data collection for this study. In hindsight it also became clear that the data might have been enhanced had the extent of flares between assessment times been recorded and analysed along with any effects of concomitant or co morbidity at that time.

Attrition occurred within this study, with 21 of 110 patients not completing all four assessments. However attrition is expected when undertaking longitudinal studies and was therefore anticipated. Analysis of the baseline data from these participants showed that these participants were not significantly different on any measure compared with those who did complete the study. Unfortunately, there was a disproportionately high attrition rate for women. The effect of this level of attrition has made interpretation of the gender-based data less secure. A similar problem was also encountered due to the small number of participants with psoriasis.

In hindsight, as the study highlighted that significance of biopsychosocial criterion, data collection could have been enhanced by the collection of information related to the socio-economic status of the participants such as changes in social circumstances, changes in relationships and days away from work caused by disease flare.. Additional clinical data such as peripheral joint flare and episodes of iritis which may have

coincided with assessments, medication changes and, biomarkers such as CRP levels may have provided more detailed knowledge particularly with flare of disease status, although CRP levels are not carried out routinely within this clinic setting.

The study made extensive use of questionnaires which required a certain level of literacy skills, as did completion of the diary. Therefore the collection of educational qualifications may have identified any issues participants may have had in completing these aspects of the study.

The analysis of each individual and identification of concomitant change in disease and psychological status required a novel approach. This involved small sets of observations (4) and therefore potentially correlations of 0.5 or above may have occurred simply by chance. Concomitant change was not identified with all the disease activity indices for each individual and for some individuals there were more associations than for others. Additionally, the focus was on anxiety and depression and did not include internality. However, for all the caveats in the methodology, there was evidence of change in disease status in association with psychological status in these individuals.

6.4.4. The clinician as a researcher

Clinicians regard research as a means of informing and developing practice by contributing to knowledge and understanding. However when clinicians undertake research, especially if conducted within the context of their own clinical practice there are factors that need to be addressed with regard to the potential impact that being a clinician/researcher can have on different stages of the research process. As a clinician within the clinical setting undertaking this study, it was appropriate to explore these issues and discuss how they were to be addressed. Chenail (1996) suggests that to researcher and therapist alike, all good enquiry starts with a good and thorough self-examination. In therapy he wrote that the self as a clinician is a central notion in a number of clinical approaches. Likewise in research genres such as qualitative inquiry the self of the researcher is an important ingredient of the formula for effective and ethical practice.

There have been concerns expressed over the ethical challenges posed by the involvement of clinicians in research that involve human participants (Miller, 1998, Pellegrino, 1992). Not only can financial conflicts of interest arise in the context of research but there may also be the clash in agendas between the clinician and researcher role. Yanos (2006) suggested that individuals who come from non-clinical backgrounds such as sociology and epidemiology have stronger training in research methodology, statistics and theory than therapists and nurses however he acknowledges that in an applied field researchers without clinical experience or direct exposure to the clinical phenomena or service systems may miss out on the 'real world' issues that can inspire and innovate relevant research. There are considerable challenges associated with integrating the clinician/researcher role in patient orientated research. In particular this combined role may not be able to avoid a clash in agendas that can create both practical and ethical conflicts (Yanos, 2006).

One ethical consideration is that the clinician/researcher may experience an internal clash between the clinical mandate to act in the patient's best interest and the scientific mandate to pursue the truth with appropriate rigor. In clinical research, the 'therapeutic misconception' (Appelbaum, 1987) occurs when participants assume that the goal of clinical research is always therapeutic and when they do not understand, for example, that they may be randomly assigned to a study condition that is not in their best personal interest. Yanos (2006) warns that this misconception is even more likely to occur if the study investigator is someone who is known to the participant's as his or her treatment provider and who is asking him or her to participate in the research study.

There will always be concerns that by integrating these roles the clinician/researcher has a great deal of responsibility to develop good judgment and that they should continue to be aware of potential biases which could lead to exploitation and poor science. It is also essential not to use this position to pressurize subjects to take part in the research project. Therefore it was important throughout this study to emphasize to participants that as the researcher was also their clinician, they should not feel coerced into participating. Methods were employed to minimize such problems especially during the recruitment stages. Participants received a full description of the study with emphasis on understanding what they were required to do and the implications of their involvement before they consented to participate. The clinician/researcher had worked with this group of patients since inception of the service. At all times it was deemed

important that the care the participants received should be no different whether they were part of the study or not. Therefore if clinical advice was needed it was given with no alteration in practice.

However the qualitative research interface posed additional considerations, as the researcher was known to the participant as his or her treatment provider. There was the potential that sensitive issues within people's lives would be revealed which could have implications for the future clinical relationships. Therefore, it was imperative to emphasise that people should only share what they felt comfortable with. Participant's consultants were also informed of their involvement in the study and agreed to offer further interventions if required. Moreover, permission to disclose information, which was felt to be detrimentally affecting the participant, was asked for before each interview. Participants were reassured that should they feel uncomfortable any issue then they should make this clear and that the interview could be terminated.

The researcher was also aware of the results from the quantitative study and this information could have potentially influenced discussion in the interviews. Every effort was made to minimise the influence this could have. The researcher was also aware that after the study, she had to return to the role of clinician. This clinician/researcher relationship relies heavily on trust and therefore could have significant influences upon outcomes. Disclosure of experiences or feelings that would otherwise not have been placed within the clinical arena was a very probable outcome from utilizing this method of research. Therefore every effort was made to ensure confidentiality and to maintain a professional rapport. A conscious effort was made not to discuss issues raised as a part of the research when working in the clinical setting other than when instigated by the participant.

Lawlor (2003) analyzed ways of perceiving, knowing and being with others while engaging in qualitative and ethnographic research and described how in a desire to gain entry into participant's lives and worlds the clinician/researcher is moving out of the clinical arena with which they are familiar into an unfamiliar world where there is an acute awareness of 'being' on someone else's 'turf'. Participant observation, interviewing and listening lead to relationship building which may expose the clinician/researcher to new and different vulnerabilities by gaining access into dimensions of people's lives not encountered within clinical contexts. Lawlor (2003)

additionally warned that participants might modify their behaviour in front of the 'researcher' possibly embellishing or performing to compel the researcher to be more interested or by disclosure of more sensitive arenas that may not otherwise have been a part of the clinician/participant discourse. It was therefore important to ensure that the 'clinician' behaviour should remain as it had been prior to the study.

For the clinician/researcher who is conducting research in environments, which replicate or resemble settings in which he/she works as a clinician there are several issues related to 'getting situated' (Lawlor, 2003). Wenger (1998) warned that changes in participation in clinical practices and research practices can lead to changes in how people do things. This may contribute to both how individuals are perceived by others and how they perceive their own identity. In addition, there could also be times when the participants in research projects want the researcher to respond more like the clinician and if this doesn't happen the clinician/researcher may be perceived as withholding sound and needed clinical judgment and feelings of betrayal or suspicion can be generated.

During ethical approval for the qualitative part of this study such issues were addressed. To try to emphasise the non-clinical nature of the interview participants were given the choice of being interviewed within their home environment as this was deemed to provide a clearer definition to the roles. However, most participants preferred to be interviewed within the 'clinical' environment. This therefore meant that the clinician/researcher was dressed in physiotherapy uniform. There was therefore a visual reminder of her role as a clinician which has the potential to reinforce that role rather than that of a researcher. Thought was given as to whether or not to change out of uniform but given that the interviews were being undertaken in a clinical setting and all the participants knew the therapist this seemed tokenistic. It was therefore deemed more important to discuss this as a potential barrier to the research process with the participants emphasising that during the interview participants should regard her as a researcher and not as their clinician. The clinician/researcher made every effort prior to commencement of the interview to reinforce this 'other' role and remained aware of this division of roles during these interviews. The focus of the interview was stressed to each participant before it commenced and their permission was also sought to disclose important clinical information should the need arise.

There are further issues related to the potential for the researcher influencing the results. Unconsciously the researcher/clinician may influence their participants responses by using non-verbal cues when interviewing such as smiling, nodding, leaning forwards when they hear things they wish to hear. Conversely the opposite effect can occur by leaning back and looking more discouraging. Researchers should therefore rigorously attempt to present themselves neutrally to minimize the extent to which they themselves intrude upon the generation of the participant's authentic accounts (Ritchie, 2003). Awareness of such issues made the clinician/researcher more conscious of personal behaviour during each interview and every attempt was made to remain as neutral as possible. In addition, personal characteristics of the researcher/clinician could be a further consideration, as the participants are likely to have an established relationship with the researcher/clinician. Hicks, (2004) points out that participants may deliberately say things, which they know, will not support the hypothesis or they may distort their responses if they like or wish to help the researcher.

The clinician/researcher relationship throughout the project potentially could impact up on the process of data analysis. Each questionnaire was scored by the clinician/researcher and obviously biasing of the results could be construed at this point especially during the physical assessment. The clinician/researcher remained as objective as possible during this stage as this study was dependant up on integrity. Potentially there could be errors with the data during in putting and calculation and therefore continual scrutiny was essential. The supervisory team with additional help and clarification from a statistician also verified data analysis.

Finally, during the qualitative data analysis the clinician/researcher had to be aware that the relationship with the participant could impact up on the data analysis. Whilst within a qualitative paradigm it is acknowledged that the relationship between the researcher and social phenomena under study is interactive the researcher must seek to produce a credible and trustworthy account of their data. Therefore researchers have to make their assumptions transparent and must be objective in his/her approach if the investigation is to be seen as being value-free (Richie and Lewis, 2003). At this stage it was therefore essential that a second person could clarify and determine the trustworthiness of the interpretation. Working closely with an experienced member of the supervisory team was invaluable to the clinician/researcher throughout the analysis and contributed greatly in enhancing credibility and trustworthiness of the analysis.

6.5. IMPLICATIONS FOR CLINICAL ASSESSMENT IN AS

This study has highlighted the associations between disease and psychological status in AS. People who are more anxious and/or depressed score their disease status as higher than those who are not. This implies that a subjective assessment of disease status such as the BASDAI would be skewed for those with psychological issues. This dilemma could be addressed by taking into account the psychological status of the individual. Within the arena of clinical trials, similar judgements should also be made both at recruitment and during analysis of the response to treatment. For example, the HADS could be used at each assessment for standard clinical practice and therefore both baseline and more importantly a longitudinal picture can be created of an individual's psychological status.

Within a small sub group of patients, this study has also confirmed that co-morbidity is a significant factor, which influences how a person manages their AS. Clinicians need to become aware of the possibility that it could be the impact of the co morbidly rather than the AS disease activity that is the reason for either poor response to treatment or increase in psychological distress. Additionally, the social context in which a person is placed has been identified as having an impact upon their ability to cope with their condition. This creates a multi-faceted and complex scenario, which requires additional elements to be integrated into AS assessments.

The development of an assessment based upon the biopsychosocial model (Engel, 1977, 1980; Kazarian and Evans, 2001, cited by Sarafino, 2006), which takes account of the broader context of people's lives, could be beneficial. To date, although there has been some recognition of the benefits, this has yet to be fully developed within AS. Clinicians should be encouraged to assess changes or problems that may be occurring in a person's wider social context during routine assessment. Such issues as sick leave as a response to disease activity need to be considered. Being more aware of possible changes being imposed by changes in work demands including stress related issues might help to build a clearer insight into people's ability to cope with their condition. Awareness of these changes could guide interpretation of disease status leading to informed clinical decision-making and instigation of appropriate interventions.

This study has also confirmed that longitudinal data collection using the current disease specific measures for AS has the potential to add to our knowledge of the natural history of this condition and that these instruments are capable of capturing changes in disease status. However further refinement has been advocated by Haywood (2004) regarding spinal mobility issues ten years after the initial introduction of the BASMI illustrating that the ASAS recommendations are different than those within the BASMI. Therefore a consensus on the most useful objective measurements of axial mobility is lacking. At present there are quality improvement initiatives within the NHS, which recognise the importance of evaluating health care outcomes. With the availability of new and expensive therapies for AS the challenge will be to provide more informative, responsive and relevant patient-based assessment of disease impact and treatment efficacy.

6.6. POTENTIAL BENEFITS OF PSYCHOLOGICALLY-BASED INTERVENTIONS

The inclusion of a psychological screening instrument as part of routine care and used within a regular monitoring programme would enable clinicians to see patterns developing in changes with psychological status. Such information could then inform the use of timely and appropriate interventions to address these problems. An example of such an intervention might involve Cognitive Behavioural Therapy (CBT) .CBT has been shown to be effective in the long term management of RA in a randomised controlled trial of patients who were newly diagnosed (Sharpe, 2003). This study demonstrated that a CBT programme offered as an adjunct to standard clinical management was efficacious in producing improvements in both psychological and physical indices and that these improvements appeared to increase over the ensuing eighteen months. Moreover, Dixon (2007) in a systematic review of RA and OA has recently concluded that there was evidence for a small but statistically significant effect on arthritis pain achieved by psychosocial interventions. It may therefore be possible to introduce such programmes for those with AS. To date only one such AS related study has been undertaken (Basler, 1991), which was conducted over sixteen years ago and this alluded to successful outcomes from such treatment.

In addition to CBT, an evolving intervention involves Mindfulness Meditation. The focus is upon using acceptance-based methods, which have been championed by McCracken (1999, 2003), which explore reactions and responses to pain along with the cultivation of certain attitudes such as acceptance, and trusting in one's own capacity for

health and well-being. This was introduced as a clinical intervention for conditions such as chronic pain and anxiety in 1979 (Kabat-Zinn, 1982; Kabat-Zinn et al 1992, cited by Monroe, 2007). Research has suggested that a significant reduction in chronic pain can be achieved (McCracken, 1999, 2003, 2007, Morone, 2007)

Unfortunately, however recent studies to explore the efficacy of a psychosocial intervention for sub acute low back pain suggested no measurable benefit (Jellema, 2005). Work in this field is acknowledged as being in an early stage (Main, 2005) and may require further development of the interventions themselves as well as assessment of their efficacy in different clinical settings.

6.7. SUGGESTIONS FOR IMPROVEMENTS IN SERVICE DELIVERY

This study has highlighted that unpredictability of AS can be very distressing, and when unfamiliar symptomatology develops, it is at this point that individuals feel they are most vulnerable to psychological distress. In clinical practice, it would therefore seem more appropriate for services to be accessible as and when they are needed rather that at routine pre-arranged times. For example, telephone help lines designated to AS patients might be beneficial as would self referred early access into clinical services such as physiotherapy. A designated telephone help line would enhance ability to manage their condition effectively thus meeting the vision created within the Musculoskeletal Services Framework (DOH, 2006).

There is a paucity of longitudinal outcome data in AS available, and if data could be collected as an integral part of routine clinical practice then this gap could be reduced. The researcher has now established a longitudinal database, with consented patients, which is currently being used in clinical care and is based at Wrightington Hospital in Lancashire. This concept has now been shared with other rheumatology units with the vision of collecting and sharing longitudinal data in the future.

Increasing attention has been placed upon the difficulty of confirming early AS. Patients are presenting earlier to secondary care and, as Sieper (2005) and Rudwaleit (2004, 2005) have highlighted, inflammatory back pain symptomatology may take many years to be clinically defined with x-ray changes of AS as indicated by the New York Criteria (1984). Clinically there are important implications from early diagnosis as Amor

(1994) indicated a younger disease onset produced a more severe disease evolution. Therefore clinicians need to be aware of the need to make earlier diagnosis and to utilise treatment regimes earlier.

There is an urgent need to educate primary care physicians and those health professionals working within Clinical Assessment and Treatment Services (CATS) to enable them to identify patients with symptoms which meet the Inflammatory Back Pain Criteria (Sieper and Rudwaleit 2005). Once identified, referral should be made into secondary care for prompt assessment and instigation of appropriate treatment regimes. The early RA clinics have been successfully introduced provide a potential model of care for patients with early AS. Such treatment pathways would ensure that patients received appropriate treatment be it rehabilitation or the introduction of biologic treatments with the aim of controlling disease status and minimising the potential for spinal deformity. Previously long delays from first symptoms to diagnosis could be minimised and patients could be treated as effectively as possible at a time when they most require medical intervention, rehabilitation and education.

6.8. VISIONS FOR THE FUTURE

This study has highlighted the benefits of a long-term monitoring service for patients with AS which begins, with initial diagnosis leading throughout the life course of the patient. The findings of this study also highlight the need for a timely biopsychosocial assessment, which identifies changes in disease activity along with potential psychological and social implications that may be linked.

This study was based entirely within secondary care and at this present time health policy is focussed on reducing the reliance on secondary care provision focusing instead on primary care. The management of AS, as a long-term health condition, is influenced by The National Service Framework [NSF] for Long-term Conditions (DOH, 2005), which encourages local Primary Care Trusts to adopt systemic holistic approaches to care management and develop high quality, personalised services to meet individual requirements for the management of musculoskeletal impairments. Such proactive interventions, which promote self-management, have become increasingly recognised as a key factor for effective management of long-term health conditions (DOH, 2005). Services therefore should be based around people's needs to help them take control of

their health, support their wellbeing and allow them to lead an independent and fulfilling life.

The NSF encourages empowerment of people to allow them to manage their own care with the help of skilled health professionals and social care staff. For people with AS, this vision should be attainable if there is uniformity in assessment and education not only for patients but for health care providers and service provision. Such an approach relies on systems which identify needs early and respond promptly to them, which implement systematic and tailored programmes and which support self-management (DOH, 2005). Models of providing rheumatology services are being explored and in essence the avocation of rheumatology based interface clinics within a primary care setting are being advocated by the British Society of Rheumatology as being a possible foundation on which to base service delivery. Therefore, future work leading from this study could be to address the management of AS over the life course with particular regard to seeking to provide optimal care within a primary care setting. Novel approaches are needed for early diagnosis within the primary care setting and education and management delivery approaches also need to be addressed. One major goal from a future project would be to study the natural history and progression of AS, to investigate the efficacy of early interventions and provide patients with a definitive diagnosis and management plan much earlier than is commonly the case.

New and novel approaches for early diagnosis may also be needed and that not only do primary care physicians but also those in secondary care need to be educated regarding both diagnostic issues but also long-term management. Investment from clinicians in the early stages of diagnosis is required so that people receive appropriate education with awareness of how to access services. Self-management programmes could be developed within the community setting. To date, AS self-management has not been informed by approaches to behavioural change adopted by other self-management programmes in musculoskeletal conditions such as the Challenging Arthritis Programme (Barlow, 2000), and Looking after Your Joints Programme (Hammond, 1999). The evidence-base for these programmes supports the need to not only inform patients but to do so in a way which facilitates behavioural change. Adopting this approach and in line with phases 1 and 2 of the MRC Framework for the Evaluation of Complex Interventions (MRC, 2000), a programme of exercise, weight management and fitness management in early AS could be developed.

With the objective of developing, implementing and evaluating the efficacy of a community-based programme to promote self-management, this project could focus on biopsychosocial approaches. Utilisation could be made also of existing approaches used by Primary Care Trusts such as Steps to Health projects and be delivered by Active Living Officers who are located in sports and leisure complexes. Such a programme could be evaluated in terms of self-efficacy, clinical and psychological status and knowledge and if this demonstrated efficacy then a further trial could be undertaken to compare a self-management programme with traditional hospital based physiotherapy programme.

6.9. CONCLUSION

This study has been the first in AS to identify associations between disease and psychological status. Furthermore, insights into these associations have provided a degree of enlightenment to further our understanding of this phenomenon. Not only can disease status be seen to be linked with psychological status but more importantly the additional influence of life circumstances and co-morbidity have now been identified as creating additional contributory factors to this symbiosis. This study has therefore made an important contribution to raise awareness that traditional biomedical assessment may be inherently limited. It has identified that psychological factors may be influencing traditional assessment measures and that a more interdependent relationship in the approach not only in assessment but also to treatment may be required.

The vision is that a fully holistic approach to the care of all AS sufferers should be championed which would be responsive to changes in disease status allowing for timely interventions which are appropriate for physical, psychological and social needs. People with AS, empowered by appropriate knowledge and skills and supported by a clinician led infrastructure, could therefore be better equipped to live with their condition throughout their life course.

REFERENCES

Abbott, C.A, Helliwell, P.S, Chamberlain, M.A. Functional Assessment in Ankylosing Spondylitis: Evaluation of a new self-administered questionnaire and correlation with anthropometric variables. British Journal of Rheumatology 1994; 33:1060-6

Adams, N, Field, L. Pain Management 1: Psychological and social aspects of pain. British Journal of Nursing 2001; 10, No 14: 903-11,

Amor, B, Santos, R.S, Nahal, R, Listrat, V, Dougados, M. Predictive factors for the long-term outcome of Spondyloarthropathies. J Rheumatol, 1994; 1883-7

Analay,Y; Ozcan,K; Diracoglu,D; Aydin,R. The effectiveness of intensive group exercise on patients with ankylosing spondylitis. Clinical Rehabilitation, 2003; 17(6): 631-6

Appelbaum, P, Lidz, C, Meisel, A. Informed consent: Legal theory and clinical practice. New York, Oxford University Press, 1987.

Averns, H.J, Oxtoby, J, Taylor, H.G, Jones, P.W, Dziedzic, K, Dawes, P.T. Radiological outcome in Ankylosing Spondylitis: use of the Stoke Ankylosing Spondylitis Spine Score. British Journal of Rheumatology 1996; 35:373-6,

Baber, Zaheer. The Science of Empire: Scientific Knowledge, Civilization, and Colonial Rule in India (1996). State University of New York Press

Bakker, C, Boers, M, van der Linden, S. Measures to assess ankylosing spondylitis: taxonomy, review and recommendations. J Rheumatol 1993; 20:1724-30

Band, D, Jones, S, Kennedy, G, Garrett, S, Porter, J, Gay, J, Richardson, J, Calin, A, Whitelock, H. Which patients with ankylosing spondylitis derive most benefit from an inpatient management program? Journal of Rheumatology 1997; 24:2381-84

Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), Encyclopedia of human behavior (Vol. 4, pp. 71-81). New York: Academic Press. (Reprinted in H. Friedman [Ed.], Encyclopedia of mental health. San Diego: Academic Press, 1998).

Barlow, J H, Macey, S J, Struthers, G R. Psychosocial factors and self help in ankylosing spondylitis patients. Clinical Rheumatology 1992; 11(2): 220-5

Barlow, J H, Macey, S J, Struthers, G. R. Gender, Depression and Ankylosing Spondylitis. Arthritis Care and Research 1993; 6, no 1:45-51

Barlow, J, Macey, S J, Struthers, G. R. Health Locus of Control, self-help and treatment adherence in relation to ankylosing spondylitis. Patient Education and Counseling. 1993; 20, 153-66

Barlow, J H, Barefoot, J. Group education for people with arthritis. Patient Education and Counseling. 1996; 27:257-67

Barlow, B, H, Williams, B, Wright, C. The Generalised Self-Efficacy Scale in people with arthritis. Arthritis Care Res, 1996; 9:189-96

Barlow, J H, Turner, A, Wright, C. A randomized controlled study of the arthritis self-management programme in the UK. Health Education Research: Theory and Practice, 2000; 15, 665-80

Barlow, JH, Wright, C, Williams, B, Keat, A. Work disability among people with Ankylosing Spondylitis. Arthritis Care and Research, 2001, 45:424-9

Barlow, J H, Wright, C, Sheasby, J, Turner, A, Hainsworth, J. An overview of self-management approaches for people with chronic conditions. A review. Patient Education and counseling, 2002, 48, 177-87

Barlow, J H, Wright, C, Turner, A, Bancroft, G. A 12-month follow-up study of self-management training for people with chronic disease: Are changes maintained over time? British Journal of Health Psychology. 2005, 10:589-99

Basler, H, Rehfisch, H. Cognitive-behavioral therapy in patients with ankylosing spondylitis in a German self-help organisation. Journal of Psychosomatic Research 1991; 35: 2/3: 345-54

Beck, A, Ward, C, Mendelson, M, Mock, J, Erbaugh, J. An inventory for measuring depression. Arch Gen Psychiatry 1961; 4: 561-71

Bekkering, G. E, Hendricks, H. Koes, B W, Dutch physiotherapy Guidelines for Low Back Pain. Physiotherapy: 2003; 89, No 2:82-96

Bellamy, N. Clinimetric concepts in outcome assessment: The OMERACT filter. J Rheumatol: 1999;26:948-50

Bennett, P, Burch, T. The epidemiological diagnosis of ankylosing spondylitis. In: Bennett, P, Wood, P, eds. Proceedings of the 3rd international symposium of population studies of the rheumatic diseases. Amsterdam: Exerpta Medica Foundation;1966:305-13

Bennett, A, Tan, A, Coates, C, Emery, P, Marzo-Ortega, H, McGonagle, D. Sustained response to anakinra in ankylosing spondylitis. Rheumatology, 2008;47:223-4

Bjelland, I, Dahl, A, Haut, T, Necklelmann, D. The validity of the Hospital Anxiety and Depression Scale: an updated literature review. J. Psychosomatic Res 2002; 52:69-77

Berkanovic, E, Oster, P, Wong, W, Bulpitt, K, Clements, P, Sterz, M, Paulus, H. The relationship between socioeconomic status and recently diagnosed rheumatoid arthritis, Arthritis Care and Research,1996;9:257-62

Blum, U, Buitago, C, Mundinger, A, Krause, T, Laubenberger, J, Vaith, P et al. Magnetic resonance imaging (MRI) for detection of active sacroiliitis – a prospective study comparing conventional radiography, scintigraphy and contrast enhanced MRI. J Rheumatol, 1996; 23:2107-15

Boers M, Brooks P, Strand CV, Tugwell P. The OMERACT filter for Outcome Measures in Rheumatology. J Rheumatol. 1998 Feb; 25(2): 198-9.

Bombardier, C. Outcome assessments in the evaluation of treatment of spinal disorders. Spine 2000; 25:3100-03,

Boonen, A, Chorus, A, Miedema, H, Van der Heijde, D. Withdrawal from labour force due to work disability in patients with ankylosing spondylitis. Annals of the Rheumatic Diseases 2001; 60 no 11:1033-40

Boonen, A, Van der Heijde, D, Landewe, R, et al. Work status and productivity costs due to ankylosing spondylitis; comparison of there European countries. Ann Rheum Dis 2002; 61:429-37

Boonen, A, van der Heijde, D, Landewe, R, Chorus, A, van Lankweld, W, Miedema, H.S, van der Temple, H, van der Linden, S. Is avoidant coping independent of disease status and stable over time in patients with ankylosing spondylitis. Ann Rheum Dis 2004; 63:1264-68

Bowling, A. Research Methods in Health. Investigating health and health services. 1997. Open University Press.

Brandt, J, Haibel, H, Cornley, D, Gilder, W, Braun, J. Successful treatment with anti-tumour necrosis factor monoclonal antibody infliximab. Arthritis and rheunmatism, 2001; 43(6): 1346-52

Brandt, J, Khariouzov, A, Listing, J, Haibel, H, Sorensen, H, Grassnickel, L, Rudwaleit, M, Sieper, J, Braun, J. Six-month results of a double blind, placebo-controlled trial of Etanercept treatment in patients with ankylosing spondylitis. Arthritis and Rheumatism, 2003; 48:1667-75

Braun, J, Bollow, M, Seyrekbasan, F, Haberle, H-J, Eggens, U, Mertz, A, Distler, A, Sieper, J. Computed tomography guided corticosteroid injection of the sacroiliac joint in patients with spondyloarthropathy and sacroiliitis: clinical outcome and follow-up by dynamic magnetic resonance imaging. J Rheumatol, 1996; 23:659-64

Braun, J, Sieper, J, Breban, M, Collantes-Estevez, E, Davis, J, Inman, R, Marzo-Ortega, H, Mielants, H. Anti-tumour necrosis factor a therapy for ankylosing spondylitis: International Experience. Ann Rheum Dis, 2002; 61 (suppl III): iii56-60

Braun, J, Brant, J, Listing, J, et al. Treatment of active ankysoing spondylitis with infliximab: a randomized controlled multicentre trial. Lancet, 2002; 359:1187-93

Braun, J, Pham, T, Sieper, J, Davis, J, Van-der-Linden, S, Dougados, M. et al. International ASAS consensus statement for the use of anti-tumour necrosis factor agents in patients with ankylosing spondylitis. Ann Rheum Dis, 2003; 62:817-24

Braun, J, Brant, J, Listing, J, et al. Long term efficacy and safety of infliximab in the treatment of ankylosing spondyiltis:an open, observational extension study of a three month, randomized controlled trial. Arthritis Rheum, 2003; 48:2224-33

Braun, J, Baraliakos, X, Golder, W, Brandt, J, Rudwaleit, M, Listing, J, Bollow, M, Sieper, J, van der Heijde, D. Magnetic resonance imaging examinations of the spine in patients with ankylosing spondylitis before and after successful therapy with infliximab. Arthritis and Rheumatism 2003,48:1126-36.

Braun, J, Davis, J, Dougados, M, Sieper, J, Van-der-Linden, S, Van der Heijde, D, et al. First update of the international ASAS consensus statement for the use of anti-TNF agents in patients with ankylosing spondylitis. Ann Rheum Dis, 2006; 65:316-20

Breen, A, Austin, H, Campion-Smith, C, Carr, E, Mann, E. 'You feel so hopeless': A qualitative study of GP management of acute low back pain. European Journal of Pain, 2007; 11, 21-29

Brink, T L, Yesavage, J A, Lum, O, Heersema, P H, Adey, M, Rose, T L. Screening tests for geriatric depression. Clin Gerontol 1982:1:37-43

Brophy, S, Pavy, S, Lewis, P, Taylor, G, Bradbury, L, Robertson, D, Lovell, C, Calin, A. Inflammatory eye, skin and bowel disease in spondyloarthritis: genetic, phenotypic and environmental factors. J Rheumatology 2001; 28:2667-73

Brophy, S, Calin, A. Ankylosing spondylitis: interaction between genes, joints, age of onset, and disease expression. J Rheumatol, 2001; 28: 2283-8

Brophy, S, Calin, A. Definition of Disease Flare in Anklosing Spondylitis: The Patients' Prospective. The Journal of Rheumatology 2002; 29:954-58

Brown, G, Nicassio, P. development of a questionnaire for the assessment of active and passive coping stategies in chronic pain patients. Pain, 1987; 31:53-64

Bulstrode, S.J, Barefoot, J, Harrison, R.A, Clarke, A.K. The role of passive stretching in the treatment of ankylosing spondylitis. British Journal of Rheumatogy 1987; 26:40-2,

Burgess, R. In the Field: an introduction to field research. London: Allen and Unwin, 1984.

Burton, A.K, Tillotson, M, Main, C. J, Hollis, S. Psychosocial predictors of outcome in acute and sub-acute low back trouble. Spine 1995; 20:722-28.

Burton, HJ, Kline, S, Hargadon, R, Shick, R, Ong, M, Cooper, B. Chronic pain patients' quality of life improves with increased life control. The Pain Clinic 1998; 11(1): 33-42,

Calin, A, Porta, J, Fries, J, Schurmann, D. Clinical history as a screening test for ankylosing spondylitis. JAMA, 1977;237:2613-14

Calin, A, Edmunds, L, Kennedy, G. Fatigue in ankylosing spondylitis – why is it ignored? J Rheumatol, 1993;20:991-5

Calin, A, Garrett, S, Whitelock, H, Kennedy, G, O'Hea, J, Mallorie, P, Jenkinson, T. A New Approach to Defining Functional Ability in Ankylosing Spondylitis: The Development of the Bath Ankylosing Spondylitis Functional Index (BASFI). Journal of Rheumatology 1994: 21:2281-85.

Calin, A. Can we define the outcome of ankylosing spondylitis and the effect of physiotherapy management? Editorial. Journal of Rheumatology 1994: 21(2) 184-5

Calin, A. Ankylosing Spondylitis. In: Maddison, Isenberg, Woo and Glass, editors. Oxford Textbook of Rheumatology. 2nd Edition. Oxford Medical Publications. 1058-60, 1998.

Calin, A, Mackay, K, Santos, H, Brophy, S. A New Dimension to Outcome: Application of The Bath Ankylosing Spondylitis Radiology Index. Journal of Rheumatology 1999; 26:988-92.

Campbell, D.A., Yellowlees, P.M., McLennan, G, Coates, J.R, et al. Psychiatric and medical features of near fatal asthma. Thorax 1995; 50:254-9

Carette, S.Graham, D, Little, H, Rubenstein, J, Rosen, P. The natural disease course of ankylosing spondylitis. Arthritis Rheum, 1983; 26:186-90

Carr, E, Thomas, V, Wilson, B. Patient experiences of anxiety, depression and acute pain after surgery: a longitudinal perspective. International Journal of Nursing Studies, 2005;vol 42, no 5:521-30

Chenail, R. Questionnaire for an autobiographical portrait of a practicing therapist and researcher. The Qualitative Report 1996, vol. 2, (4)

Cieza, A, Stucki, G. Understanding functioning, disability and health in rheumatoid arthritis: the basis for rehabilitation care. Curr Opin Rheumatol, 2005;17:183-9

Coughlin, A M, Badura, A S, Fleischer, T D, Guck, T P. Multidisciplinary Treatment of Chronic Pain Patients: Its Efficacy in Changing Patient Locus of Control. Arch Phys Med Rehabil 2000; 81(6): 739-40

Covic, T, Adamson, B, Spencer, D, Howe, G. Biopsychosocial model of pain and depression in rheumatoid arthritis: a 12-month longitudinal study. Rheumatology 2003; 42:1287-94

Crawford, J, Henry, J, Crombie, C, Taylor, E. Normative data for the HADS from a large non-clinical sample. British Journal of Clinical Psychology, 2001, 40: 4, 429-34

Creswell, J, Plano Clark, V. Mixed Methods Research. 2007. Sage Publications.

Crisson, J E, Keefe, F.J. The relationship of locus of control to pain coping strategies and psychological distress in chronic pain. Pain. 1998; 35: 147-54

Crook, J, Milner, R, Schultz, I, Stringer, B. Determinants of occupational disability following a low back injury: A critical review of the literature. Journal of Occupational Rehabilitiation 2002 Vol 12. No. 4: 277-95

Crotty, M, McFarlaine, A, Brooks, P, Hopper, J, Bieri, D, Taylor, S. The psychosocial and clinical status of younger women with early rheumatoid arthritis: a longitudinal study of frequent measures. British Journal of Rheumatology, 1994; 33:754-60

Da Costa, D, Dritsa, M, Ring, A, Fitzcharles, M. Mental health status and leisure-time physical activity contribute to fatigue intensity in patients with spondyloarthropathy. Arthritis and Rheumatism (Arthritis Care and Research) 2004; 51: 1004-8

Dagfinrud, H, Hagen, K, Kvien, T K. Physiotherapy interventions for ankylosing spondylitis. The Cochrane Database of Systematic Reviews 2004, Issue 4. Art. No: CD002822. DOI: 10.1002/14651858.CD002822.pub2.

Dagfinrud, H, Kjeken, I, Mowinckel, P, Hagen, K, Kvien, T. Impact of functional impairment in ankylosing spondylitis: Impairment, activity limitation and participation restrictions. J Rheumatol 2005; 32:516-23

Daltroy, L H, Larson, M G, Roberts, W N, Liang, M H. A modification of the Health Assessment Questionnaire for Spondyloarthropathies. J Rheumatol 1990; 17:946-50

Davies, J, van der Heijde, D, Braun, J, Dougados, M, Cush, J, Clegg, D, Kivitz, A, Fleischmann, R, Inman, R, Tsuji, W. Recombinant Humam Tumor Necrosis Factor Receptor (Etanercept) for treating ankylosing spondylitis. A randomised controlled trial. Arthritis and Rheumatism; 2003;Vol. 48, No 11, 3230-3226

Davis, J. C, van der Heijde, D, Dougados, M, Woolley, J.M. Reductions in health-related quality of life in patients with ankylosing spondylitis and improvements with Etanercept therapy. Arthritis and Rheumatism (Arthritis Care and Research) 2005; 53:494-501

Dekkers, J, Geenen, R, Evers, A, Kraaimaat, F, Bijlsma, J, Godaert, G. Biopsychosocial mediators and moderators of stress-health relationships in patients with recently diagnosed rheumatoid arthritis. Arthritis and Rheumatism 2001; vol. 34, no. 4: 307-16

Denzin, N, Lincoln, Y. Handbook of qualitative research (2nd edition). Thousand Oaks, CA: Sage

Department of Health. Supporting People with Long Term Health Conditions. An NHS and Social Care Model to support local innovation and integration. Crown Copyright, 2005

Department of Health. The National Service Framework for Long-term Conditions. Crown Copyright, 2005

Department of Health. The Musculoskeletal Services Framework. A joint responsibility: doing it differently. Crown Copyright, 2006

Diggle P J, Liang K Y, Zeger S L. The analysis of longitudinal data. Oxford Science Publications; 1994.

Dixon, K E, Keefe, F J, Scipio, C D et al. Psychosocial interventions for arthritis pain management in adults : a meta-analysis. Health psychol, 2007 :26 :241-50

Doan, B, Wadden, N. Relationships between depressive symptoms and descriptions of chronic pain. Pain, 1989;vol. 36:75-84.

Doeglas, M, Suurmeijer, T, Krol, B, Sanderman, R, van Rijswijk, M, van Leeuwen, M. Social support and social disability and psychological well being in rheumatoid arthritis. Arthritis Care and Research, 1994; 7:10-15

Donald, A. What is quality of life? Hayward Medical Communications, 2003. Vol 1, No 9

Dougados, M, Gueguen, A, Nakache, J P, Nguyen, M, Amor, B. Evaluation of a functional index and an articular index in ankylosing spondylitis; J Rheumatol 1988; vol. 15: 302-7

Dougados, M, van der Linden, S, Juhlin, R, Amor, B, Calin, A, Cats, A, Dijkmans, B, Olivieri, I, Pasero, G, et al. The European Spondyloarthopathy Study Group pereliminary criteria for the classification of spondyloarthropathy. Arthritis and Rheumatism, 1991; 34 (10): 1228 - 27

Dougados, M, Dijkmans, B, Khan, M, Maksymowych, W, Van-der-Linden, S, Brandt, J. Conventional treatments for Ankylosing Spondylitis. Ann Rheum Dis 2002; 61 (suppl III): iii40-iii50

Doward, L.C., Spoorenberg, A, Cook, S.A. Development of the ASQoL: a quality of life instrument specific to ankylosing spondylitis. Ann Rheum Dis 2003; 62:20-6

Downe-Wamdoldt, B, Melanson, P. A causal model of coping and well-being in elderly people with arthritis. Journal of Advanced Nursing, 1995; 27:1109-16

Emery, C, Leatherman, N, Burker, E, MacIntyre, N. Psychological Outcomes of a Pulmonary Rehabilitation Program. Chest 1991; 100:613-6

Ettinger, W H, Davies, M A, Neuhaus, J M, Mallon, K P. Long-term physical functioning in persons with knee osteoarthritis from NHANES.1 :Effects of comorbid medical conditions. J Clin Epidemiol. 1994 Jul; 47(7): 719-30

Engel, G. The need for a New Medical Model: a Challenge for Biomedicine. Science, 1977: Vol 196, No 4286: 129 –136

Engel, G. The clinical application of the Biopsychosocial Model. Am J Psychiatry, 1980; 137: 535 - 544

Eyres, S, Tennant, A, Kay, L, Waxman, R, Helliwell, P. Measuring disability in Ankylosing Spondylitis: Comparison of Bath Ankylosing Spondylitis Functional index with Revised Leeds Disability Questionnaire. J Rheumatol 2002; 29:979-86

Falkenbach, A, Franke, A, van der Linden, S. Factors associated with body function and disability in patients with ankylosing spondylitis: a cross-sectional study. The Journal of Rheumatology, 2003; 30:10, 2186-92

Fisher, K, Johnston, M. Emotional distress and control cognitions as mediators of the impact of chronic pain on disability. British Journal of Health Psychology 1998; 3:225-36

Fossa, S, Dahl, A. Short Form 36 and the Hospital Anxiety and Depression Scale. A comparison based on patients with testicular cancer. Journal of Psychosomatic Research 52, 2002:79-87

French, S, Reynolds, F, Swain, J. Practical Research. A Guide for Therapists. Second Edition, 2001. Butterworth Heinemann.

Furnes, O, Lie, S, Espehaug, B, Vollset, S, Engesaeter, L, Havelin, L. Hip disease and the prognosis of total hip replacements. A review of 53,698 primary hip replacements reported to the Norwegian Arthroplasty Register 1987-99. J Bone Joint Surg Br 2001; 83:579-86

Gall, V. Exercise in the Spondyloarthropathies. Arthritis Care and Research 1994; 7:215-20,

Garrett, S, Jenkinson, T, Kennedy, G, Whitelock, H, Gaisford, P, Calin, A. A new approach to defining disease status in Ankylosing Sponylitis: The Bath Ankylosing

Sponylitis disease activity index (BASDAI). Journal of Rheumatology 1994; 21:2286-91

Gildenberg, P. Management in chronic pain. Appl Neurophysiol, 1984; 47:157-70

Goldberg, D. Identifying psychiatric illness among general medical patients. BMJ, 1985; 29:161-2

Goodson, N, Solomon, D. The cardiovascular manifestations of rheumatic diseases. Current Opinion in Rheumatology, 2006; 18:135-40

Gorman, J D, Sack, K E, Davis, J C. Treatment of Ankylosing Spondylitis by Inhibition of Tumor Necrosis Factor a. The New England Journal of Medicine 2002; 346, No 18:1349-56

Graham, J, Ramirez, A, Love, S, Richards, M, Burgess, C. Stressful life experiences and risk of relapse of breast cancer: observational cohort study. BMJ 2002; 324:1420-22

Gran, J T, Skomsvoll, J. The Outcome of Ankylosing Spondylitis: A Study of 100 Patients. British Journal of Rheumatology, 1997; 36:766-71

Granfors, K, Marker-Hermann, E, de Keyser, F, Khan, M, veys, E, Yu, D. the cutting edge of spondyloarthropathy in the millennium. Arthritis and rheumatism, 2002; vol 46, No 3: 606 – 13

Gray, D, Hendershot, G. The ICIDH-2: Developments for a new era of outcomes research. Arch Phy Med Rehabil, 2000; 81, suppl 2:S10-S14

Groarke, A, Curtis, R, Coughlan, R, Gsel, A. The role of perceived and actual disease status in adjustment to rheumatoid arthritis. Rheumatology 2004; 43(9): 1142:49

Gunther, V, Mur, E, Traweger, C, Hawel, R. Stress coping of patients with ankylosing spondylitis. Journal of Psychosomatic Research 1994 38/5:419-27

Guba, E, Lincoln, Y. Paradigmatic controversies, contradictions and emerging confluences. The Sage Handbook of qualitative research (3rd edition). Thousand Oaks, CA: Sage

Haibel, H, Brandt, H C, Rudwaleit, M, Listing, J, Braun, J, Kupper, H, Grozanovic, M, Sieper, J. Adalimumab reduces spinal symptoms in active ankylosing spondylitis: clinical and magnetic resonance imaging results of a fifty-two-week open-label trial. Arthritis and Rheumatism 2006 54, issue 2:678-81

Hammond, A, Lincoln, N, Sutcliffe, L. A crossover trial evaluating an educational-behavioral joint protection program for people with rheumatoid arthritis. Patient Educ Couns. 1999; 37:19-32

Harkapaa, K, Jarvikoski, A, Mellin, G, Hurri, H, Luoma, J. Health locus of control beliefs and psychological distress as predictors for treatment outcome in low-back patients: results of a 3 -month follow-up of a controlled intervention study. Pain 1991; 41:35-41,

Harkapaa, K, Jarvikoski, A, Vakkari, T. Associations of locus of control beliefs with pain coping strategies and other pain-related cognitions in back pain patients. British Journal of Health Psychology 1996; 1:51-63,

Harland, N, Lavallee, D. Biopsychosocial management of chronic low back pain patients with psychological assessment and management tools. Physiotherapy 2003; vol. 89 no 5: 305-12

Hasenbring, M, Marienfeld, G, Kuhlendahl, D, Soyka, D. Risk factors of chronicity in lumbar disc patients. Spine, 1994; Vol.19, No 4, 2795-65

Haythornthwaite, J, Sieber, W, Kerns, R. Depression and the chronic pain experience. Pain, 1991; 46: 177-84

Haywood, K, Garratt, A, Dziedzic, K. Dawes, P. Patient centered assessment of ankylosing spondylitis-specific health related quality of life: evaluation of the Patient Generated Index. The Journal of Rheumatology 2003; 30:764-73,

Haywood, K, Garratt, A, Jordan, K, Dziedzic, K, Dawes, P. Spinal mobility in ankylosing spondylitis: reliability, validity and responsiveness. Rheumatology, 2004; 43: 750-57

Haywood, K, Garratt, A, Dawes, P T. Patient-assessed health in ankylosing spondylitis: A structured review. Rheumatology, 2005; 44:577-86

Haslock, I. Ankylosing Spondylitis: Management. In: Klippel, J H, Dieppe,PA, editors. Rheumatology. 2nd ed. St. Louis: Mosby. 6. 190- 8; 1998.

Hazard, Munro, B. Statistical methods for health care research 4th edition. Lippincott Publishers (2001)

Helliwell, P, Abbott, C A, Chamberlain, M A. A randomised trial of three different physiotherapy regimes in ankylosing spondylitis. Physiotherapy, 1996, Vol 82, issue 2: 85-90

Heijmanns, H, Foets, M, de Ridder, M, Rijken, K, Schreurs, Bensing, J. Stress in chronic disease: Do the perceptions of patients and their general practitioners match? British Journal of Health Psychology 6:229-42, 2001.

Herrmann C. International experiences with the hospital anxiety and depression scale - a review of validation data and clinical results. J Psychosom Res 1997; 42:17-41.

Heuft-Dorenbosch, E, Vosse, D, Landewe, R, Spoorenberg, A, Dougados, M, Meilants, H, Van der Temple, H, Van-der-Linden, S, van der Heijde, D. Measurement of spinal mobility in Ankylosing Spondylitis: Comparison of occiput to wall and tragus to wall distance. J Rheumatol 2004; 31: 1779-84

Hewlett, S, Cockshott, Z, Byron, M, Kitchen, K, Tipler, S, Pope, D, Hehir, M. Patient's perceptions of fatigue in rheumatoid arthritis: Overwhelming, uncontrollable, ignored. Arthritis Care and Research 2005; Vol 53: 5:697- 702

Hicks, C. Research Methods for Clinical Therapists. Applied project design and analysis. Fourth Edition. 2004. Churchill Livingstone.

Hider, S, Wong, M, Ortiz, M Dulku, A, Mulherin, D. Does a regular exercise program for ankylosing spondylitis influence body image? Scandinavian J Rheumatol, 2002; 31:168-71

Hidding, A, van der Linden, S, de Witte, L. Therapeutic effects of individual physical therapy in ankylosing spondylitis related to duration of disease. Clinical Rheumatology, 1993; 12 (3): 334-40

Hidding, A, de Witt, L, van der Linden, S. Determinants of self-reported health status in AS. J Rheumatol, 1994; 21:275-8

Hidding, A, van-der-Linden, S, Gielen, X, De-Witte, L, Dijkmans, B, Moolenburgh, D. Continuation of group physical therapy is necessary in ankylosing spondylitis. Arthritis care and research 1994; 7:90-6

Hidding, A. van-der-Linden, S. Factors Related to Change in Global Health after Group Physical Therapy in Ankylosing Spondylitis. Clinical Rheumatology 1995; 14(3): 347-51

Heikkila, S, Viitanen, J, Kautiainen, H, Kauppi, M. Functional long-term changes in patients with spondyloarthropathy. Clin Rheumatol 2002; 21:119-22

Hopwood, P, Stephens, R. Depression in patients with lung cancer: Prevalence and risk factors derived from quality of life data. Journal of Clinical Oncology, 2000;18: 4: 839

Horn, S. Munafo, M. Pain: theory, research, intervention. Open University Press. 1997.

Hurley, D, Dusoir, T, McDonough, S, Moore, A, Linton, S, Baxter, G. Biopsychosocial screening questionnaire for patients with low back pain: preliminary report of utility in physiotherapy practice in Northern Ireland. Clin J Pain 2000 16(3): 214-28

Hunt, M, Birmingham, T, Skarakis, E, Vandervoort, A. Towards a biopsychosocial framework of osteoarthritis of the knee. Disability and Rehabilitation, 2008; 30(1): 54:61

Huynh H, Feldt, L S. Estimation of the Box correction for degrees of freedom from sample data in randomized block and split-plot designs. Journal of Educational Statistics 1976; 1:69-82.

Huyse, F Y, Lyons, F S, Stiefel, F C, Slaets, J P, de Jonge, P, Fink, P. "INTERMED": a method to assess health service needs. Development and first results on it's reliability. General Hospital Psychiatry, 1999, Vol 21, 39-48

Jaeschke, R, Singer, J, Guyatt, G. Measurement of health status. Ascertaining the minimally clinically important difference. Controlled Clinical Trails, 1989; 10: 407-15

James and Hardardottir, Influence of attention focus and trait anxiety of tolerance of acute pain. British Journal of Health Psychology, 2002; 7, 149-62

Jellema, P, van der Windt, D, van der Horst, H, Twisk, J, Stalman, W, Bouter, L. Should treatment of (sub) acute low back pain be aimed at psychosocial prognostic factors? Cluster randomized clinical trial in general practice. BMJ 2005; 331:87-7

Jenkinson, C, Layte, R, Wright, L, Coulter, A. The U.K. SF-36: An analysis and interpretation manual. Health Services Research Unit, March 1996.

Jenkinson, T. R. Mallorie, P.A. Whitelock, H. Kennedy, G. Garrett, S.L. Calin, A. Defining Spinal mobility in Ankylosing Spondylitis: The Bath Ankylosing Spondylitis Metrology Index. Journal of Rheumatology 1994; 21:1694-98,

Jimenez-Balderas, F. J, Mintz, G. Ankylosing Spondylitis: Clinical course in women and men. J.Rheumatol, 1993; 20:2069-72

Johnston, M. Marteau, T. Partridge, C. Gilbert, P. Changes in patient perceptions of chronic disease and disability with time and experience. In: L. R. Schmidt et al (Eds) Theoretical and Applied Aspects of Health Psychology. Glasgow: Harwood Academic Publishers:1990; 361-71,

Jones, S, Steiner, A, Garratt, A, Calin, A. The Bath Ankylosing Spondylitis Patient Global Score (BAS-G). British Journal of Rheumatogy 1996; 35:66-71

Jones, S, Calin, C, Steiner, A. An update on the Bath Ankylosing Spondylitis Disease Activity and Functional Indices (BASDAI, BASFI): Excellent Chronbach's Alpha Scores. J. Rheumatol, 1996; Feb (23) (2) 407

Jones, S, Koh, W, Steiner, A, Garrett, S, Calin, A. fatigue in ankylosing spondylitis: Its prevalence and relationship to disease activity, sleep and other factors. J rheumatol, 1996; 23:487-90

Karatay, S, Melikoglu, M, Senel, K. The relationship between functional disability and depression in patients with rheumatoid arthritis and ankylosing spondylitis. Pain clinic 2004; 16: no4, 457-6

Karjalainen, J, Malmivaara, A, van Tulder, M, Roine, R, Jauhiainen, M, Hurri, H, Koes, B. Multidisciplinary biopsychosocial rehabilitiation for sub-acute low-back pain among working age adults. A Systematic Review Within the Framework of the Cochrane Collaboration Back Review Group. Cochrane Collaboration Review Spine. 26(3): 262-269, February 1, 2001

Keat, A, Barkham, N, Gaffney, K, Marzo-Ortega, H, et al. BSR Guidelines for prescribing TNFα blockers for adults with ankylosing spondylitis. Report of a working party of the British Society of Rheumatology. Rheumatology 2005; 44:939-47

Keele, K. D. The Pain Chart. The Lancet 1948; vol. 2:6-8

Keefe, F, Buffington, A, Studts, J, Smith, S, Gibson, J, Caldwell, D. Recent advances and future directions in the biopsychosocial assessment and treatment of arthritis. Journal of Consulting and Clinical Psychology, 2002:70, 3, 640-55

Kennedy, L.G, Edmunds, L, Calin, A. The natural history of ankylosing spondylitis. Does it burn out? J Rheumatol 1993; 20:688-92

Kerns, R. D. Turk, D.K. Rudy, T.E. The West Haven-Yale Multidimensional Pain Inventory (WHYMPI). Pain 1987; 23:345-56,

Khan, M. A. Medical and surgical treatment of seronegative spondyloarthropathy. Current Opinion in Rheumatology, 1990; 2: 592-99

Khan, M. A. Ankylosing Spondylitis: Clinical Features. In: Klippel, J H, Dieppe,PA, editors. Rheumatology. 2nd ed. St. Louis: Mosby. 6.16.1-5, 1998

Khan, M. A. Ball, E. J. Genetic aspects of ankylosing spondylitis. Best Pract Res Clin Rheumatol 2002; 16:675-90

Kidd, B, Mullee, M, Frank, A, Cawley, M. Disease expression of ankylosing spondylitis in males and females. The Journal of Rheumatology, 1988: 15: 1470-09

Koch, N, Stiefel, F, de-Jonge, P, Fransen, J, Chamot, A, Gerster, J, Huyse, F, So, A. Identification of case complexity and increased health care utilization in patients with rheumatoid arthritis. Arthritis and Rheumatism 2001;45:3: 216-21

Koopman, W.J. Arthritis and Allied Conditions. A Textbook of Rheumatology.13th Edition. Williams and Wilkins. 1997.

Kraag, G, Stokes, B, Groh, J, Helewa, A, Goldsmith, C. The effects of comprehensive home physiotherapy and supervision on patients with ankylosing spondylitis – a randomised controlled trial. Journal of Rheumatology, 1990; 17(2): 228-33

Kulkarni, A, Balkrishnan, R, Camacho, F, Anderson, R, Feldman, S. Medication and health care service utilisation related to depressive symptoms in older adults with psoriasis. J Drugs Dermatol 2004; 3(6): 661-66

Law, M, Baptiste, S, Carswell, A, McColl, M A, Polatajko, H, Pollock, N. Canadian Occupational Performance Measure (manual). 3rd edition. Hamilton, ON: CAOT Publications ACE; 1998

Lawlor, M. Gazing Anew: The shift from a clinical gaze to an Ethnographic lens. American Journal of Occupational Therapy 2003, 57, 29-39

Leventhal, H, Diefenbach, M. Illness Cognition: Using common sense to understand treatment adherence and affect cognition interactions. Cognitive Therapy and Research 1992; 16:143-63

Liang, M H, Lew, R A, Stucki, G, Fortin, P R, Daltroy, L. Measuring clinically important changes in-patient orientated questionnaires. Med Care 2002; 40 (suppl):II45-51

Lorig, K, Chastain, R, Ung, E, Shoor, S, Holman, H. Development and evaluation of a scale to measure perceived self efficacy in people with arthritis. Arthritis Rheum, 1989; 32:37-44

Lorig, K, Sobel, D, Stewart, A, Brown, B, Bandura, A, Ritter, P, Gonzalez, V, Laurent, D, Holman, H. Evidence suggesting that a chronic disease self management program can improve health status whilst reducing hospitalization. A randomised trial. Medical Care, 1999; 37, 5-14

Mackay, K. Mack, C. Brophy, S. Calin, A. The Bath Ankylosing Spondylitis Radiology Index: a new validated approach to disease assessment. Arthritis and Rheumatism 1998; 41:2263-70,

Macleod, L, Macleod, G. Control cognitions and psychological disturbance in people with physically disabling conditions. Disability and Rehabilitation 1998; 20:448-56

Mader, R. Atypical clinical presentation of ankylosing spondylitis. Semin Arthritis Rheum, 1999; 29:191-6

Mander, M, Simpson, JM, McLellan, A, Walker, D, Goodacre, JA, Carson Dick W. Studies with an enthesis index as a method of clinical assessment in ankylosing spondylitis. Ann Rheum Dis 1987; 46:197-202

Manne, S, Zautra, A. Couples coping with chronic illness: women and rheumatoid arthritis and their healthy husbands. Journal of behavioural Medivcine, 1990; 13:327-42

Main, C. Commentary: Early psychosocial interventions for low back pain in primary care. BMJ 2005; 331:88

Maksymowych, W, Jhangri, G, Lambert, R, Mallon, C, Buenvaije, H, Pedrycz, E, Luongo, R, Russell, A. Infliximab in Ankylosing spondylitis: A Prospective Observational Inception Cohort Analysis of Efficacy and Safety. The Journal of Rheumatology, 2002; 29:959-65

Maksymowych, W, Mallon, C, Richardson, R, Conner-Spady, Jauregui, E, Chung, C, Zappala, L, Pile, K, Russesll, A. Development and validation of the Edmonton Ankylosing Spondylitis Metrology Index. Arthritis and Rheumatism (Arthritis Care and Research), 2006; 55, 4: 575-82

Martindale, J, Smith, J, Sutton, C, Grennan, D, Goodacre, L, Goodacre, J. Disease and psychological status in ankylosing spondylitis. Rheumatology 2006; 45:1288-93

Mays, N, Pope, C. Qualitative research in health care. Assessing quality in qualitative research. BMJ 2000; 320, 50-52

McCracken, L, Spertus, I, L, Janeck, A, S, Sinclair, D, Wetzel, T, Behavioral dimensions of adjustment in persons with chronic pain: pain-related anxiety and acceptance. Pain 1999; 80:283-89

McCracken, L, Eccleston, C. Coping or acceptance: what to do about chronic pain. Pain, 2003; 105, 197-204

McCracken, L, Gauntlett-Gilbert, J, Vowles, K. The role of mindfulness in a contextual cognitive-behavioral analysis of chronic pain-related suffering and disability. Pain, 2007: 131: 63-9

Medical Research Council. A framework for the development and evaluation of RCTs for complex interventions to improve health; 2000

Melzack, R. The McGill Pain questionnaire: major properties and scoring methods. Pain. 1975; 1:277-99

Melzack, R. The puzzle of pain. 1979. New York, Basic Books.

Melzack, R. and Wall, P. D. The Challenge of pain. 1982. New York, Basic Books.

Melzack,R. The Short-Form McGill Pain Questionnaire. Pain, 1987; 30:191-7

Mielants, H, Veys, E, Joos, R, Noens, L, Cuvelier, C, De vos, M. HLA antigens in sero-negative spondyloarthropathies. Reactive arthritis and arthritis in ankylosing spondylitis: relation to gut inflammation. J Rheumatol, 1987; 14:466-71

Mielants, H, Veys, E, Cuvelier, C, De Vos, M. S. Course of gut inflammation in spondyloarthopathies and therapeutic consequences. Ballieres Clin Rheumal, 1996; 10:147-64

Miller, F, Rosenstein, D, DeRenzo, E. Professional integrity in clinical research. JAMA, 1998; 280:1449-54

Moncur, C. Patient Outcomes in Rheumatology. A review of measures. Arthritis and Rheumatism 2003, 49, No 5 (supplement).

Morone, N, Greco, C, Weiner, D. Meditation for the treatment of chronic low back pain in older adults: A randomized controlled pilot study. Pain (2007) doi:10.1016/j.pain

Morse, J. Approaches to qualitative-quantitative methodological triangulation. Nursing Research, 1991; 40, 120-23

Murray and McMillan, Health belief, locus of control, emotional control and woman's cancer screening behaviour. British Journal of Clinical Psychology 1993, 32:87-100

Narsavage, G, Weaver, T. Physiologic status, Coping and Hardiness As Predictors of Outcomes in Chronic Obstructive Airways Disease. Nursing Research 1994; 43:90-4

NICE technology appraisal guidance No. 143, May 2008

Ogden, J. Health Psychology: A textbook. 2000. Buckingham, Open University Press.

Ogden, J. Health Psychology. A textbook. 3rd edition 2004, Open University Press

Oniankitan, O, Ranaivo, N, Carton, L, Chevalier, X, Claudepierre, P. Poorly and well controlled sponyloarthropathies: A comparison of 2 groups of patients. J Rheumatol 2005; 32:77-9

Packman, J C, Bowness, P. Seronegative Spondyloarthropathies. Rheumatic Disease Topical Reviews; Jan 2001, Number 4.

Parker, S, Smarr, K, Walker, J, Hagglund, K, Anderson, S, Hewett, J, Bridges, A, Caldwell, C. Biopsychosocial parameters of disease activity in rheumatoid arthritis. Arthritis Care and Research 1991; vol. 4. No. 2: 73-80

Pavy, S, Brophy, S, Calin, A. Establishment of the minimum clinically important difference for the Bath Ankylosing Spondylitis Indicies: A prospective study. J. Rheumatol 2005; 32: 80-5

Pearlin, L I, Schooler, I. The structure of coping. J Health Soc Behav, 1981; 19:2-21

Pellegrino, E. Beneficence, scientific autonomy and self interest: ethical dilemmas in clinical research. Crambridge Quarterly of Healthcare Ethics, 1992; 4:361-69

Phares, E. Locus of Control in Personality. 1976. Morristown, NJ: General Learning Press

Picavet, S. Vlaeyen, J. Schouten, J. Pain Catastrophizing and Kinesiophobia: Predictors of Chronic Low Back Pain. American Journal of Epidemiology 156:1028-34, 2002.

Pincus, T, Callahan, L, Bradley, L, Vaughn, W, wolfe, F. Elevateed MMPI scores for hypochondriasis, depression, and hysteria in patients with rheumatoid arthritis reflect disease rather than psychological status. Arthritis and rheumatism, 1986; 29:1456-66

Pincus, T, Burton, K, Vogel, S. Field, A. A Systemic Review of Psychological Factors as Predictors of Chronicity/Disability in Prospective Cohorts of Low Back Pain. Spine 2002; 27:109-120

Pope, C, Ziebland, S, Mays, N. Qualitative Research in Health Care. Analysing qualitative data. BMJ 2000; 320, 114-116

Pradeep, D, Keat, A, Gaffney, K. Predicting outcome in ankylosing spondylitis. Rheumatology, 2008; 47:942-945

Radloff, L S. The CES-D scale: A self-report depression scale for research in general population. Appl Psychol Meas, 1977; 1: 385- 401

Rhee, S H, Parker, J, Smarr, K, Petroski, G, Johnson, J, Hewett, J, Wright, G, Multon, K, Walker, S. Stress Management in Rheumatoid Arthritis: What Is the Underlying Mechanism? Arthritis Care and Research 2000; 13:435-42

Richards, H, Fortune, D, Chong, S, Mason, D, Sweeney, S, Main, C, Griffiths, C. Divergent beliefs about psoriasis are associated with increased psychological distress. J Invest Dermatol 2004; 123:49-56

Ries, A, L, Kaplan, R M, Limberg, T M, Prewitt, L M. Effects of Pulmonary Rehabilitation on Physiologic and Psychosocial Outcomes in Patients with Chronic Obstructive Pulmonary Disease. Annals of Internal Medicine 1995; 122:823-32

Ritchie, J, Lewis, J. Qualitative Research Practice. Sage, 2003

Robson, C. Real World Research - A resource for social scientists and practitioner-researchers. Blackwells Publishers, 1999

Roberts, L. Chapman, J. Sheldon, F. Perceptions of control in people with acute low back pain. Physiotherapy 2002; 88, No 9:543-52,

Robertson, L P, Davies, M J. A longitudinal study of disease activity and functional status in a hospital cohort of patients with ankylosing spondylitis. Rheumatology, 2004; 43:1565-68

Roscam, S. Application of health locus of control typology approach toward predicting depression and medical adherence in rheumatoid arthritis. Unpublished doctorial dissertation, Vanderbilt University, Nashville, T.N. cited in Barlow, 2003.

Rotter, J. B. Generalised expectations for internal versus external control of reinforcement. Psychological Monographs. 1966: 80:609

Rouf, J, Stucki, G. Validity aspects of erythrocyte sedimentation rate and C-reactive protein in ankylosing spondylitis: a literature review. Journal of Rheumatology 1999; 26:966-70,

Roussou, E, Kennedy, G, Garret, S, Calin, A. Socioeconomic status in Ankylosing spondylitis: Relationship between occupation and disease activity. The Journal of Rheumatology 1997; 24: 908-11

Ruben, H., Rubin, I. Qualitative interviewing. The Art of Hearing Data. Thousand Oaks Sage Publications, 1995.

Rudwaleit, M, van der Heijde, D, Khan, M, Braun, J, Sieper, J. How to diagnose axial spondyloarthritis early. Ann Rheum Dis 2004; 63:535-43

Rudwaleit, M, Khan, M, Sieper, J. The Challenge and classification in early AS. Arthritis and Rheumatism, 2005; 52: 4:1000-08

Rudwaleit, M, Metter, A, Listing, J, Sieper, J, Braun, J. Inflammatory Back Pain in ankylosing spondylitis. A reassessment of the clinical history for the application as classification and diagnostic criteria. Arthritis Rheum, 2006; 54:569-78

Ruof, J, Sangha, O. Stucki, G. Comparative Responsiveness of Three Functional Indices in Ankylosing Spondylitis. Journal of Rheumatology 1999; 26:1959-63

Russell, P. Unsworth, A. Haslock, I. The effect of exercise on ankylosing spondylitis - a preliminary study. British Journal of Rheumatology 1993; 32:498-506

Sandelowski, M. Focus on research methods. Combining qualitative and qualitative sampling, data collection, and analysis techniques in mixed-method studies. Research in Nursing and Health, 2000, 23, 246-55

Sarafino, E. Health Psychology. Biopsychosocial Interactions, 5th Edition. 2006. John Wiley and Sons

Schoenfeld-Smith, K, Petroski, G, Hewett, J, Johnson, J, Wright, G, Smarr, K, Walker, S, Parker, J. A biopsychosocial model of disability in rheumatoid arthritis. Arthritis Care and Research 1996; 9:5:368-75

Sharpe, L, Sensky, T, Timberlake, N, Ryan, B, Allard, S. Long-term efficacy of a cognitive behavioural treatment from a randomized controlled trial for patients recently diagnosed with rheumatoid arthritis. Rheumatology 2003; 42: 435-41

Sherer, M, Maddux, J, Mercandante, B, Prentice-Dunn, S, Jacobs, B; Rogers, R. The Self-Efficacy Scale: Construction and validation. Psychol Rep 1982; 52:663-71

Sieper, J. Braun, J. Boonen, A. Zink, A. Ankylosing Spondylitis: an overview. Ann Rheum Dis 61(sup III): iii8-iii18, 2002.

Sieper, J, Rudwaleit, M. Early referral recommendations for ankylsoing spondylitis (including pre-radiographic and radiographic forms) in primary care. Ann Rheum Dis 2005; 64:659-63

Sigl, T, Cieza, A, van der Heijde, D, Stucki, G. ICF based comparison of disease specific instruments measuring physical functional ability in ankylosing spondylitis. Ann Rheum Dis, 2005; 64:1576-81

Silverstone, P. Poor efficacy of the Hospital anxiety and Depression scale in the diagnosis of major depressive disorder in both medical and psychiatric patients. J Psychosomatic Res, 1994; 441-50

Sirmali, M, Ozcakar, L, Findil, G, Kaya, S. Ankylosing Spondylitis: A perturbing psychosocial concern? Rheumatol Int 2003: 23; 324-5

Skevington, S. Psychology of Pain. Chichester: John Wiley and Sons. 1995.

Skevington, S. Health Psychology. Blackwell Publishing. 2004

Smith, R. Changes in locus of control as a function of life crisis resolution. Journal of Abnormal Psychology, 1970; 75(3): 328- 32

Smith, D, McMurray, N, Disler, P. Early intervention for acute back injury: can we finally develop an evidence-based approach? Clinical Rehabilitation 2002; 16: 1-11

Spielberger, C D. Manual for the State-Trait Anxiety Inventory (Form V). Consulting Psychologists Press, Palo Alto (CA) 1983

Sochart, D, Porter, M. Long-term results of total hip replacement in young patients who had ankylosing spondylitis. J Bone Joint Surg Am 1997; 79:1181-9

Spoorenberg, A, van der Heijde, D, de Klerk, E, Dougados, M, de Vlam, K, Meilants, H. Relative value of erythrocyte sedimentation rate and C-reactive protein in assessment of disease activity in ankylosing spondylitis. Journal of Rheumatology 1999; 26:980-4

Spoorenberg, A, de Vlam, K, van-der-Linden, S, Dougados, M, Meilants, H, van de Temple, H, van der Heijde, D. Radiological scoring methods in ankylosing Spondylitis. Reliability and change over 1 and 2 years. The Journal of Rheumatology 2004; 31:125-31

Streiner, D, Norman, G. Health Measurement Scales. A Practical guide to their development and use. 2nd Edition. 1995 Oxford Medical Publications

Stucki G, Boonen A, Tugwell P, Cieza A, Boers M. The World Health Organisation International Classification of Functioning, Disability and Health: A Conceptual Model and interface for the OMERACT Process. J.Rheumatol, 2007; 34(3):600-6

Sundstrom, B, Ekergard, H, Sundelin, G. Exercise habits among patients with ankylosing spondylitis. Scand J Rheumatol 2002; 31:163-7

Sweeney, S, Gupta, R, Taylor, G, Calin, A. Total hip arthroplasty in ankylosing spondylitis: Outcome in 340 patients. The Journal of Rheumatology, 2001; 28:1862-6

Sweeney, S, Taylor, G, Calin, A. The effect of a home based exercise intervention package on outcome in ankylosing spondylitis: a randomised controlled trial. J. Rheumatology 29:763-6, 2002.

Tattersall, R. The expert patient: a new approach to chronic management for the twenty-first century. Clinical Medicine: Vol 2 No 3 May/June 2002.

Taylor, H. G, Wardle, T, Beswick, E.J, Dawes, P.T. The relationship of clinical and laboratory measurements to radiological change in ankylosing spondylitis. British Journal of Rheumatology 1991; 30:330-5

Taylor, A, Balakrishnan, C, Calin, A. Reference Centile Charts for Measures of Disease Activity, Functional Impairment, and Metrology in Ankylosing Spondylitis. Arthritis and Rheumatism 1998; 41: 1119-25

Tomlinson, M. Barefoot, J. Dixon, A. Intensive in-patient physiotherapy courses improve movement and posture in ankylosing spondylitis. Physiotherapy 1986; 75:238-40

Treharne, GJ, Hale, ED, et al. Cardiovascular disease and psychological morbidity amoung rheumatoid arthritis patients. Rheumatology 2005; 44:241-46

Truchon, M, Fillion, L. Biopsychosocial determinants of chronic disability and low-back pain: A review. Journal of Occupational Rehabilitation 2000; 10:No.2, 117-42

Tugwell P, Boers M. OMERACT Conference on Outcome Measures in RA Clinical Trials: Introduction. J Rheumatol. 1993;20:528–530

Unruh, A. M. Gender variations in clinical pain. Pain 1996; 65:123-67.

van der Heijde, A, Jocobs, J, van Albada-Kuipers, G, Kraaimaat, F, Geenen, R, Bijlsma, J. Physical disability and psychological well being in recent onset rheumatoid arthritis. J Rheumatol 1994; 21:28-32

van der Heijde, D, Bellamy, N, Calin, A, Dougados, M, Khan, M. A, van-der-Linden, S. Preliminary Core Sets for Endpoints in Ankylosing Spondylitis. Journal of Rheumatology 1997; 24:2225-9

van der Heijde, D, Calin, A, Dougados, M, Khan, M. A, van-der-Linden, S, Bellamy, N. Selection of Instruments in the Core Set for DC-ART, SMARD, Physical Therapy, and Clinical Record Keeping in Ankylosing Spondylitis. Progress Report of the ASAS Working Group. Journal of Rheumatology 1999; 26:951-4

van der Heijde, D, Braun, J, McGonagle, D, Siegel, J. Treatment trials in ankylosing spondylitis: current and future considerations. Ann Rheum Dis 2002 ; 61(suppl III):iii24-iii32

Van der Heijde, D, Boonen, A. Development of the ICF core sets for ankylosing spondylitis.2007:http://www.icf.research-branch.org/research/ankylosing spondylitis%20spondylitis.htm

van der Linden, S. Ankylosing Spondylitis. In: Kelly, Harris, Ruddy, Sledge, Editors. Textbook of Rheumatology. 5th Edition, vol 2. W.B. Saunders Company: 969-82, 1981.

van der Linden S, Valkenburg HA, Cats A. Evaluation of diagnosis criteria for ankylosing spondylitis. A proposal for modification of the New York criteria. Arthritis Rheum 1984; 27:361-8.

van Tubergren, A, Landewe, R.van der HD, Hidding, A, Wolter, N, Asscher, M et al. Combined spa-exercise therapy is effective in patients with ankylosing spondyltis: a randomised controlled trial. Arthritis and Rheumatism, 2001; 45(5): 430-8.

van Tubergren, A, Boonen, A, Landewe, R, Van der Heijde, D, Hidding, A, van der Linden, S. Cost effectiveness of combined spa-exercise therapy in ankylosing spondylitis: a randomised controlled trial. Arthritis and Rheumatism (Arthritis Care and Research) 2002; 47, No. 5: 459-67

van Tubergren, A, Coenen, J, Landewe, R, Spoorenberg, A, Chorus, A, Boonen, A. Assessment of fatigue in patients with ankylosing spondylitis: a psychometric analysis. Arthritis and Rheumatism 2002; 47:8-16

VanDyke, M, Parker, J, Smarr, K, Hewett, J, Johnson, G, Slaughter, J, Walker, S. Anxiety in Rheumatoid Arthritis. Arthritis and Rheumatism 2003; 49:221-27

Viitanen, J, Suni, J, Kautiainen, H, Liimatainen, M, Takala, H. Effect of physiotherapy on spinal mobility in ankylosing spondylitis. Scand J Rheumatol 1992; 21:38-41

Visvanathan, S, Wagner, C, Marini, J, et al. Inflammatory biomarkers, disease activity, and spinal disease measures in patients with ankylosing spondylitis after treatment with infliximab. Ann Rheum Dis, 2008; 67:511-7

Wallston, KA, Wallston, BS, DeVellis, R. Development of the multi-dimensional health locus of control scales. Health Educ Monogr: 1978; 6:160-70

Wallston, K A, Stein, M. J, Smith, C. A. Form C of the MHLC Scales: A condition-specific measure of locus of control. Journal of Personality Assessment 1994; 63(3): 534-53,

Wand, B, Bird, C, McAuley, J, Dore, C, Mac-Dowell, De-Souza, L. Early intervention for the management of acute low back pain: a single-blind randomised controlled trial of biopsychosocial education, manual therapy and exercise. Spine 2004; 29(21); 2350-6

Wanders, A, Van der Heijde, D, Landewe, R, Behier, J.M, Calon, A, Olivieri, I, Zieller, H, Dougados, M. Nonsteroidal Anti-inflammatory drugs reduce radiographic progression in patients with ankylosing spondylitis. Arthritis Rheum 2005; 52:1756-65

Ward, M, Kuzis, S. Validity and Sensitivity to Change of Spondylitis - Specific Measures of Functional Disability. J Rheumatol, 1999; 26: 121-7

Ward, M. Health-related quality of life in ankylosing spondylitis: A survey of 175 patients. Arthritis Care and Research,1999;12: 247-55

Ward, M, Marx, A, Barry, N. Psychological distress and changes in the activity of Systemic Lupus Erythematous. Rheumatology 2002; 41:184-88

Ward, M. Outcome measurement: Health status and quality of life. Current Opinion in Rheumatology 2004; 16:96-101,

Ward, M, Weisman, M.H, Davis, J.C, Reveille, J. Risk factors for functional limitations in patients with long-standing ankylosing spondylitis. Arthritis and Rheumatism (Arthritis Care and Research) 2005;52:710-17

Ware, J. E, Sherbourne, C. D. The MOS 36-item Short Form Health Survey (SF36). Medical Care 1992; 30:473-81,

Ware, J, Jr. SF-36 Health Survey Update. Spine, 2000; 25 (24): 3130-39

Weiner, B. 'On being sane in insane places' a process (attributional) analysis and critique. Journal of Abnormal Psychology, 1975; 84:433-41

Wells, H, Pincus, T, McWilliams, E. Information processing biases among chronic pain patients and ankylosing spondylitis patients: the impact of diagnosis. European Journal of Pain 2003; 7: 105-11

Willoughby, S, Hailey, B, Mulkana, S, Rowe, J. The effect of laboratory induced depressed mood state on responses to pain. Behav Med 2002; 28:23-31

World Health Organisation (WHO). Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

World Health Organisation (WHO), 1986. The Ottawa Charter for Health Promotion, Ottawa.

World Health Organisation (1980) ICIDH: International Classification of Impairment, Disabilities and Handicaps. World Health Organisation, Geneva.

World Health Organisation (1997) ICIDH: International Classification of Impairments, Activities and Participation. A Manual of dimensions of disablement and functioning, ICIDH-2, Beta 1 draft for field trials. World Health Organisation, Geneva.

World Health Organisation (2001) ICIDH: International Classification of Functioning, Disability and Health. World Health Organisation, Geneva.

Will, R, Edmunds, L, elswood, J, Calin, A. Is there sexual equality in ankylosing spondylitis? A study of 498 women and 1202 men. The Journal of Rheumatology, 1990; 17: 1649-52

Williams, L, Jacka, F, Pasco, J, Dodd, S, Berk, M. Depression and Pain: an overview. Acta Neuropsychiatrica. 2006: 18: 79-87

Wright, R J, Rodriguez, M, Cohen, S. Review of psychological stress and asthma: An integrated biopsychosocial approach. Thorax 1998; 53:1066-74

Yanos, P, Ziedonis, D. The patient-orientated clinical-researcher: Advantages and challenges of being a double agent. Psychiatr Serv 2006, 57: 249-53

Zigmond, A. S, Snaith, R. P. The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, 1983; 67:361-70

Zink, A, Braun, J, Listing, J, Wollenhaupt, J. Disability in rheumatoid arthritis and ankylosing spondylitis – results from the German Rheumatological Database. J Rheumatol 2000; 27:613-22

Zink, A, Thiele, K, Schneider, M, et al. Healthcare and burden of disease in psoriatic arthritis. A comparison with rheumatoid arthritis and ankylosing spondylitis. J Rheumatol 2006; 33: 86-90

Zochling, J, Van der Heijde, D, Burgos-Vargas, R, Collantes, E, Davis, J, Braun, J, et al. ASAS/EULAR recommendations for the management of ankylosing spondylitis. Ann Rheum Dis, 2006; 65:442-452

APPENDICES

CONTENTS OF APPENDICES

ROUTINE SEARCH TERMS

1

1. Ankylosing Spondylitis
2. Spondyloarthropathy
3. BASDAI
4. BASFI
5. BASMI
6. Psychological status
7. Anxiety
8. Depression
9. Physiotherapy
10. Physical therapy
11. Exercise
12. Treatment

Combined searches included:

1 and 6
2 and 6
1 and 7
2 and 7
1 and 8
2 and 8

Search Term	DATABASE									
	AMED		CINAHL		EMBASE		MEDLINE		PsycINFO	
	No restriction	Limited by language	No restriction	Limited by language	No restriction	Limited by language	No restriction	Limited by language	No restriction	Limited by language
(1) Ankylosing spondylitis	175	162	452	0	5339	4276	6980	5567	49	38
(2) Spondyloarthropathy	11	10	70	0	901	806	993	902	0	0
(3) BASDAI	21	19	32	0	232	205	272	247	3	2
(4) BASFI	21	19	27	0	167	148	199	175	4	4
(5) BASMI	9	7	7	0	60	53	70	62	0	0
(6) Psychological status	407	389	2007	0	6992	6004	8410	7251	10556	9490
(7) Anxiety	2438	2332	13157	0	59383	51465	72407	64261	91333	81196
(8) Depression	3689	3520	22437	0	127625	112994	154864	138278	112638	102235
(9) Physiotherapy	3194	2717	4616	0	7331	5216	7601	5124	600	539
(10) Physical therapy	3706	3416	8498	0	22170	17492	25583	20189	6077	5513
(11) Exercise	10134	9756	26422	0	103796	92674	130863	115280	18984	17988
(12) Treatment	30061	27434	148972	0	1640261	1369260	2156046	1702733	285740	261731

Combined Search Term	DATABASE									
	AMED		CINAHL		EMBASE		MEDLINE		PsycINFO	
	No restriction	Limited by language	No restriction	Limited by language	No restriction	Limited by language	No restriction	Limited by language	No restriction	Limited by language
(1)Ankylosing spondylitis and (6) psychological status	1	1	2	0	6	5	4	4	3	2
(1)Ankylosing spondylitis and anxiety (7)	0	0	3	0	15	9	14	8	7	3
(1)Ankylosing spondylitis and depression (8)	6	5	5	0	38	28	35	29	10	5
Spondyloarthropathy (2) and psychological status (6)	0	0	0	0	0	0	0	0	0	0
Spondyloarthropathy (2) and anxiety (7)	0	0	0	0	0	0	1	0	0	0
Spondyloarthropathy (2) and depression (8)	0	0	0	0	2	2	2	2	0	0

2a

1. Patient invitation letter

Dear

I have included this letter along with your next appointment card to invite you to take part in a research project designed to study the long term effects of Ankylosing Spondylitis.

I am currently undertaking a research degree at the University of Central Lancashire. I have been extremely interested in Ankylosing Spondylitis for many years and now I have the opportunity to study the condition in a greater depth. The aim of my study is to try to monitor the activity of the disease whilst at the same time studying the psychological implications.

Those of you who have attended for several years will be familiar with our present assessment, which monitors your movement and posture. We have already adapted the assessment on several occasions in order to improve the standard of our service and it is because of the value of these measures that I feel that further investigation may have a value for patients with A.S.

The format of the study is to measure your spinal movements in the usual way. We already ask you to complete a Questionnaire and many of the questions would be familiar but asked in a slightly different way. There would also be additional questions, which ask more about your feelings and your perception of how you are coping at the present time.

The study will involve four assessments at six monthly intervals as would be our usual arrangement. All of the assessment will be kept within your current Physiotherapy file. The data for the research study would however be transferred to a secure database held within the hospital. All information will be treated respecting your confidentiality at all times. I will be the only person who will be dealing with your information directly. The data collected will be analysed at the University but I must stress that by this stage it will be anonymous. When you attend for your appointment, I will be more than happy to discuss any questions with you.

If you would like to take part, I will ask for your consent. I must emphasise to you that your participation would be entirely voluntary and that you should feel free to withdraw at any time.

For those not wishing to take part, your assessments will be conducted as normal with the measurements and questionnaires as before. I must however point out that there will be a permanent alteration with the format of one page to comply with a national assessment which will make our monitoring more effective.

Yours sincerely,

Mrs. Jane Martindale, Senior Physiotherapist

Version 1 (14/12/01) JM

2. **CONSENT FORM**

2b

Title of Project : A study of the relationship between Disease Activity and Psychological Status in Ankylosing Spondylitis

Name of Researcher : Jane Harriet Martindale
Senior Physiotherapist,
Wrightington Hospital.

Please initial box

1. I confirm that I have read and understood the letter describing this project dated ..... and that I have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that the data collected will be stored and analysed on a secure database. ☐
4. I agree to take part in the above study. ☐

Name of Patient	Date	Signature
Name of Researcher taking consent	Date	Signature

1 for patient, 1 for researcher, 1 to be kept in hospital notes.

Version 1 (14/12/01) JM

3. **PATIENT INFORMATION SHEET** 2c

A Study of the Relationship between Disease Activity and Psychological Status in Ankylosing Spondylitis

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

You might be interested to know that Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions potential recruits may want to ask. Members of the public may obtain a copy FREE from CERES by writing to PO Box 1365, London N16 0BW.

What is the purpose of the study?
Ankylosing Spondylitis (AS) is a chronic inflammatory arthritis involving the spine and sacroiliac joints, often with involvement of peripheral joints. The course of the disease is characterised by flares and remissions. Medication is available to reduce symptoms of pain and stiffness. However, the mainstay of treatment is the performance of regular exercise programmes including stretching and strengthening exercises designed to maintain spinal mobility improve posture and achieve general fitness (Gall 1994), (Barlow-JH & Barefoot 1996).

I am currently undertaking a research degree at the University of Central Lancashire. I have been extremely interested in Ankylosing Spondylitis for many years and now I have the opportunity to study the condition in a greater depth. The aim of my study is to try to monitor the activity of the disease whilst at the same time studying the psychological implications and I would like to invite you to take part.

Why have I been chosen?
Because you have Ankylosing Spondylitis and are currently attending out Review Group.

What will I do if I take part?
The study will last for two years and it will involve at least 100 patients. Those of you who have attended for several years will be familiar with our present assessment, which monitors your movement and posture. We have already adapted the assessment on several occasions in order to improve the standard of our service and it is because of the value of these measures that I feel that further investigation may have a value for patients with A.S.

The format of the study is to measure your spinal movements in the usual way. We already ask you to complete a Questionnaire and many of the questions would be familiar but asked in a slightly different way.

The only change to your usual assessment will be in the form of a questionnaire asking additional questions, which are about your feelings and your perception of how you are coping at the present time.

The study will involve four assessments at six monthly intervals, as would be our usual arrangement.

What are the possible benefits of taking part?

The information we get from this study may help us to treat other patients with your condition.

What if something goes wrong?

Your treatment will be managed in exactly the same way as before. Regardless of this, if you are not happy with, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Confidentiality

All of the assessment will be kept within your current Physiotherapy file. The data for the research study would however be transferred to a secure database held within the hospital. All information will be treated respecting your confidentiality at all times. I will be the only person who will be dealing with your information directly. The data collected will be analysed at the University but I must stress that by this stage it will be anonymous. I will be more than happy to discuss any questions with you concerning this issue.

Do I have to take part?

No, taking part is voluntary. If you would prefer not to take part, you do not have to give a reason. Your doctor would not be upset and your treatment would not be affected. Your assessments will be conducted as normal with the measurements and questionnaires as before. I must however point out that there will be a permanent alteration with the format of one page to comply with a national assessment, which will make our monitoring more effective.

What will happen to the results of the research study?

The results of the research will be published in a medical journal for other doctors and health staff who have patients with Ankylosing Spondylitis to help them make decisions about how they care for patients. It will also be discussed at scientific meetings. You will not be identified in any report/publication following this study.

Who is organising the research?

I am currently studying for my MPhil/PhD at the University of Central Lancashire and Professor John Goodacre is my tutor.

The Research Ethics Committee for Wrightington, Wigan and Leigh have reviewed and approved the research ethics of this study. The University of Central Lancashire Psychology Ethics Committee have also given ethical approval.

What do I do now?

If you would like to take part, I will ask for your consent. I must emphasise to you that your participation would be entirely voluntary. If you take part but later change your mind, you can withdraw at any time.

Contact for Further Information

Contact: Mrs. Jane Martindale

Thank you for agreeing to take part in this study. Please discuss this information with your family and friends if you wish.

This information sheet will be given to you to keep.
[January 2002 (version 1)]

The Bath Ankylosing Spondylitis Metrology Index (BASMI)

Date				
Height				
Chest Expanision				
Schobers				
Intermalleolar Straddle				
Cervical Rotation Right				
Cervical Rotation Left				
Cervical Rotation Mean				
Tragus to wall Right				
Tragus to wall Left				
Tragus to wall Mean				
Lumbar Side Flexion Right				
Lumbar Side Flexion Left				
Lumbar Side Flexion Mean				
Total Score				

Scoring Guide

	0	1	2	3	4	5	6	7	8	9	10
Schobers	>7	6.4-6.9	5.7-6.3	5.0-5.6	4.3-4.9	3.6-4.2	2.9-3.5	2.2-2.8	1.5-2.1	0.8-1.4	<0.7
IMD	>120	110-119.	100-109.	90-99.9	80-89.9	70-79.9	60-69.9	50-59.9	40-49.9	30-39.9	<30
Cervical Rot	>85.1	76.6-85	68.1-76.5	59.6-68	51.1-59.5	42.6-51	34.1-42.5	25.6-34	17.1-25.5	8.6-17	<8.5
Tragus	<9.9	10-12.9	13-15.9	16-18.9	19-21.9	22-24.9	25-27.9	28-30.9	31-33.9	34-36.9	>37
Lumbar Side Flex	>20.1	18.0-20.0	15.9-17.9	13.8-15.8	11.7-13.7	9.6-11.6	7.5-9.5	5.4-7.4	3.3-5.3	1.2-3.2	<1.1

Wrightington Wigan and Leigh NHS Trust

Questionnaire on the effects of Ankylosing Spondylitis on health, daily activities and general well being.

Please try to answer all the questions.

The information gained from this questionnaire will be treated in strictest confidence.

Name _____ Date _____

Questionnaire number- 1 2 3 4

GENERAL INFORMATION ABOUT YOU

1. Are you Male ☐ Female ☐

2. Date of birth ☐☐☐☐☐☐

3. Are you Single ☐ Married/cohabiting ☐ Separated/divorced ☐ Widowed ☐

4. Do you live Alone ☐ With spouse or partner ☐ With relatives ☐ With friends ☐ With another person/people ☐

5. Are you working Yes full time ☐ Yes part time ☐ No ☐

6. If you have stopped working or reduced your hours, was this due to ill health?

Yes ☐ No ☐

7. How many years have you had Ankylosing Spondylitis? _____

HAD Scale

me: Date:

ctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be e to help you more.

s questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite reply which comes closest to how you have been feeling in the past week.

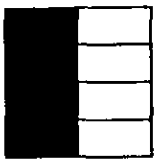
n't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought- response.

Tick only one box in each section

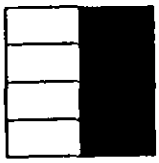
eel tense or 'wound up':
- Most of the time
- A lot of the time
- Time to time, Occasionally
- Not at all

I feel as if I am slowed down:
- Nearly all of the time
- Very often
- Sometimes
- Not at all

still enjoy the things I used to enjoy:
- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

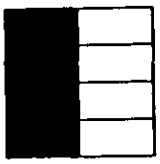


I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all
- Occasionally
- Quite often
- Very often

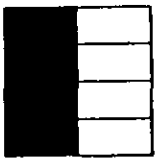


get a sort of frightened feeling as if omething awful is about to happen:
- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

I have lost interest in my appearance:
- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

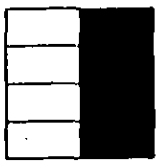


I can laugh and see the funny side of things:
- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

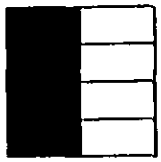


I feel restless as if I have to be on the move:
- Very much indeed
- Quite a lot
- Not very much
- Not at all

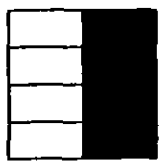
Worrying thoughts go through my mind:
- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally



I look forward with enjoyment to things:
- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

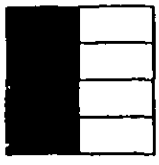


I get sudden feelings of panic:
- Very often indeed
- Quite often
- Not very often
- Not at all



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

I can enjoy a good book or radio or TV programme:
- Often
- Sometimes
- Not often
- Very seldom



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

Do not write below this line

The following questions ask what you believe about your back problems.
There are no right or wrong answers.
For every statement, there are large numbers of people who agree or disagree.

Tick the box for the answer which describes what you believe.

			Strongly disagree 1	Disagree 2	Slightly disagree 3	Slightly agree 4	Agree 5	Strongly Agree 6
I	1	If my back problem worsens, it is my own behaviour which determines how soon I feel better again.						
C	2	No matter what I or anyone else does, if my back is going to get worse, it will get worse.						
PO	3	If I see my doctor regularly, I am less likely to have problems with my back.						
C	4	Most things that effect my back happen by chance.						
PO	5	Whenever my back worsens, I should consult a health professional.						
I	6	I am directly responsible for my back getting better or worse.						
PO	7	Other people play a big role in whether my back improves, stays the same or gets worse.						
I	8	Whatever goes wrong with my back is my own fault.						
C	9	Luck plays a big part in determining how my back improves.						
PO	10	Health professionals are responsible for seeing that my back improves.						
C	11	Whatever improvement occurs with my back is largely a matter of good fortune.						

		Strongly disagree 1	Disagree 2	Slightly disagree 3	Slightly agree 4	Agree 5	Strongly Agree 6
12	The main thing that affects my back is what I do myself.						
13	If my back worsens, it's a matter of fate.						
14	If I take the right actions, my back should improve, or at least not get any worse.						
15	Following doctor's orders to the letter is the best way to keep my back from getting any worse.						
16	If my back takes a turn for the worse, it is because I have not been taking care of myself.						
17	The type of help I receive from other people determines how soon my back improves.						
18	Even when I take care of myself, things outside of anyone's control can make my back get worse.						
19	In order for my back to improve, it is up to other people to see that the right thing happens						
20	I deserve the credit when my back improves and the blame when it gets worse.						
21	If I am lucky, my back will get better.						
22	Regarding my back, I should only do what my doctor tells me to do.						
23	I'm the one with responsibility for what happens to my back.						
24	As to my back, what will be will be.						
	C ☐ PO ☐ I ☐	1	2	3	4	5	6

The Bath Ankylosing Spondylitis Functional Index (BASFI)

PLEASE DRAW A MARK ON EACH LINE BELOW TO INDICATE YOUR LEVEL OF ABILITY WITH EACH OF THE FOLLOWING ACTIVITIES DURING THE PAST MONTH.

EXAMPLE

Easy ——|—— Impossible

N.B An aid is a piece of equipment which helps you to perform an action or movement.

1. Putting on your socks or tights without help or aids (eg sock aid)

   Easy _____ Impossible

2. Bending forward from the waist to pick up a pen from the floor without an aid

   Easy _____ Impossible

3. Reaching up to a high shelf without help or aids (eg helping hand)

   Easy _____ Impossible

4. Getting up out of an armless dining room chair without using your hands or any other help

   Easy _____ Impossible

5. Getting up off the floor from lying on your back without help

   Easy _____ Impossible

6. Standing unsupported for 10 minutes without discomfort

   Easy _____ Impossible

7. Climbing 12-15 steps without using a handrail or walking aid (**One foot on each step**)

   Easy _____ Impossible

8. Looking over your shoulder without turning your body

   Easy _____ Impossible

9. Doing physically demanding activities (eg physiotherapy exercises, gardening or sports

   Easy _____ Impossible

10. Doing a full days activities whether it is at home or at work

    Easy _____ Impossible

The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)

a) If you are currently taking medication for your AS, please give the name and dose that is on the bottle or packet:

a) Place a mark on the line below to indicate the effectiveness of the medication in relieving your symptoms.

No Effect _____ Very Effective

PLEASE PLACE A MARK ON EACH LINE BELOW TO INDICATE YOUR ANSWER TO EACH QUESTION, RELATING TO THE PAST WEEK.

EXAMPLE

None _____|_____ Very Severe

1. How would you describe the overall level of fatigue/tiredness you have experienced?

None _____ Very Severe

2. How would you describe the overall level of AS neck, back or hip painyou have had?

None _____ Very Severe

3. How would you describe the overall level of pain/swelling in joints other than neck, back or hips you have had?

None _____ Very Severe

4. How would you describe the overall level of discomfort you have had from any areas tender to touch or pressure?

None _____ Very Severe

5. How would you describe the overall level of morning stiffness you have had from the time you wake up?

None _____ Very Severe

6. How long does your morning stiffness last from the time you wake up?

_____

0 hrs ½ 1 1 ½ 2 or more hrs

YOUR HEALTH AND WELL-BEING

1. In general, would you say your health is [Mark an x in the one box that best describes your answer.]

Excellent	Very good	Good	Fair	Poor
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. Compared to one week ago how would you rate your health in general now?

Much better now than one week ago	Somewhat better now than one week ago	About the same as one week ago	Somewhat worse now than one week ago	Much worse now than one week ago
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Mark an x in a box on each line.]

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐ 1	☐ 2	☐ 3
b **Moderate activities** such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
c Lifting or carrying groceries	☐ 1	☐ 2	☐ 3
d Climbing **several** flights of stairs	☐ 1	☐ 2	☐ 3
e Climbing **one** flight of stairs	☐ 1	☐ 2	☐ 3
f Bending, kneeling or stooping	☐ 1	☐ 2	☐ 3
g Walking **more than a mile**	☐ 1	☐ 2	☐ 3
h Walking **several hundred yards**	☐ 1	☐ 2	☐ 3
i Walking **one hundred yards**	☐ 1	☐ 2	☐ 3
j Bathing or dressing yourself	☐ 1	☐ 2	☐ 3

4. During the <u>past week</u>, how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health?</u>

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Cut down on the **amount of time** you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b **Accomplished less** than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Were limited in the **kind** of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d Had **difficulty** performing the work or other activities (for example it took extra effort)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. During the <u>past week</u> how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Cut down on the **amount of time** you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b **Accomplished less** than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Did work or other activities **less carefully than usual**	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. During the <u>past week</u>, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. How much <u>bodily</u> pain have you had during the <u>past week</u>?

None	Very mild	Mild	Moderate	Severe	Very severe
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

8. During the <u>past week</u> how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework?)

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐1	☐2	☐3	☐4	☐5

9. These questions are about how you feel and how things have been with you <u>during the past</u> week. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the <u>past week</u>...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Did you feel full of life?	☐1	☐2	☐3	☐4	☐5
b Have you been very nervous?	☐1	☐2	☐3	☐4	☐5
c Have you felt so down in the dumps that nothing could cheer you up?	☐1	☐2	☐3	☐4	☐5
d Have you felt calm and peaceful?	☐1	☐2	☐3	☐4	☐5
e Did you have a lot of energy?	☐1	☐2	☐3	☐4	☐5
f Have you felt downhearted and depressed?	☐1	☐2	☐3	☐4	☐5
g Did you feel worn out?	☐1	☐2	☐3	☐4	☐5
h Have you been happy?	☐1	☐2	☐3	☐4	☐5
i Did you feel tired?	☐1	☐2	☐3	☐4	☐5

10. During the <u>past week</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐1	☐2	☐3	☐4	☐5

11. How TRUE and FALSE is <u>each</u> of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
A. I seem to get sick a little easier than other people	☐	☐2	☐3	☐4	☐5
B. I am as healthy as anybody I know	☐1	☐2	☐3	☐4	☐5
C. I expect my health to get worse	☐1	☐2	☐3	☐4	☐5
D. My health is excellent	☐1	☐2	☐3	☐4	☐5

Thank you for taking time to complete this questionnaire.

Before returning it, please can you check that you have answered as many questions as possible.

3

My Diary

Name

---

[1] [January 2005 (version 1)]

How to use your diary

Living with Ankylosing Spondyltis can affect how you feel about yourself in many different ways. Often you are asked to tell people about the pain or stiffness you are experiencing but in this study I am interested in finding out how you feel that your Ankylosing Spondylitis affects you emotionally.

Over the next four weeks please can you use the diary to tell me about how your Ankylosing Spondylitis affects your mood. For example you may want to tell me how you feel emotionally when you are in more pain or when you are feeling stiffer than normal. On the other hand, you could be having a particularly good day with very few symptoms, how does this make you feel?

The diary contains pages on which you can record your feelings. You do not need to complete this every day, only on days when you feel you have something you would like to share with me.

There is no right or wrong way to complete this diary. I am interested in your feelings about what it is like for you to live day to day with Ankylosing Spondyltis.

Please feel free to contact me on 01257 256305 if you have any questions or worries about your diary. I will phone you half way through the four weeks just to check that you are OK with keeping the diary.

Please start your diary on .....

and finish on .....

[1] [January 2005 (version 1)]

Entry number _____ **Date** _____

Please use the space below to tell me how your Ankylosing Spondylitis has made you feel today. Don't feel that you have to fill in all the space – use as little or as much as you like.

Please mark the line below with a cross to tell me how your Ankylosing Spondyltis has been today?

Very Good _____ Very Bad

Please mark the line below to tell me how much your Ankylosing Spondylitis has affected the way you feel emotionally today?

Not at all _____ Very much

[1] [January 2005 (version 1)]

4a

Dear

As you aware I have been researching Ankylosing Spondylitis for several years now. You kindly agreed to participate in my earlier study, which has allowed me now to see this condition not only affects physical health but also has psychological implications on how people cope with their daily lives. I am now a PhD student at the University of Central Lancashire and am very much interested in understanding in greater depth how people cope with this condition on a day to day basis. The reason for this letter is to invite you to take part within the final stage of the project.

This final stage of my research will involve asking a small group of people to complete a diary for a month recording how active their Ankylosing Spondylitis has been and how this has affected their everyday life. The diary to help me to have some insight into the current problems and then to explore this further an interview will be arranged either at home or hospital to your convenience. The interview will last for approximately one hour and will be tape recorded and then transcribed. The diary will be returned and along with a copy of the interview if you wish to receive one. All information will be treated respecting your confidentiality at all times and I will be the only person who will be dealing with your information directly. The data collected will be analysed at the University and at all times it will be anonymous.

If you are interested in taking part, please could you return the slip enclosed in the pre-paid envelope indicating a telephone number and convenient times for me to contact you (this does not need to be within working hours). I will ask for your consent as in the earlier study and give you more information. I must emphasise to you that your participation would be entirely voluntary and that you should feel free to withdraw at any time.

Should you not wish to take part, may I take this opportunity to thank you for your earlier participation within the study. I hope to present my findings in the not too distant future and will contact everyone concerned.

Yours sincerely,

Mrs. Jane Martindale (Clinical Specialist Physiotherapist)

Reply Slip

I would be interested in receiving more information regarding the proposed study with Jane Martindale.

Name _____

My contact phone number is: _____

Convenient times to ring are: _____

Reply Slip

I would be interested in receiving more information regarding the proposed study with Jane Martindale.

Name _____

My contact phone number is: _____

Convenient times to ring are: _____

Reply Slip

I would be interested in receiving more information regarding the proposed study with Jane Martindale.

Name _____

My contact phone number is: _____

Convenient times to ring are: _____

PATIENT CONSENT FORM

4b

Centre Name: Wrightington Hospital
Study Number:
Patient Identification Number for this trial:

Title of Project: Disease and Psychological Status in Ankylosing Spondylitis
Name of Researcher: Jane Harriet Martindale

Please initial box

I confirm that I have read and understood the information sheet dated January 2005 (version 1) for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

I understand that sections of any of my medical notes may be looked at by responsible individuals from Wrightington Hospital or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐

I agree to take part in the above study[1] ☐

Name of Patient	Date	Signature
Name of Person taking consent (if different from Researcher)	Date	Signature
Researcher	Date	Signature

1 for patient, 1 for researcher, 1 to be kept with hospital notes

[1] [January 2005 (version 1)]

4c

PATIENT INFORMATION SHEET

Disease and Psychological status in Ankylosing Spondylitis

Researcher: Jane Harriet Martindale

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with us if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?
We are trying to understand how Ankylosing Spondylitis affects people's mood. This study is designed to help us to understand the psychological implications which can be associated with living with a chronic condition which has periods of increased symptoms and how this affects people at that time.

Why have I been chosen?
We are writing to you because you took part in the original stage of the study.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and a decision not to take part will not affect the standard of care you receive in the long term.

What will happen to me if I take part?
You will be asked to keep a personal diary for a month to record how active your Ankylosing Spondylitis has been and how this has affected your everyday life. I will then ask you to return your diary and arrange a convenient time and place to interview you about your experiences. This interview could take place at your home or at the hospital and will last for approximately one hour. It will be arranged at your convenience. Your diary will help me to see some of the problems that you may have had and the interview will help to increase my understanding. The interview will be tape recorded and then written down word for word. I will return your diary and you will be asked if you would like to keep a written copy of the interview.

What are the benefits of taking part?
The information we get from this study may help us to comprehend how Ankylosing Spondylitis impacts upon people's lives. This will help us to treat a person with greater understanding of their needs.

Will my taking part in this study be kept confidential?
All information, which is collected, about you during the course of this research will be kept strictly confidential. Any information about you, which leaves the hospital, will have

your name and address removed so that you cannot be recognized from it. I will be happy to discuss with you any questions you may have concerning this issue.

If a scientific paper is written about the results your name and details will be removed completely.

Who has reviewed this study?
The Wrightington, Wigan and Leigh local research and ethics committee have reviewed this study. The University of Central Lancashire Psychology Ethics Committee have also given ethical approval.

What will happen to the results of the research study?
The results of the research will be published in a medical journal for other doctors and health staff who have patients with Ankylosing Spondylitis to help them make decisions about how they care for patients. It will also be discussed at scientific meetings.

Who is organising the research?
I am currently studying for my PhD at the University of Central Lancashire and Professor John Goodacre is my tutor.

What do I do now?
If you would like to take part, please return the reply slip containing a contact telephone number and a convenient time for me to contact you in the enclosed reply-paid envelope. I must emphasise to you that your participation would be entirely voluntary. If you take part but later change your mind, you can withdraw at any time.

Contact for Further Information
Contact: Mrs. Jane Martindale

Should you require any further independent information or have any concerns, you can contact Jill Martin or Sandra Latham, Research and Development Department, Wrightington Hospital – 01257 256465

Thank you for agreeing to take part in this study. You will be given a copy of this information sheet as well as the consent form for taking part in the study.
Please discuss this information with your family and friends if you wish.

[January 2005 (version 1)]

4d

Dear Dr.

Re: Disease and psychological status in ankylosing spondylitis

Your patient .....(Unit Number.....)
has agreed to take part in the above titled study.

As you may be aware, I am currently studying for a PhD at the University of Central Lancashire. I am now embarking on the final stage of my project. I am writing to inform you that your patient has agreed to participate in my study.

They have agreed to complete a diary over a period of one month to indicate changes in their condition along with any psychological implications which this may generate.
I will then conduct a semi-structured interview based on the contents of their diary.

Yours sincerely,

Mrs. Jane Martindale (Clinical Specialist Physiotherapist)

Interview: Patient 7

5

J. Well can we just start off by telling me about your self? How old you are and what interests you have.
R. Well I am 63 years old and I have taken early retirement so I basically idle away my days. I do all the fun jobs these days so I have a mountain of ironing to do and I read a lot. I have an interest in history and I do a little bit of travelling around when I can and that it basically it.

J. You tell me that you walk the dog.
R. Oh yes I walk the dog 6 mornings a week. I have a lie in on Sunday. I do about 4 miles a day primarily for the exercise basically because I have got this heart condition. It doesn't really affect my back in the sense that I get a bit tired sometimes and I get a bit achy. I generally sit down for an hour or so when I get home and have a cup of tea and what have you as you do and I find that if I pace myself then I can do most things. It is things like when I have to dig the garden over and things like that. I can mow the lawn all right whereas bending down and weeding and doing any heavy work it is a complete no, no. Five minutes and I am in agony even just bending down like weeding and if I am on my feet a long time that gets me as well but apart from that it doesn't bother me in that sense. I get a few days when it is quite painful I mean I think in there when I did the MRI scan I felt absolutely rough for a few days with a lot of pain u-in my rib cage and everything. Whether that is an affect from the MRI I don't know because when I had my bone scan it was nothing.

J. How long have you had your AS?
R. Well I was diagnosed; it is nearly 3 years now in the January. It took over 2 years or more to diagnose because historically I have always been going to the doctors with backache. I can go back to the 70's with that. The doctor who I had been going to originally because I had backache and pain in my ribs and his diagnosis then in the early 70's was 'Bornos' disease would you believe. He said well you will be all right it just mimics pleurisy the pain. So that was it so I put up with that a bit longer and then I kept going back and went to see different doctors in the same practice up the road there and all he ever did was give me lectures on posture, didn't do anything for me. I eventually went to see Dr .....and he is the one who has done more for me the last 3 years. Originally he referred me to Ormskirk to see the Haematologist because every time I went to see him I had high blood pressure. And they kept taking blood tests and every blood test I had came back not quite what it should be, the white cells or something and he couldn't get to the bottom of this. So he sent me to the haematologist at Ormskirk so I went to see him and he x-rayed me and prodded and poked me. The second time I went to see him, he said that he suspected that I had got this AS and I will refer you to .....to see Dr..... And the rest is history because once I saw him he put me on the anti-inflammatories and within a week I sort of got my life back because prior to that I was in an awful lot of pain.

J. Was it constant pain?
R. Oh every, every day. I was in complete agony. I would wake up crying with the pain. I couldn't sleep properly. If I wanted to turn over in bed, I had to get out of bed and turn over. I just couldn't turn over as you would normally do. I was like that for a good 2 or 3 years and I got worse and worse.

J. Did that really get you down?

R. At that particular time I wasn't eating. I wouldn't eat enough to feed a mouse. I just couldn't be bothered eating. I was loosing weight. When I finally got diagnosed I was down to 74 kilos. I was getting to be a bag of bones and as soon as I went on the Indomethacin within a week I was pain free. I wouldn't say discomfort free. I have never been, there has always been a discomfort with it, but there is no real hard pain. Sometimes there is but you have your good days and you have more good days than you have bad days. After the first fortnight of that I had changed and I had started eating like a horse again. Since then I have put on well over 20 kilos in weight. I have gone from about 76 kilos up to about 99 and I am getting it off now with the walking, I am back to about 89 which is a healthier state.

J. Is it contentment that made you eat more?
R. It's just that the pain wasn't there. I mean I could sit here and watch the television and now to stand up and go up stairs it was agony just to stand up. It got that you got onto your hands and knees just to get up. Once the anti inflammatories started to work and I could move better. I wasn't in pain when I moved, I could turn over in bed, I could get a decent night sleep and within 6 months of that, certainly within a week I felt the difference.

J. Did you feel a difference emotionally as well, did you change?
R. Well yes I suppose I did because I was a pain in the but and it is very difficult for other people because they think you still look relatively fit. You are still mobile, you are still doing this that and the other but it is hard for them to know that you are in pain. Because you don't look as if you are in pain. There are times when you did. I remember when we went to London one Christmas and we went to the Theatre and after that we went just for a drink and I remember in this bar in London some where and I was in agony. I just wanted to get out and get away from it. I couldn't be bothered with people or being sociable or enjoying social things. But now it's all different. I can get out and I do enjoy a social life. We have our friends and that but prior to that, certainly the last 18 months before diagnosis that was purgatory.

J. Describe 'pain in the but' what were you like?
R. I wasn't eating. I was grumpy. I wasn't the best person to live with because my other half couldn't understand it. She knew that there was something wrong because she knew that I wasn't eating and I was waking up at night and I was moaning in my sleep at night so she knew that something was wrong. And all this time I was going to the hospital as I say originally with the haematologist and that all takes time and when I saw Dr..... he x-rayed me and I had to wait for the results. We went back but you are not going back in a couple of days, oh come back in a couple of months and this sort of thing. Oh he says yes this is what you have got, gave me the prescription and within a week there was a difference. Now I eat like there is no tomorrow now. I just pig out on everything but prior to that diagnosis.

J. Are you more patient now, what are you like in yourself?
R. I am all right. I am quite tolerant. I know what I am dealing with now. Prior to that you didn't know what you were dealing with and as my GP said when I was diagnosed he said I really thought that you had a cancer because it was that bad and I was definitely skeletal. He was right I have got one now. But once you know what you are dealing with you can handle it and it doesn't really bother me. It bothers me in the sense there are a lot of things that I can't do that I would like to do. I can get out and walk with the dog but I couldn't go up to the Lakes and go fell walking.

J. Does that frustrate you that you can't do that?
R. It does in the sense. It frustrates in the way that as I say just digging the garden I have to pay somebody to weed the borders now. I can mow my own lawn, it is no problem because these hover things there is no work involved in that is there? But when you have got to bend down and do things, as I say I do all the fun jobs here. It took me half a day just to was through here yesterday, the dusting, hovering, washing and doing the floor. It took half a day to do that. Normally it is an hours work if that. I do. I feel a bit sore. I sit down and have a cup of tea for 20 minutes, do a bit more and that's what I tend to do you know. So jobs that normally take half an hour turn into half a day. So there is that side to it but I am resigned to that. You know what you are dealing with. When you didn't know what you were dealing with, that was the problem.

J. Taking early retirement did that make a difference for you?
R. Well I retired before all this came on. I was feeling rough when I did. I got out in 1998 and I was feeling humpty then.

J. What's humpty?
R. Well as I say I was feeling under the weather all the time. This was playing up. This is how far we are going back when it really became a problem. But talking to Dr .....he says you have had this for 30 odd years and when you think back and you read about what this does to you and the symptoms of it then all of a sudden a lot of the pieces of the jigsaw fall into place. Going back to the 70' and this GP saying you have got Bornos disease and the lectures on posture. Then ok fair enough posture has got a lot to do with it but that didn't do anything for me. He could have done a bit more than what he did and it wasn't until I changed my doctor and went to see Dr....., and they are all in the same practice, and he decided to look back in over the history. He went back to the year dot with my records and he started to pick trends up. In the 80's I used to go to a well man clinic and you just had a physical every year and a blood test. And every blood test I had was showing and all Dr .....ever said was oh yes you are probably getting over an infection and I knew bloody well that I hadn't. And this is what he put it down to instead of taking it a stage further and as I say I went to Mullen and he reckoned my blood pressure was high and he sorted that out. And doing all the blood tests and he kept getting the same sort of a result and he said that he didn't know what this is. He referred me to the Haematologist and it him who sussed it and he made me the appointment to see Dr. .....but that put months and months and months on and those months of waiting and waiting, you just didn't feel like doing anything. Going to bed was agony, getting out of bed was agony, sitting around was agony, walking was pain. You couldn't do anything that you could enjoy. You knew that you had survive so you were doing the best that you could and all you were doing was eating to keep yourself alive basically. You couldn't sit down and enjoy your dinner.

J. Did that really get you down at that point?
R. Yes. I mean I could look at a plate of food and just want to be sick. Even now although my appetite is well back, if I go somewhere and they give me a massive plate of food, it just puts me right off. I like to take small portions and have more if I need it. I think that stems from there. I just couldn't eat a full plate of food.

J. Did it really stress you the fact that you couldn't sleep very well?
R. Oh yes I used to dread going to bed. As I say I would get to sleep and I would wake up many, many a night crying out in pain it was that bad and if I wanted to turn over, I had to get out of bed to turn over. I couldn't turn over in bed as normal.

J. Do you sleep well now?
R. Oh yes, I sleep like a brick. I have no problems sleeping now. I have no problems eating in fact I over eat. I have put too much weight on. Certainly since the diagnosis, it has certainly improved. There is no doubt about it. Not only physically on the pain side but mentally you know what you are dealing with and you adapt. You get on with it. I mean I wouldn't say that it gets me down very much now. I get wound up now and then when I can't do what I want to do or it takes me so long to do stuff. I mean this room needs decorating badly and I am wondering whether to start it because I know if I start it instead of getting stuck in and finishing it in a week, it is going to take me a month or so to do it. And these are the sort of things that get me going and you know that if you start doing it and if you start to feel a bit sore you are going to cut corners. So you are not doing to do it right. So I say I am not going to pay anyone to do it because up stairs I paid a guy to come and do the bedroom. I was bad and he made a worse job than I do and a couple of hundred quid down the drain. I mean I will get around and I will do it and the intention is to get it done before Christmas. We are going to Canada on 10th September and I will probably get stuck in when we come home. I will give myself a couple of months before Christmas to get it done.

J. Does that bother you that you can't do it as you would want to?
R. Oh yes. I mean normally, traditionally if I was going to do it, I get stuck in and do it. I am one of those who once I start will finish and even if I have to, I will work through the night to do it. I if start at 8 o'clock in the morning, I will keep on going until 8o'clock the following morning to finish it. That is the way I have always been. But the thought of OK I have got to do that, I might get a wall done in a day if I am lucky. The hard part is stripping it. The actual putting the paper up isn't hard you see. The hard part is maybe up and down steps and that can really wind you up. Because when it gets me, it gets my lower back. If I stand up for too long or sit down for too long, it gets my lower back. Shoulders are stiff but I have got better movement in my neck now than I had when I was first diagnosed. Driving was a pain because I couldn't see what was coming behind because I couldn't turn my head round. It is just my lower back that is the worst. If it is going to ache, that is where it is going to ache.

J. When the pain gets worse how does that make you feel?
R. It doesn't make me feel particularly down because I know what the pain is. Obviously I would prefer to do without it. You don't want it but you have got it so you have got to live with it. It is not persistent. I mean if I am standing up as I say and doing a job and my backs starts, I will just sit down for 20 minutes. Then go back and do a bit more.

J. Would you change your mood? Would that alter at all?
R. Not particularly. Not to the extent that you go all grumpy and humpty. I might get a bit noughty depending who is around. It is not violent mood swings, it's just little things that niggle you. You just feel a bit niggled from time to time ' go away I don't want to talk to you' sort of thing'. Or you know or a few minutes and then you are back to normal again. I don't take painkillers. I have got them if I need them but I only take the Indomethacin and that keeps the lid on it. Very rarely have I needed to resort to the codeine and the paracetamol. In the last three years maybe no more than on 2 or 3 occasions where I have taken it and you don't want to do that. It's not that you are worried about what you are putting into your system because codeine and paracetamol bung you up something horrible. Really speaking, the pain isn't so severe to justify taking a painkiller like that. Whether I have got a better tolerance to pain than a lot of

people because when you meet some people, the wind has only got to blow on them and they are in agony. I suppose people are different aren't they?

J. When you describe that you have to sit down. If you are in the middle of a job and you have to sit down, what sort of feelings does that give you?
R. A bit deflating. I think OK, sit down. I will make a cup of tea whilst I'm at it and put the tele on and see what is happening in the world for 10 minutes.

J. Would you feel guilty because you have to do that?
R. Not now. I used to, used to and that's because you are used to a working life and you are used to working to specific times and deadlines and getting things done for certain times. That's an awful hard thing to get out of. You feel, if you feel anything it's as if your discipline is going. You are used to living a very disciplined ordered routined sort of existence. Now because I don't have to, you feel as if you are not doing things, as you should. I am doing little things that sound stupid just to keep self-discipline, don't let myself go too much. When I am ironing, I am ironing all the underpants and everything. I mean who the hell irons underpants? But that is a discipline. I think I don't have to get shaved today. I am not going anywhere. I could end up with a beard down here. You do keep on top of silly little things like that just to keep yourself in a sense focused in some respects. But the idea that you no longer need to be, 'I have to have this done by 10 o'clock' that is a terrible thing to get out of even with out the AS. That is the big draw back to retirement and they always advise if you are going to retire, know what you are going to do when you get out. That is the best advise that any body can give you. Since I have gone, I keep relatively busy and there are times when you can say I don't know how the hell I found time to work. But if you just retire and do nothing that is the worse thing that you can do. You just vegetate away and it doesn't matter what you have got. Whether you have AS or not, you are just going to go down the tubes at a rate of knots. So you have got to keep some form of discipline but you have got to do it in a different sort of way I think.

J. Is that almost like an acceptance as well?
R. Yes I suppose it is because you have these little bench marks in your life. You sort of think well I had better do this and that because you are very conscious of the fact that you could just become a sluven heap in a corner somewhere. So you have got to keep focussed on the things that you wanted to do that you didn't when you were working. So you just indulge yourself in your hobbies and the things that you like to do.

J. Do you have the concept of flare up? Do you still have times when your AS can be very severe compared to it being fairly quiet?
R. It's relatively keeps a steady pattern. There are times but I wouldn't say there are massive peaks and troughs. As I say, I mean after the MRI, I mean that was quiet painful for a day, day and a half afterwards but that just settled down again and back to the old routine. I mean you are never free of it. You can't say that you are constantly in pain because you are not but there is that degree of discomfort, this 'Oh god', you know just slight restrictions in movement and a bit of an ache from time to time. If you keep yourself mobile as I say. I mean I walk every morning with her and I can do anything up to 5 miles in the morning and that doesn't really bother me. I know I have done it because my back is saying 'bloody hell, time you had a sit down here pall'. But it doesn't bother me in the sense that I am in a lot of pain or anything.

J. Is there not really a concept of change, there is not a big change?
R. No I remember reading that you can have flare ups but I can't honestly say that since I have been diagnosed that I have had a major flare up.

J. Before the diagnosis, if your pain did get a lot worse, would you have been aware that it might affect your mood at that point?
R. Oh yes, yes. I mean before the diagnosis it was constant. It was 24 – 7.

J. Would it get worse?
R. It would get worse at certain times. It got worse at night obviously and there were very few days when you could say that you were totally pain free. Everything that you wanted to do. As I say simple things like just standing up and going to answer the door to somebody. There was pain to stand up. There was pain to sit down again. Pain to walk up stairs. Everything involved a degree of pain. Some times to a greater degree of lesser degree. But since diagnosis I can't say. I can stand up without lots of pain. I can walk up stairs without holding the banister and this like that. So I am a lot more mobile. A lot more fluid shall we say but I am not as agile or as nimble as I was 30 years ago. I suppose I wouldn't be any way because I am that bit older.

J. That is one of my questions really. I know that you have had AS for all these years but you have only recently known about it recently as such. One of the things that has come through is that as people have got older it has become more difficult to cope with almost. When you were younger you were more active and more able to work through it but you didn't know what you had so you are different in that respect.
R. That was the thing you see, when you are at work and the job that I did you were always wary of people pulling that fast one with backache. Now that is the one when people wanted a bit of time off they came with the old backache and nobody could prove one way or the other. When you have actually got it, you have got it at the back of your mind that people are going to think 'old glass back'. So you do. You work through it and the job I did I was in a managerial position and I thought well I have to deal with these people. Ninety nine percent of the time I used to think they were swinging the lead. Although I had this bit of a problem from time to time, I used to think that I have a bad back and it is not stopping me doing stuff so I used to judge people like that. Probably now in retrospect I was probably quite unfairly in some respects. I am sure that there was the odd malingerer although there probably were lots of genuine people. One of the hard things to come to come to terms with is that outwardly you look as fit as a flee. To people in the street they see you walking around and think that there is nothing wrong with you. It is terribly hard to explain to them what it is without them thinking 'who is he trying to kid?'

Super codes created within the analysis

Code Family: AGE
Codes (5): [Impact of age - getting older] [Impact of age - harder when older] [Impact of age - wish you were younger] [Impact of age - younger cope better] [Implications of age of onset]
Quotation(s): 22

Code Family: BELIEFS
Codes (31): [AS - worsening] [AS improving] [Avoidance of aides] [Avoidance of increased activity - exacerbating symptoms] [being told what to do at medicals] [Beliefs surrounding external influences on AS-weather] [Finality of death] [Guilt - non achievement] [Hope for the future] [hopelessness] [Lack of achievement] [Neglecting yourself] [Normal people] [Not doing enough] [one day at a time] [Pay for it - surprise not happened] [Paying for it] [Perception of treatment outcome] [Pride - maintain independence] [Quality of life] [Quality of life - mobility] [Reaching a point when it won't work] [Remembering back to first attack] [Self blame causing AS] [Self help groups] [Stigma - bad back] [Subconscious fears] [Surprise at doing more] [Trauma precipitating AS] [weather/seasonal differences] [Wish to be normal/go away]
Quotation(s): 109

Code Family: COMPARISON
Codes (4): [Comparing yourself to what you were like before you had AS] [Comparison to others who don't have AS] [Comparison to others with AS] [Comparison to others with AS - You have mild disease]
Quotation(s): 52

Code Family: COPING STRATEGIES
Codes (26): [Coping strategy - recharge batteries] [Coping strategies - absence of] [Coping strategies - better with distraction] [Coping strategies - better with experience] [Coping strategies - better with sleep] [Coping strategies - exercise -better] [Coping strategies - heat] [Coping strategies - medication] [Coping strategies - tiredness] [Coping strategy - active at work] [Coping strategy - against advise] [coping strategy - AS coexistent pathology] [coping strategy - being alone] [Coping strategy - beliefs effect of exercise] [coping strategy - better with moving] [coping strategy - diet] [Coping strategy - get through it gritted teeth] [Coping strategy - listen to your body] [Coping strategy - loss of control] [Coping strategy - mood] [coping strategy - older patients doing well] [coping strategy - others worse off] [Coping strategy - physical] [Coping strategy - recognition of symptoms] [Coping strategy - reliance on medics] [Coping strategy - unsure about exercise amount]
Quotation(s): 149

Code Family: DIARY
Codes (7): [Diary - confusion between mixed pathologies] [Diary - implications/difficulties] [Diary - more aware of AS] [Diary - more aware of how bad you are] [Diary - now aware pain blocked out previously] [Diary - partner more aware of your feelings] [Diary - seeing link with emotion]
Quotation(s): 27

Code Family: FATIGUE
Codes (7): [Fatigue - untreatable] [Fatigue -confusion over cause] [Fatigue stopping you doing things] [Fatigue/Tiredness] [Mood - influence of fatigue] [Motivation - link with tiredness] [Sleep disturbance - influence on fatigue]
Quotation(s): 47

Code Family: FEAR
Codes (13): [Fear increased activity will make you worse] [Fear of being alone] [Fear of deformity] [Fear of falling] [Fear of giving in] [Fear of losing independence] [Fear of losing mobility] [Fear of losing mobility - transport] [Fear of losing mobility and needing a wheelchair] [Fear of passing on to children] [Fear that treatment won't be as effective] [Subconscious fears] [Worry about repeating medical procedure]
Quotation(s): 42

Code Family: FLARE
Codes (6): [Description of flare] [Flare - frequency] [Flare - impact on mood] [Flare - increased coping strategies] [Flare - recognition of warning signs] [Flare duration]
Quotation(s): 20

Code Family: HIDING
Codes (6): [Disclosure of limitations] [Hiding emotions] [Hiding own limitations] [Hiding pain] [Non- disclosure of emotions] [Non disclose of AS to others]
Quotation(s): 30

Code Family: INFLUENCES AFFECTING MOOD
Codes (18): [AS affecting mood] [Coping strategy - mood] [Exercise and mood] [Iritis - affect on mood] [Medication - affect on mood] [Mood - altered by external factors] [Mood - distress pre diagnosis] [Mood - effect of exercise] [Mood - impact of uselessness] [mood - influence of distraction] [Mood - influence of fatigue] [Mood - influence of treatment] [Mood - influence on motivation] [mood - recognition of change] [Motivation -link to mood] [Pain- influencing mood] [Sleep disturbance - influence on mood] [Unpredictability - link to mood]
Quotation(s): 208

Code Family: IRITIS
Codes (15): [Co-existent pathology -AS] [Iritis - affect on mood] [Iritis - anxiety/compliance] [Iritis - comparisons to others] [Iritis - coping strategy] [Iritis - description] [Iritis - diagnosis] [Iritis - foreign travel] [Iritis - impact on you] [Iritis - less active than was] [Iritis - limitations] [Iritis - loss of control] [Iritis - main concern] [Iritis - recognition will get better] [Irtitis - link with tiredness]
Quotation(s): 38

Code Family: LIVING WITH AS- PHYSICAL IMPLICATIONS
Codes (27): [Acknowledgement of limitations] [AS - lose ability to fight/takes it out of you] [AS others unable to see] [AS stopping you doing what you loved to do] [Avoidance of increased activity - exacerbating symptoms] [Limitations with DIY]

[Living with AS- always there] [Living with AS- needs reminders] [Living with AS - comparison to other flares] [Living with AS - Early morning stiffness] [Living with AS - forget that you have it/or how bad] [Living with AS - inability to get comfortable] [Living with AS - inability to stay still] [Living with AS - knowledge helps control] [Living with AS - knowledge it will get better] [Living with AS - limitation of activity] [Living with AS - limiting ADL] [Living with AS - new area involvement] [Living with AS - no change] [Living with AS - slowing you down] [Living with AS - uncertainty new symptoms] [Living with AS - understanding symtomology] [Living with AS - worse with prolonged sitting/standing] [Peripheral joints -limitations] [Reaction to diagnosis] [Recognition of deformity] [Remembering back to first attack]
Quotation(s): 187

Code Family: LIVING WITH AS - EMOTIONAL ASPECTS VER2
Codes (13): [Acceptance] [Anxiety pre diagnosis] [AS - dictating your limitations] [AS affecting mood] [AS dictating] [AS improving] [AS stopping you doing what you loved to do] [Cure] [Delayed diagnosis] [Enforced change in life style] [Reaction to diagnosis] [Uncertainty of the future] [Why me?]
Quotation(s): 156

Code Family: MEDICAL INTERVENTION
Codes (12): [Coping strategies - medication] [Coping strategy - against advise] [Coping strategy - reliance on medics] [Medical intervention] [Medication - affect on mood] [Medication - effective] [medication - emotional crutch] [Medication - ineffective] [Medication - reliance on] [Medication - stopping/reluctance to take] [Mood - influence of treatment] [Sleep disturbance - link to medication]
Quotation(s): 75

Code Family: MOOD
Codes (9): [Mood - aggression] [Mood - anger] [Mood - annoyed] [Mood - depression] [Mood - frustration] [Mood - good day] [Mood - grumpy] [Mood - irritable] [Mood - short tempered]
Quotation(s): 75

Code Family: MOTIVATION
Codes (6): [Mood - influence on motivation] [Motivation] [motivation - influence of flare] [Motivation - link with tiredness] [Motivation - need to recharge] [Motivation - link to mood]
Quotation(s): 63

Code Family: OTHERS
Codes (10): [Others - dictating to you] [Others - letting them do things for you] [Others - making you question your ability to cope] [Others - noticing your limitations or commenting about your limitations] [Others - perception of you] [Others - taking it out on those close to you] [Others - worrying about limiting them because of your limitations] [Others -wanting to know what is wrong with you] [Others noticing change in mood] [Others supporting you]
Quotation(s): 69

Code Family: PAIN
Codes (20): [Pain- influencing mood] [Pain - ability to differentiate] [Pain - ability to differentiate between] [Pain - adrenaline rush] [Pain - alcohol] [Pain - anorexia] [Pain - being without it] [Pain - description] [Pain - emotion taking over] [Pain - forget what it is like] [Pain - influence of achievement] [Pain - influence of distraction] [Pain - lack of concentration] [Pain - limiting activities] [Pain - never free from it] [Pain - reminds you] [Pain - seeing/holding helps] [Pain - severity] [Pain -disclosure to others] [Sleep disturbance - due to pain]
Quotation(s): 110

Code Family: PARTNERS
Codes (4): [Partner - influencing treatment] [Partner - recognising behaviour] [Partner - recognition of change] [Partner - supportive/controlling]
Quotation(s): 21

Code Family: PERCEPTIONS/GENERALISATIONS
Codes (44): [ability to adapt] [Avoidance of aides] [being told what to do at medicals] [Beliefs surrounding external influences on AS-weather] [Conflicting advise] [Cure] [Disclosure of limitations] [Disclosure to researcher] [Driving] [Enforced change in life style] [Exercise and mood] [Finality of death] [Individuality] [Lack of achievement] [Lack of hobbies] [Memory problems] [Neglecting yourself] [Non-disclosure of emotions] [Non disclose of AS to others] [Normal people] [Not doing enough] [Not putting on others] [Perception of treatment outcome] [Pre diagnosis symptoms] [Pride - maintain independence] [Quality of life] [Quality of life - mobility] [Reaching a point when it won't work] [Reassurance from others] [Recognition of deformity] [Recognition of your limitations] [Reluctance to ask for help] [response to diagnosis] [Self blame causing AS] [Self help groups] [Sharing diagnosis with others] [Sharing emotions] [Stigma - bad back] [Subconscious fears] [Surprise at doing more] [Time not dictating] [Trauma precipitating AS] [Wish to be normal/go away] [Worries about excess alcohol]
Quotation(s): 85

Code Family: PERSONALITY
Codes (10): [Get on with it] [Giving in to it] [Individuality] [one day at a time] [Personality] [Personality - changes due to AS] [Personality - recognition of need to change] [Personality change] [Personality change - non AS] [Why me?]
Quotation(s): 90

Code Family: SLEEP
Codes (17): [Sleep change] [Sleep disturbance] [Sleep disturbance - due to pain] [Sleep disturbance - effects of] [Sleep disturbance - impact on everyday life] [Sleep disturbance - inability to get comfortable] [Sleep disturbance - influence on fatigue] [Sleep disturbance - influence on mood] [Sleep disturbance - link to medication] [Sleep disturbance - menopause] [Sleep disturbance - non refreshing sleep] [Sleep disturbance - other pathology] [Sleep disturbance - partner] [sleep disturbance - perception of needs] [Sleep disturbance - quality of sleep] [Sleep disturbance - reliance on medication] [Sleep disturbance due to anxiety]
Quotation(s): 101

Code Family: SOCIAL IMPLICATIONS
Codes (15): [Social circumstance - recognition of limitations] [Social impact - living alone] [Social implications - boredom] [Social implications - carer for other] [Social implications - commitments to others] [Social implications - early retirement] [Social implications - emotional stress link with job] [Social implications - financial worries] [Social implications - move house] [Social implications - redundancy] [Social implications - work pressures] [Social pressures -potential worry associated with being forced to move home] [Socialising - enjoying] [Socialising - no enjoyment - non AS] [socialising - no enjoyment caused by AS]
Quotation(s): 74

Code Family: UNCERTAINTY/UNPREDICTABILITY
Codes (7): [Uncertainty created by mixed pathologies] [Uncertainty of the future] [Unpredictability - link to mood] [Unpredictability and control] [Unpredictability of AS] [Worry about repeating medical procedure] [Worrying about what could happen]
Quotation(s): 71

Data for each of the 89 participants who completed the study

7a

ID	Gender	Age	Age onset	Age diagnosis	Disease duration
1	M	44	28	40	16
2	M	54	25	30	29
4	M	38	25	27	13
5	M	71	58	58	13
6	M	53	44	46	9
7	M	40	30	33	10
8	M	40	18	21	22
11	M	32	13	14	19
12	F	56	16	18	40
14	M	51	29	44	22
15	F	59	9	44	50
16	M	27	14	14	13
18	M	39	20	35	19
19	M	50	33	43	17
21	M	28	16	20	12
22	M	64	26	46	38
23	M	46	36	36	10
24	M	31	25	28	6
25	M	42	18	23	24
26	M	54	47	48	7
27	M	39	25	28	14
28	M	31	15	19	16
29	M	55	28	28	27
30	M	46	31	32	15
31	M	38	27	33	11
32	F	36	15	18	21
33	M	55	22	48	33
34	M	53	23	40	30
35	M	43	41	42	2
37	F	60	34	54	26
39	M	33	20	33	13
40	M	54	20	45	34
42	M	48	17	22	31
43	M	56	19	26	37
45	M	57	41	41	16
46	F	29	20	23	9
47	M	54	52	52	2
48	M	46	38	38	8
49	M	54	33	35	21
50	M	41	28	39	13
51	M	63	42	42	21
53	M	60	33	59	27
54	M	34	19	19	15
55	M	28	22	22	6

ID	Gender	Age	Age onset	Age diagnosis	Disease duration
57	F	35	14	.	21
58	M	53	20	32	33
59	F	34	19	.	15
60	M	32	12	19	20
62	M	40	19	37	21
64	M	56	42	42	14
65	F	55	37	37	18
66	M	42	16	25	26
67	M	59	18	.	41
68	F	53	26	.	27
69	M	38	16	34	22
70	M	52	40	51	12
71	M	52	37	38	15
72	M	54	44	44	10
73	M	66	21	.	45
74	M	36	18	22	18
75	M	56	15	42	41
76	F	46	28	42	18
78	M	54	40	41	14
79	M	50	38	46	12
80	F	57	48	52	9
81	M	56	27	47	29
84	M	42	15	15	27
85	M	57	15	48	42
86	M	59	50	52	9
87	F	59	47	48	12
88	F	53	12	42	41
89	M	47	19	21	28
90	M	45	27	27	18
91	M	33	18	26	15
92	M	18	12	12	6
93	M	26	10	15	16
94	M	60	18	18	42
95	M	53	32	33	21
96	M	50	20	40	30
97	M	46	31	33	15
99	M	28	22	24	6
100	M	77	55	59	22
101	M	47	32	39	15
102	M	49	33	33	16
104	F	57	25	32	32
105	M	38	26	30	12
106	M	44	17	33	27
107	M	51	25	43	26
108	M	56	30	40	26

Baseline scores for the 89 participants who completed the study

ID	BASMI	BASFI	BASDAI	LOC Chance	LOC PO	LOC Internal	HADS Anxiety	HADS Depression
1	3.6	7.46	5.13	22	26	38	8	8
2	5	4.47	5	31	19	29	6	3
4	4.4	6.8	7.38	27	29	27	15	11
5	3	1.86	0.66	23	25	36	0	1
6	2.6	5.78	3.58	30	27	29	15	7
7	5.4	5.69	5.3	18	34	23	8	2
8	5	4.25	4.18	24	32	40	2	0
11	3.4	3.34	3.9	20	25	38	6	7
12	4.6	7.78	4.6	13	31	38	8	10
14	1.8	0.5	1.8	17	17	20	0	0
15	4.4	7.71	6.3	36	32	31	9	7
16	1.2	6.57	2.05	20	26	43	2	0
18	0.6	0.3	0.73	19	23	32	3	1
19	3.4	4.46	4.69	14	23	26	6	7
21	0.6	1.9	6.3	28	20	35	3	2
22	7.3	7.29	7.4	25	31	22	9	4
23	6.2	9.16	7.3	20	18	25	18	13
24	1.8	2.91	4.4	24	20	36	8	1
25	3.8	7.12	4.79	19	15	33	9	7
26	4.2	6.89	7.6	16	19	19	14	19
27	1.2	8.59	7.5	27	20	33	10	15
28	2.4	3.79	5.6	21	25	37	3	3
29	1.6	6.53	5.3	12	31	41	3	1
30	0.8	3.87	5.4	34	17	32	13	9
31	4.1	6.95	6.6	36	29	26	16	12
32	4	2.5	5.26	31	18	28	5	5

ID	BASMI	BASFI	BASDAI	LOC Chance	LOC PO	LOC Internal	HADS Anxiety	HADS Depression
33	2.6	2.56	2.56	32	28	32	5	1
34	5.2	4.27	4.1	23	28	25	9	11
35	1.4	0.71	1.04	29	25	22	3	0
37	2.8	4.72	5.3	18	39	26	12	4
39	4	7.82	7	28	21	23	6	8
40	3.2	4.14	5.9	17	22	34	18	10
42	2.4	4.09	5.5	28	22	25	13	8
43	3	2.22	5.9	20	20	22	4	1
45	4.8	7.07	7.02	19	34	37	7	4
46	0.6	0.03	3.92	26	31	22	7	2
47	4.6	7.04	7.2	15	21	21	14	10
48	2.8	5.45	5.04	33	23	20	12	4
49	5.6	3.05	0.94	18	37	37	0	2
50	6.2	7.77	8.84	13	19	16	4	11
51	3.8	8.82	9.04	17	30	27	12	8
53	3.8	5.23	4.24	21	31	36	7	4
54	6.2	8.65	6.64	13	21	18	13	5
55	1.2	0.82	3.6	29	23	32	4	0
57	1	0.77	1.3	20	22	28	1	0
58	4.4	3.79	5.91	24	31	18	11	7
59	5.5	5.19	5.8	32	28	40	8	6
60	2.2	2.83	8.92	23	21	41	8	7
62	2.6	1.43	6.98	34	20	29	7	1
64	3.8	2.2	1.06	21	27	36	0	0
65	4.2	3.64	5.62	22	29	40	4	2
66	2.8	4.62	5.3	26	24	30	7	2

ID	BASMI	BASFI	BASDAI	LOC Chance	LOC PO	LOC Internal	HADS Anxiety	HADS Depression
67	0.8	1.22	4.16	25	19	33	2	3
68	6.5	6.64	3.18	25	19	28	6	1
69	5.2	6.52	8	29	27	17	10	10
70	6.4	7.67	5.36	24	28	36	8	9
71	1.4	3.37	6	27	29	36	3	4
72	4.8	6.82	5.81	26	24	25	11	11
73	3.2	8.56	5.34	31	29	32	7	3
74	1.1	3.69	5.66	25	21	41	4	6
75	2.8	5.5	5.23	26	28	26	9	7
76	3	1.02	2.12	27	36	35	1	4
78	4.2	6.74	6.5	23	33	27	3	3
79	4	5.6	7.08	23	25	29	12	10
80	5.2	6.45	7.6	19	17	19	5	9
81	1.8	2.11	2.02	16	17	31	2	3
84	3	1.17	0.2	17	20	33	5	5
85	4.8	9.74	8.36	16	32	22	0	0
86	5.8	6.45	6.46	31	31	23	1	1
87	3	7.9	7.4	30	33	28	9	8
88	2.8	6.8	5.9	39	17	19	10	6
89	0.8	0.4	1.1	12	27	38	5	2
90	2.6	4.7	6.9	19	37	32	4	1
91	1.2	0.9	5.18	21	32	29	5	1
92	1	0.2	0.8	24	27	34	7	7
93	0.4	0.3	2.7	12	22	36	11	14
94	6.4	5.8	7.18	19	25	37	12	10

ID	BASMI	BASFI	BASDAI	LOC Chance	LOC PO	LOC Internal	HADS Anxiety	HADS Depression
95	4.8	6.2	6.4	23	47	30	5	9
96	1.8	3.4	7	31	23	24	2	3
97	3.2	2.65	2.03	16	26	28	5	5
99	1.2	0.41	0.44	30	37	36	0	0
100	3.8	2.3	3.1	38	47	41	1	1
101	5.6	4.86	3.14	24	26	28	9	8
102	6.4	5.59	6.42	8	28	27	10	6
104	3.8	3.57	3.96	29	30	33	5	2
105	1	0.42	0.74	18	28	31	4	1
106	2	1.59	2.7	30	20	25	5	1
107	4.8	2.7	3	18	28	41	7	7
108	2.4	4.6	5.62	32	38	38	11	14

Baseline SF36 scores for the 89 participants who completed the study

ID	Physical Functioning	Physical Problems	Limitation Emotion	Social Functioning	Mental Health	Energy/ Vital	Pain	Gen Health Perception	Change in Health
1	20	65	60	44	32	35	22	5	50
2	70	15	0	55	76	50	33	45	50
4	60	50	46	33	16	20	22	45	50
5	85	5	0	88	72	55	88	80	50
6	65	70	33	11	48	20	44	20	25
7	85	0	6	77	72	50	55	70	50
8	90	30	0	88	72	50	66	45	50
11	70	45	40	33	32	25	44	35	50
12	15	70	53	44	60	50	33	35	50
14	100	0	0	88	72	60	77	100	50
15	30	55	60	33	40	30	44	20	75
16	95	0	0	88	72	65	77	55	50
18	100	5	0	66	72	60	55	100	50
19	65	40	13	55.5	60	30	55.5	20	25
21	90	15	0	77	52	40	33	75	12
22	25	60	60	44	52	13	22	25	50
23	5	65	73	33	40	0	22	25	50
24	85	8	0	88	60	40	55	55	50
25	20	60	20	33	44	25	44	55	50
26	0	55	80	11	12	0	11	5	50
27	20	75	46	22	40	22	22	15	50
28	40	40	0	66	68	20	22	70	75
29	35	20	0	44	64	45	55	50	50
30	65	55	13	44	36	20	22	65	25
31	30	60	60	22	20	5	22	5	50
32	70	10	13	89	56	30	66	40	50
33	95	0	0	89	72	65	89	80	50
34	50	65	40	33	44	40	44	25	50
35	95	0	0	88	72	53	88	90	50

ID	Physical Functioning	Physical Problems	Limitation Emotion	Social Functioning	Mental Health	Energy/ Vital	Pain	Gen Health Perception	Change in Health
37	40	30	40	67	48	40	67	20	50
39	15	65	40	67	48	25	22	20	50
40	70	20	26	66	28	10	44	60	50
42	60	25	27	77	40	40	44	55	50
43	90	40	0	89	72	60	67	45	50
45	25	65	80	55	52	25	11	45	25
46	100	0	0	88	60	12	100	35	50
47	40	60	47	44	40	30	46	25	50
48	55	28	33	55	28	30	44	35	50
49	80	5	0	88	76	65	100	90	75
50	15	60	40	33	52	20	33	0	50
51	5	80	80	11	24	30	11	5	50
53	50	25	6	88	72	50	66	60	50
54	0	80	80	22	52	0	22	15	50
55	100	0	0	88	48	45	33	50	25
57	80	15	0	77	56	45	77	80	75
58	40	60	40	44	36	15	22	10	50
59	60	40	20	44	36	35	55	50	50
60	70	40	33	0	24	0	0	0	50
62	100	0	0	88	76	55	88	0	50
64	100	0	0	88	72	65	100	80	50
65	60	35	26	66	72	45	55	50	50
66	85	10	26	33	36	20	55	75	25
67	75	30	66	77	72	45	55	70	25
68	90	0	0	88	72	60	77	65	25
69	35	55	13	44	44	0	33	25	50
70	55	45	0	77	68	35	44	25	50
71	45	65	66	55	72	50	22	35	100
72	15	60	40	44	36	40	22	25	50

ID	Physical Functioning	Physical Problems	Limitation Emotion	Social Functioning	Mental Health	Energy/ Vital	Pain	Gen Health Perception	Change in Health
73	0	60	46	88	68	60	33	30	75
74	40	30	0	66	56	45	44	70	75
75	30	65	53	77	56	40	22	60	50
76	95	0	0	88	72	45	44	70	50
78	10	60	0	11	52	25	33	25	25
79	70	25	6	55	48	20	22	30	25
80	40	70	80	22	24	20	22	35	50
81	80	10	0	88	80	60	88	85	50
84	100	0	0	77	60	80	88	95	50
85	0	0	0	22	44	40	11	30	50
86	45	50	46	22	20	15	0	20	0
87	15	55	0	77	72	30	44	55	50
88	40	70	33	22	66	5	33	10	50
89	95	0	0	88	80	65	88	95	50
90	55	35	13	44	40	0	33	40	25
91	90	10	0	88	72	55	44	40	75
92	90	5	0	33	72	60	88	45	50
93	100	15	1	66	68	60	55	55	50
94	35	75	80	22	20	10	22	45	50
95	20	80	80	44	52	10	33	15	25
96	40	40	40	44	92	45	44	30	50
97	100	0	0	88	64	55	88	70	50
99	85	0	0	88	76	55	0	75	50
100	85	10	0	77	72	45	88	70	50
101	65	20	26	66	28	30	55	25	50
102	25	80	80	33	48	20	22	35	0
104	70	20	0	88	72	40	55	55	50
105	95	5	0	88	72	60	77	75	75
106	40	5	0	88	72	65	66	85	50
107	90	35	40	88	60	35	88	65	50
108	50	55	60	44	36	35	22	45	50

Comparative data from recent studies

8

Author	Study	Mean BASDAI (SD)	Mean BASFI (SD)	Mean BASMI (SD)
Heuft-Dorenbsch (2004)	Influence o f peripheral arthritis	4.4 (2.3)	3.4 (2.6)	
Auleley (2002)	Smallest detectable change	4.03 (2.72)	3.94 (2.79)	
Band (1997)	Physiotherapy	4.67 (1.91)	5.01 (2.31)	4.51 (2.14)
Sweeney (2002)	Physiotherapy	3.9 (2.4)	3.5 (2.4)	
Robertson (2004)	5 year longitudinal study	4.73	4.90	
Taylor (1998)	Reference centile charts	Male 3.95 Female 4.38	Male 3.95 Female 4.18	Male 4.03 Female 3.28
Braun (2002)	Anti -TNF	6.24	7.74	
Braun (2002)	Anti -TNF	6.5 (1.2)	5.4 (1.8)	3.7 (2.0)
Brandt (2003)	Anti -TNF	6.5 (1.2)	6.2 (1.8)	4.1 (1.7)
Gorman (2002)	Anti -TNF	4.5 (2.1)	3.0 (0.7)	
Maksymowych (2002)	Anti -TNF	6.2 (1.4)	6.1 (2.0)	3.6 (2.5)

Table A.1 Correlations between disease status and depression score (HADS –D) (n=89)

	ASSESSMENT			
	1	2	3	4
BASMI	$r_s = 0.43^{**}$	$r_s = 0.53^{**}$	$r_s = 0.46^{**}$	$r_s = 0.43^{**}$
BASFI	$r_s = 0.61^{**}$	$r_s = 0.71^{**}$	$r_s = 0.62^{**}$	$r_s = 0.68^{**}$
BASDAI	$r_s = 0.64^{**}$	$r_s = 0.65^{**}$	$r_s = 0.66^{**}$	$r_s = 0.67^{**}$

Table A.1 shows correlations between these variables as assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$

Table A.2 Disease scores in anxious and non-anxious subgroups (HADS-A)

ASSESSMENT							
1		2		3		4	
Non anxious n= 74	**Anxious n =15**	**Non anxious n= 69**	**Anxious n =20**	**Non anxious n= 69**	**Anxious n =20**	**Non anxious n= 71**	**Anxious n =18**
BASMI							
3.24 (1.74)	4.02 (1.64)	3.29 (1.72)	4.16 (1.50)	3.12 (1.63)	4.40 (1.43)	3.20 (1.70)	4.42 (1.49)
P = <0.114		P < 0.046		P < 0.002		P < 0.007	
BASFI							
4.10 (2.61)	6.31 (1.70)	4.19 (2.76)	6.17 (1.90)	4.21 (2.71)	6.58 (2.04)	4.21 (2.83)	4.78 (1.52)
P < 0.000		P <0.001		P < 0.000		P < 0.000	
BASDAI							
4.57 (2.30)	6.41 (1.33)	4.37 (2.40)	6.76 (1.33)	4.42 (2.28)	7.02 (1.23)	4.37 (2.33)	6.75 (1.40)
P < 0.000		P < 0.000		P < 0.000		P < 0.000	

Table A.2 shows mean (SD) values for each measure of disease status in anxious and non-anxious subgroups, using HADS scores of 11 or above to identify clinical anxiety. Between-group differences were tested using independent-samples t-tests.

Table A.3. Correlations between disease scores (HADS –D) and scores for belief in powerful others or belief in chance (LOC)

	ASSESSMENT			
	1	2	3	4
	BASMI			
Belief in powerful others	$r_s = 0.18$	$r_s = 0.21$*	$r_s = 0.23$*	$r_s = 0.26$*
Belief in chance	$r_s = -0.12$	$r_s = 0.09$	$r_s = 0.05$	$r_s = 0.06$
	BASFI			
Belief in powerful others	$r_s = 0.09$	$r_s = 0.19$	$r_s = 0.21$*	$r_s = 0.18$
Belief in chance	$r_s = -0.03$	$r_s = 0.04$	$r_s = 0.01$	$r_s = 0.08$
	BASDAI			
Belief in powerful others	$r_s = -0.02$	$r_s = 0.09$	$r_s = 0.18$	$r_s = 0.08$
Belief in chance	$r_s = 0.05$	$r_s = 0.07$	$r_s = 0.04$	$r_s = 0.11$

Table A.3 shows correlations between variables as assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.4. Correlations between depression scores (HADS-D) and disease scores in subgroups with low or high belief in chance (LOC).

	ASSESSMENT			
	1	2	3	4
BASMI	*$r_s = 0.58$*** $r_s = 0.28$	*$r_s = 0.57$*** $r_s = 0.49$*	*$r_s = 0.53$*** $r_s = 0.38$*	*$r_s = 0.50$*** $r_s = 0.38$*
BASFI	*$r_s = 0.59$*** $r_s = 0.63$**	*$r_s = 0.75$*** $r_s = 0.67$**	*$r_s = 0.68$*** $r_s = 0.51$**	*$r_s = 0.69$*** $r_s = 0.67$**
BASDAI	*$r_s = 0.67$*** $r_s = 0.58$**	*$r_s = 0.70$*** $r_s = 0.58$**	*$r_s = 0.73$*** $r_s = 0.56$**	*$r_s = 0.65$*** $r_s = 0.68$**
Low belief in chance	***n=45***	***n=46***	***n=51***	***n=43***
High belief in chance	**n=44**	**n=43**	**n=38**	**n=46**

Table A.4 shows correlations between each disease measure and depression scores in subgroups with high or low belief in chance. Subgroups were defined according to median scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.5. Correlations between anxiety scores (HADS-A) and disease scores in subgroups with low or high belief in powerful others (LOC).

	ASSESSMENT			
	1	2	3	4
BASMI	*$r_s = 0.52$*** $r_s = 0.31$*	*$r_s = 0.27$* $r_s = 0.35$*	*$r_s = 0.44$** $r_s = 0.45$*	*$r_s = 0.37$** $r_s = 0.27$
BASFI	*$r_s = 0.67$*** $r_s = 0.53$**	*$r_s = 0.67$*** $r_s = 0.42$*	*$r_s = 0.60$*** $r_s = 0.50$*	*$r_s = 0.56$*** $r_s = 0.60$**
BASDAI	*$r_s = 0.60$*** $r_s = 0.58$**	*$r_s = 0.71$*** $r_s = 0.55$**	*$r_s = 0.70$*** $r_s = 0.63$**	*$r_s = 0.52$*** $r_s = 0.70$**
Low belief in powerful others	***n=46***	***n=45***	***n=46***	***n=46***
High belief in powerful others	**n=43**	**n=44**	**n=43**	**n=43**

Table A.5 shows correlations between anxiety scores and disease scores in subgroups with high or low belief in powerful others. Subgroups were defined according to median scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.6. Correlations between depression scores (HADS-D) and disease scores in subgroups with low or high belief in powerful others (LOC).

	ASSESSMENT			
	1	2	3	4
BASMI	*$r_s = 0.52$*** $r_s = 0.35$*	*$r_s = 0.44$** $r_s = 0.55$**	*$r_s = 0.44$** $r_s = 0.45$*	*$r_s = 0.33$** $r_s = 0.44$*
BASFI	*$r_s = 0.73$*** $r_s = 0.48$*	*$r_s = 0.78$*** $r_s = 0.56$**	*$r_s = 0.66$*** $r_s = 0.51$**	*$r_s = 0.63$*** $r_s = 0.71$**
BASDAI	*$r_s = 0.74$*** $r_s = 0.54$**	*$r_s = 0.72$*** $r_s = 0.52$**	*$r_s = 0.66$*** $r_s = 0.63$**	*$r_s = 0.60$*** $r_s = 0.73$**
Low belief in powerful others	***n=46***	***n=45***	***n=46***	***n=46***
High belief in powerful others	**n=43**	**n=44**	**n=43**	**n=43**

Table A.6 shows correlations between each disease measure and depression scores in subgroups with high or low beliefs in powerful others at each assessment. Subgroups were defined by median scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.7. Correlations between BASFI and SF36 domain scores.

	ASSESSMENT			
	1	**2**	**3**	**4**
Physical functioning	$r_s = -0.84^{**}$	$r_s = -0.90^{**}$	$r_s = -0.89^{**}$	$r_s = -0.89^{**}$
Role limitation due to physical function	$r_s = 0.69^{**}$	$r_s = 0.78^{**}$	$r_s = 0.76^{**}$	$r_s = 0.78^{**}$
Role limitation due to emotional problems	$r_s = 0.59^{**}$	$r_s = 0.59^{**}$	$r_s = 0.47^{**}$	$r_s = 0.64^{**}$
Social functioning	$r_s = -0.60^{**}$	$r_s = -0.70^{**}$	$r_s = -0.69^{**}$	$r_s = -0.75^{**}$
Mental health	$r_s = -0.51^{**}$	$r_s = -0.49^{**}$	$r_s = -0.49^{**}$	$r_s = -0.56^{**}$
Energy and vitality	$r_s = -0.54^{**}$	$r_s = -0.66^{**}$	$r_s = -0.63^{**}$	$r_s = -0.69^{**}$
Bodily pain	$r_s = -0.59^{**}$	$r_s = -0.71^{**}$	$r_s = -0.77^{**}$	$r_s = -0.74^{**}$
General health perception	$r_s = -0.62^{**}$	$r_s = -0.58^{**}$	$r_s = -0.66^{**}$	$r_s = -0.65^{**}$
Change in health	$r_s = -0.10$	$r_s = -0.10$	$r_s = -0.11$	$r_s = -0.29^{*}$

Table A.7 shows correlations between scores for BASFI and each SF36 domain at assessments 1, 2, 3, and 4. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.8. Correlations between BASDAI and SF36 domains.

	ASSESSMENT			
	1	2	3	4
Physical functioning	$r_s = -0.70^{**}$	$r_s = -0.76^{**}$	$r_s = -0.73^{**}$	$r_s = -0.78^{**}$
Role limitation due to physical function	$r_s = 0.65^{**}$	$r_s = 0.76^{**}$	$r_s = 0.73^{**}$	$r_s = 0.78^{**}$
Role limitation due to emotional problems	$r_s = 0.59^{**}$	$r_s = 0.58^{**}$	$r_s = 0.50^{**}$	$r_s = 0.66^{**}$
Social functioning	$r_s = -0.63^{**}$	$r_s = -0.67^{**}$	$r_s = -0.72^{**}$	$r_s = -0.78^{**}$
Mental health	$r_s = -0.56^{**}$	$r_s = -0.58^{**}$	$r_s = -0.65^{**}$	$r_s = -0.65^{**}$
Energy and vitality	$r_s = -0.71^{**}$	$r_s = -0.72^{**}$	$r_s = -0.73^{**}$	$r_s = -0.79^{**}$
Bodily pain	$r_s = -0.71^{**}$	$r_s = -0.82^{**}$	$r_s = -0.88^{**}$	$r_s = -0.80^{**}$
General health perception	$r_s = -0.69^{**}$	$r_s = -0.57^{**}$	$r_s = -0.60^{**}$	$r_s = -0.60^{**}$
Change in health	$r_s = -0.14$	$r_s = -0.03$	$r_s = -0.15$	$r_s = -0.26^{*}$

Table A.8 shows correlations between scores for BASDAI and each SF36 domain at assessments 1, 2, 3, and 4. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.9. Correlations between social functioning and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = - 0.58**	r_s = - 0.70**	r_s = - 0.69**	r_s = - 0.66**
DEPRESSION	r_s = - 0.67**	r_s = - 0.78**	r_s = - 0.77**	r_s = - 0.72**
INTERNALITY	r_s = 0.22*	r_s = 0.13	r_s = 0.21*	r_s = 0.32*

Table A.9 shows correlations between social functioning and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.10. Correlations between energy and vitality and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = - 0.68**	r_s = - 0.67**	r_s = - 0.70**	r_s = - 0.55**
DEPRESSION	r_s = - 0.70**	r_s = - 0.75**	r_s = - 0.77**	r_s = - 0.73**
INTERNALITY	r_s = 0.32*	r_s = 0.21*	r_s = 0.15	r_s = 0.18

Table A.10 shows correlations between energy and vitality and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.11. Correlations between bodily pain and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = - 0.55**	r_s = - 0.65**	r_s = - 0.68**	r_s = - 0.58**
DEPRESSION	r_s = - 0.63**	r_s = - 0.68**	r_s = - 0.71**	r_s = - 0.65**
INTERNALITY	r_s = 0.19	r_s = 0.25*	r_s = 0.193	r_s = 0.30*

Table A.11 shows correlations between pain and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.12. Correlations between general health perception and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = - 0.59**	r_s = -0.60**	r_s = - 0.62**	r_s = - 0.56**
DEPRESSION	r_s = - 0.64**	r_s = - 0.68**	r_s = - 0.73**	r_s = - 0.65**
INTERNALITY	r_s = 0.37**	r_s = 0.31*	r_s = 0.26*	r_s = 0.28*

Table A.12 shows correlations between general health perception and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A. 13. Correlations between role limitation due to physical problems and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = 0.56**	r_s = 0.62**	r_s = 0.66**	r_s = 0.64**
DEPRESSION	r_s = 0.67**	r_s = 0.73**	r_s = 0.72**	r_s = 0.70**
INTERNALITY	r_s = - 0.19	r_s = - 0.30*	r_s = - 0.11	r_s = - 0.30*

Table A.13 shows correlations between role limitation due to physical problems and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.14. Correlations between role limitation due to emotional problems and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = 0.66**	r_s = 0.74**	r_s = 0.77**	r_s = 0.76**
DEPRESSION	r_s = 0.71**	r_s = 0.71**	r_s = 0.79**	r_s = 0.73**
INTERNALITY	r_s = - 0.23*	r_s = - 0.14	r_s = - 0.19	r_s = - 0.28*

Table A.14 shows correlations between role limitation due to emotional problems and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.15. Correlations between change in health and anxiety, depression and internality

	ASSESSMENT			
	1	2	3	4
ANXIETY	r_s = - 0.18	r_s = 0.06	r_s = - 0.05	r_s = - 0.25*
DEPRESSION	r_s = - 0.10	r_s = - 0.00	r_s = - 0.13	r_s = - 0.17
INTERNALITY	r_s = 0.12	r_s = - 0.04	r_s = 0.00	r_s = 0.02

Table A.15 shows correlations between change in health and anxiety, depression and internality scores at each assessment. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.16. Correlations between disease scores and depression in participants with and without a history of iritis.

ASSESSMENT			
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.43**	*r_s = 0.60***	*r_s = 0.51**	*r_s = 0.50**
r_s = 0.47*	r_s = 0.50**	r_s = 0.45*	r_s = 0.37*
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.59***	*r_s = 0.66***	*r_s = 0.57***	*r_s = 0.74***
r_s = 0.62**	r_s = 0.74**	r_s = 0.66**	r_s = 0.66**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.53***	*r_s = 0.60***	*r_s = 0.65***	*r_s = 0.73***
r_s = 0.72**	r_s = 0.69**	r_s = 0.65**	r_s = 0.61**

Table A.16 shows correlations between each disease measure and depression scores at each assessment in people with (shown in italics) and without a history of iritis. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.17. Correlations between disease scores and anxiety in participants with and without psoriasis.

	ASSESSMENT		
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
r_s = 0.31	*r_s = 0.06*	*r_s = 0.14*	*r_s = 0.15*
r_s = 0.46**	r_s = 0.38*	r_s = 0.51**	r_s = 0.43**
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.72**	*r_s = 0.55**	*r_s = 0.49*	*r_s = 0.59**
r_s = 0.58**	r_s = 0.58**	r_s = 0.59**	r_s = 0.61**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.79**	*r_s = 0.58**	*r_s = 0.61**	*r_s = 0.61**
r_s = 0.53**	r_s = 0.62**	r_s = 0.67**	r_s = 0.61**

Table A.17 shows correlations between each disease measure and anxiety scores in subgroups with (shown in italics) and without psoriasis. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.18. Correlations between age and depression scores in subgroups younger than and older than 50 years

	ASSESSMENT		
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.49**	*r_s = 0.55***	*r_s = 0.50***	*r_s = 0.45**
r_s = 0.36*	r_s = 0.41*	r_s = 0.37*	r_s = 0.35*
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.68***	*r_s = 0.75***	*r_s = 0.66***	*r_s = 0.69***
r_s = 0.48*	r_s = 0.58*	r_s = 0.45*	r_s = 0.60**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.71***	*r_s = 0.70***	*r_s = 0.63***	*r_s = 0.65***
r_s = 0.54**	r_s = 0.55**	r_s = 0.62**	r_s = 0.66**

Table A.18 shows correlations between each disease measure and depression scores at in subgroups defined according to whether people were younger (shown in italics) or older than 50 years at the beginning of the study. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.19. Correlations between disease scores and depression with subgroups with disease duration less and more than 20 years.

	ASSESSMENT		
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.53***	*r_s = 0.54***	*r_s = 0.55***	*r_s = 0.50***
r_s = 0.29	r_s = 0.52*	r_s = 0.34*	r_s = 0.32*
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.64***	*r_s = 0.72***	*r_s = 0.66***	*r_s = 0.69***
r_s = 0.57**	r_s = 0.66**	r_s = 0.57**	r_s = 0.66**
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.70***	*r_s = 0.68***	*r_s = 0.65***	*r_s = 0.65***
r_s = 0.55**	r_s = 0.60**	r_s = 0.68**	r_s = 0.72**

Table A.19 shows correlations between each disease measure and depression scores in subgroups defined according to whether participants had a disease duration of less (shown in italics) or more than 20 years at the beginning of the study. Correlations between variables were assessed using Spearman's rank correlations (r_s).
P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Table A.20. Correlations between disease scores and anxiety in subgroups defined by gender.

	ASSESSMENT		
1	2	3	4
BASMI	**BASMI**	**BASMI**	**BASMI**
*r_s = 0.77**	*r_s = 0.79**	*r_s = 0.76**	*r_s = 0.65**
r_s = 0.36*	r_s = 0.26*	r_s = 0.40*	r_s = 0.32
BASFI	**BASFI**	**BASFI**	**BASFI**
*r_s = 0.53**	*r_s = 0.73**	*r_s = 0.67**	*r_s = 0.63**
r_s = 0.63*	r_s = 0.52*	r_s = 0.56*	r_s = 0.59*
BASDAI	**BASDAI**	**BASDAI**	**BASDAI**
*r_s = 0.75**	*r_s = 0.69**	*r_s = 0.72**	*r_s = 0.68**
r_s = 0.54*	r_s = 0.62*	r_s = 0.66*	r_s = 0.62*

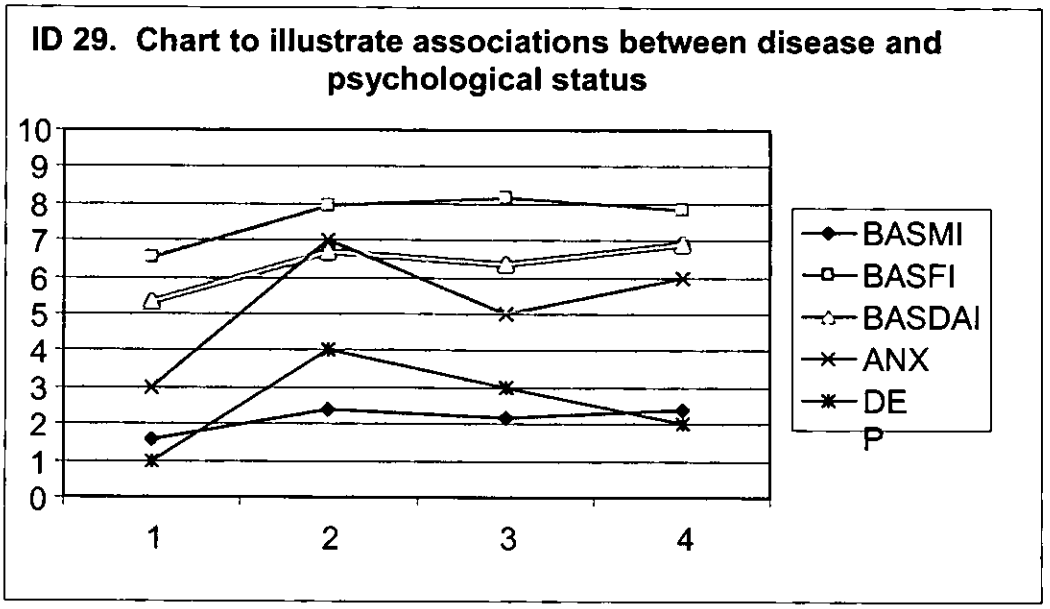
Table A.20 shows correlations between each disease measure and anxiety scores in males (shown in italics) and females. Correlations between variables were assessed using Spearman's rank correlations (r_s). P-values are denoted as: * $P < 0.05$, ** $P < 0.001$.

Disease and psychological scores for individuals who entered the qualitative study

The tables and charts for each of the 11 individuals who went on to the qualitative study are shown. Each table shows strengths of correlations between disease and psychological scores. The highest change which occurred for both the disease and psychological score are also shown, together with the percentage change which this reflects. The range of scores for the individual recorded over the course of the study has also been included to demonstrate the extent of variation, which occurred.

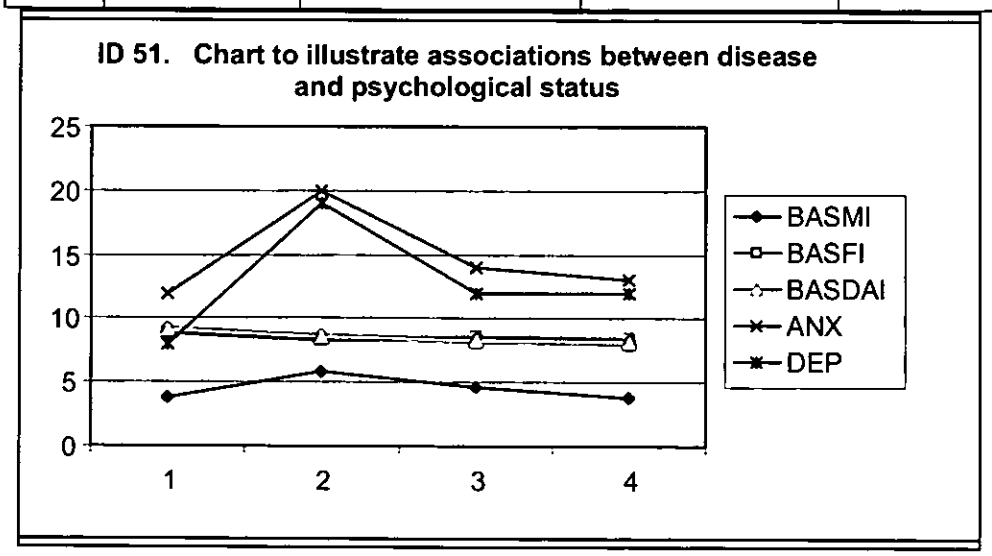
Individual 29

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
29	BASMI Anxiety r = 0.95	0.8 4	50% 133%	1.6 to 2.4 3 to 7
	BASFI Anxiety r = 0.80	1.4 4	22% 133%	6.53 to 8.2 3 to 7
	BASDAI Anxiety r = 0.92	1.4 4	26% 133%	5.3 to 6.9 3 to 7
	BASMI Depression r = 0.75	0.8 3	50% 300%	1.6 to 2.4 1 to 4
	BASFI Depression r = 0.81	1.4 3	22% 300%	6.5 to 8.2 1 to 4
	BASDAI Depression r = 0.67	1.4 3	26% 300%	5.3 to 6.9 1 to 4



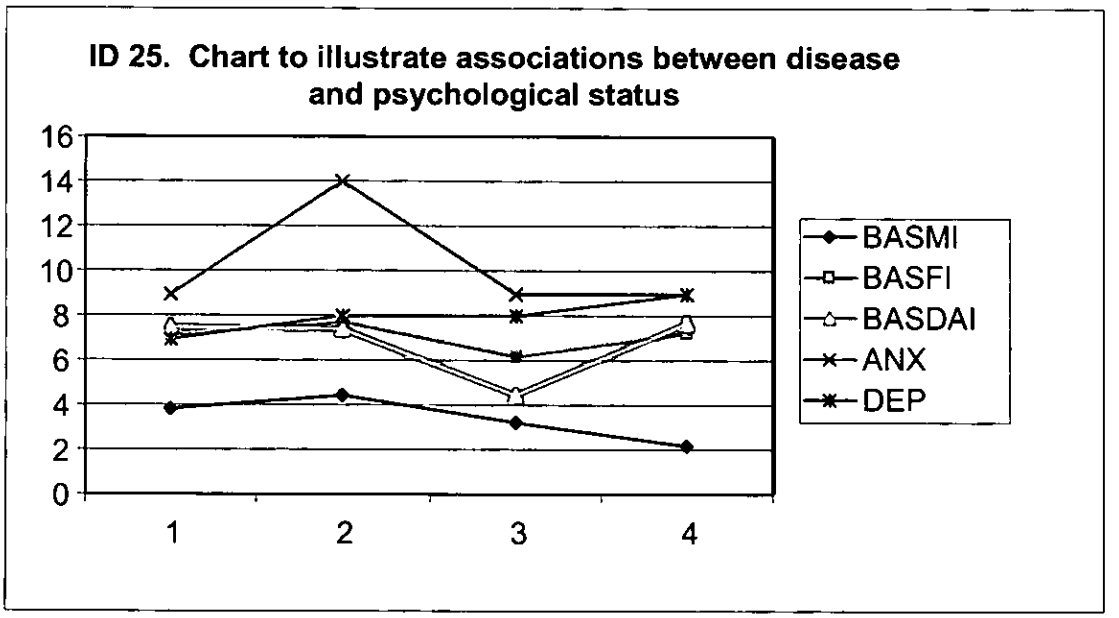
Individual 51

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
51	BASMI Anxiety r = 0.97	2.0 8	53% 66%	3.8 to 5.8 12 to 20
	BASMI Depression r = 0.92	2.2 11	53% 137%	3.8 to 5.8 12 to 20



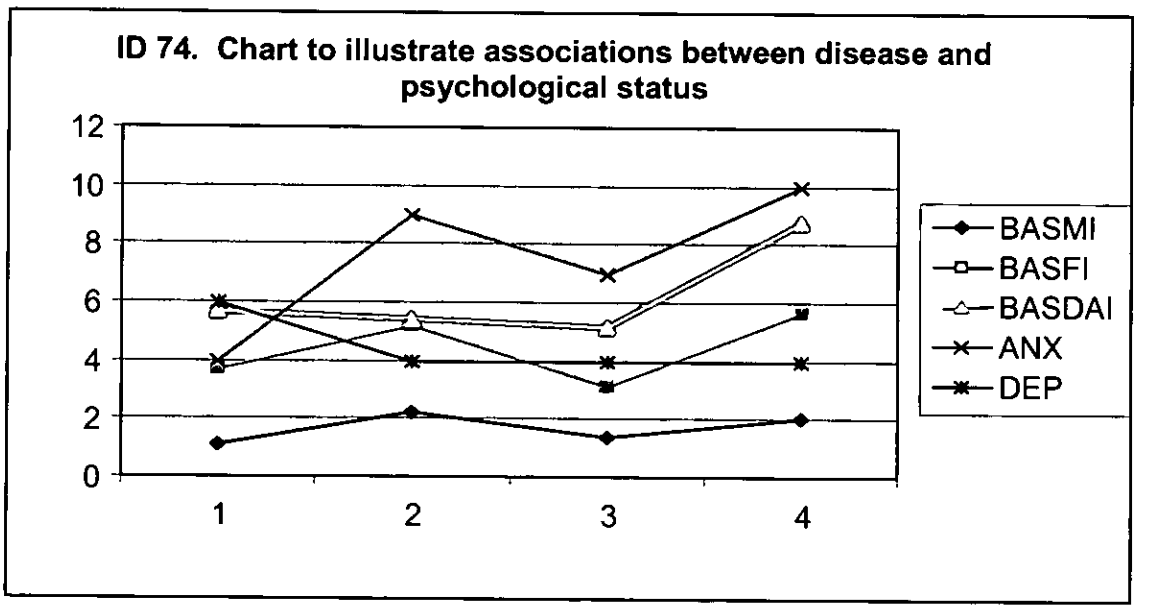
Individual 25

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
25	BASFI Anxiety r = 0.66	1.5 5	25% 55%	6.2 to 7.7 9 to 14
	BASMI Anxiety r = 0.71	1.2 5	37% 55%	4.4 to 2.2 9 to 14



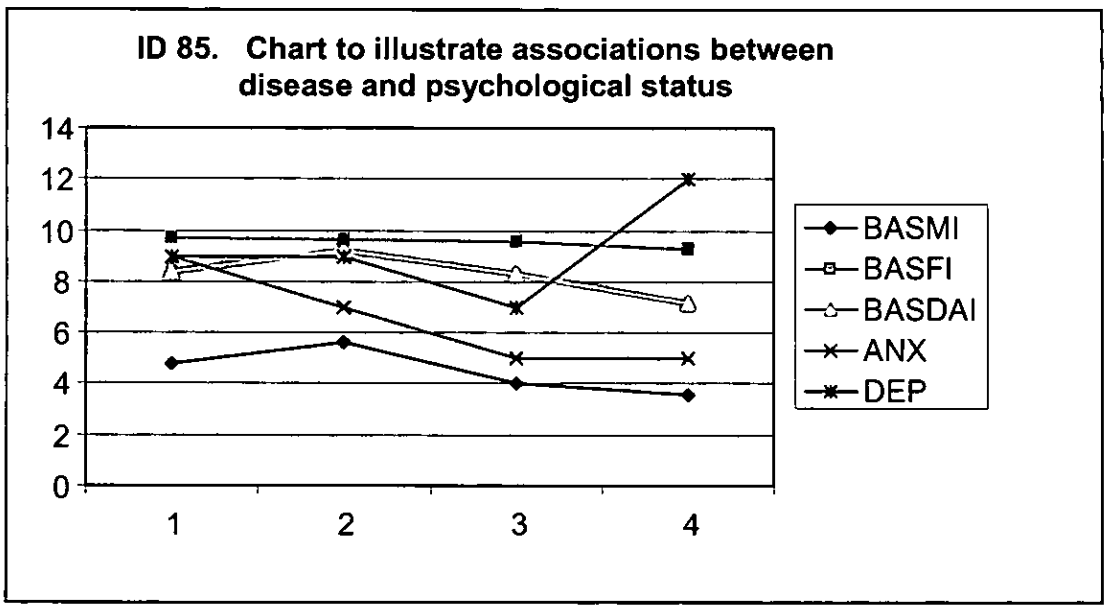
Individual 74

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
74	BASMI Anxiety r = 0.92	1.1 6	100% 125%	1.1 to 2.2 4 to 10
	BASFI Anxiety r = 0.78	2.6 6	80% 125%	3.1 to 5.7 4 to 10
	BASDAI Anxiety r = 0.57	3.6 6	69% 125%	5.2 to 8.7 4 to 10



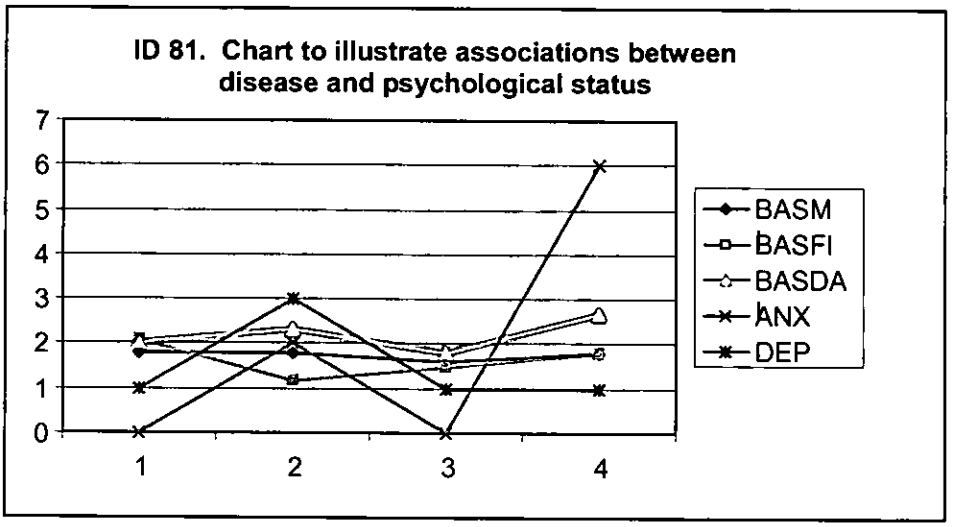
Individual 85

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
85	BASMI Anxiety r = 0.67	1.6 4	40% 40%	3.6 to 5.6 5 to 9
	BASFI Anxiety r = 0.83	0.2 4	40% 40%	9.3 to 9.7 5 to 9



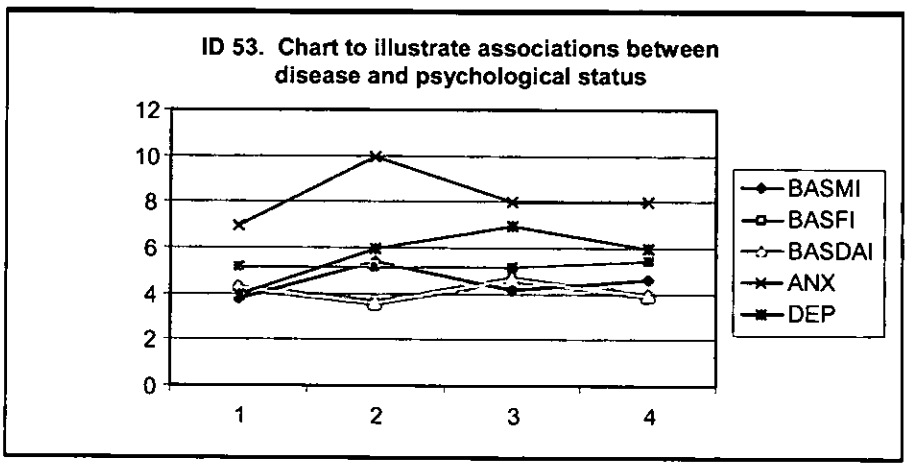
Individual 81

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
81	BASDAI Anxiety r = 0.93	0.9 6	49% 100%	1.8 to 2.7 0 to 6



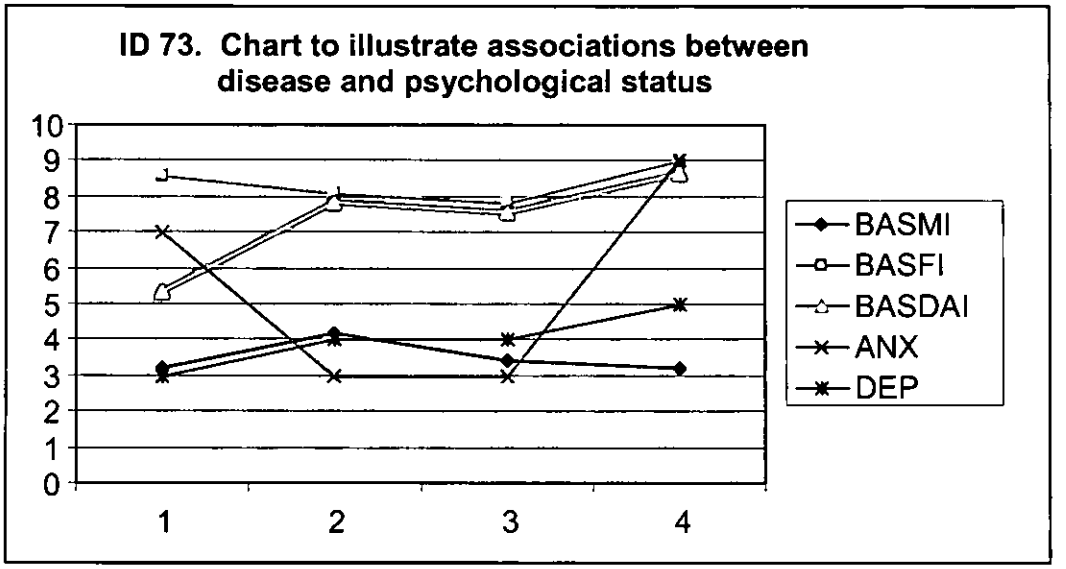
Individual 53

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
53	BASMI Anxiety r = 0.97	1.6 3	42% 43%	3.8 to 5.4 7 to 10



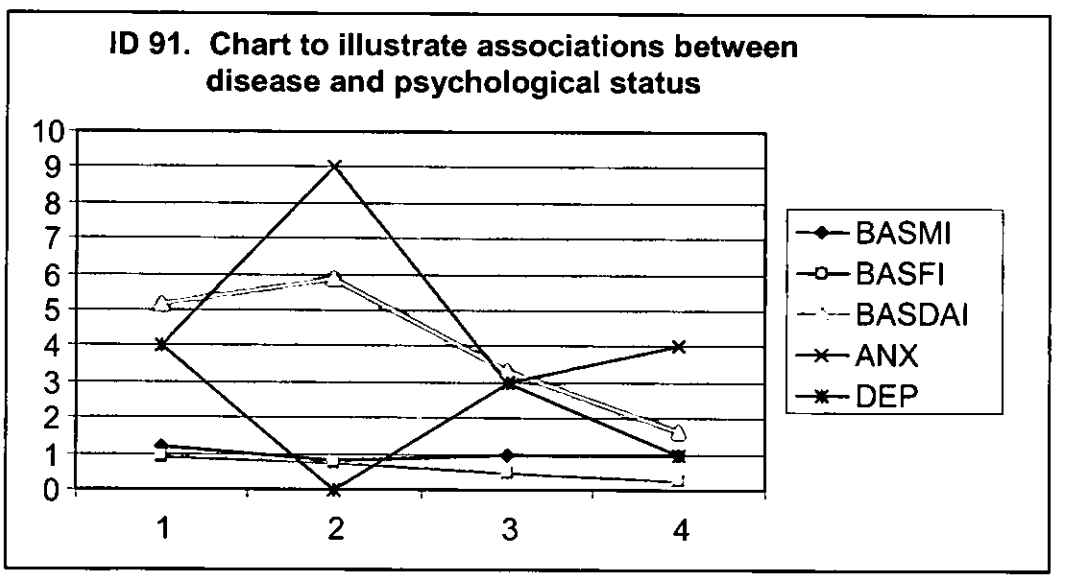
Individual 73

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
73	BASFI Anxiety r = 0.97	1.2 6	15% 200%	7.8 to 9.0 3 to 9
	BASDAI Depression r = 0.95	2.5 1	47% 25%	5.3 to 8.7 3 to 5



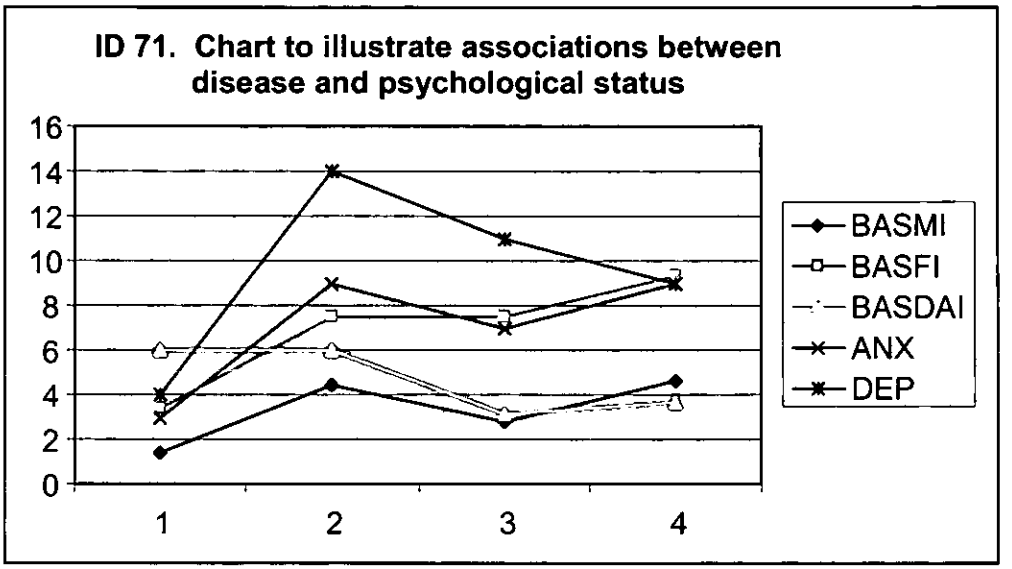
Individual 91

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
91	BASDAI Anxiety r = 0.65	2.6 6	78% 200%	1.6 to 5.9 3 to 9
	BASMI Depression r = 0.89	2.5 4	50% 100%	0.8 to 1.2 4 to 0



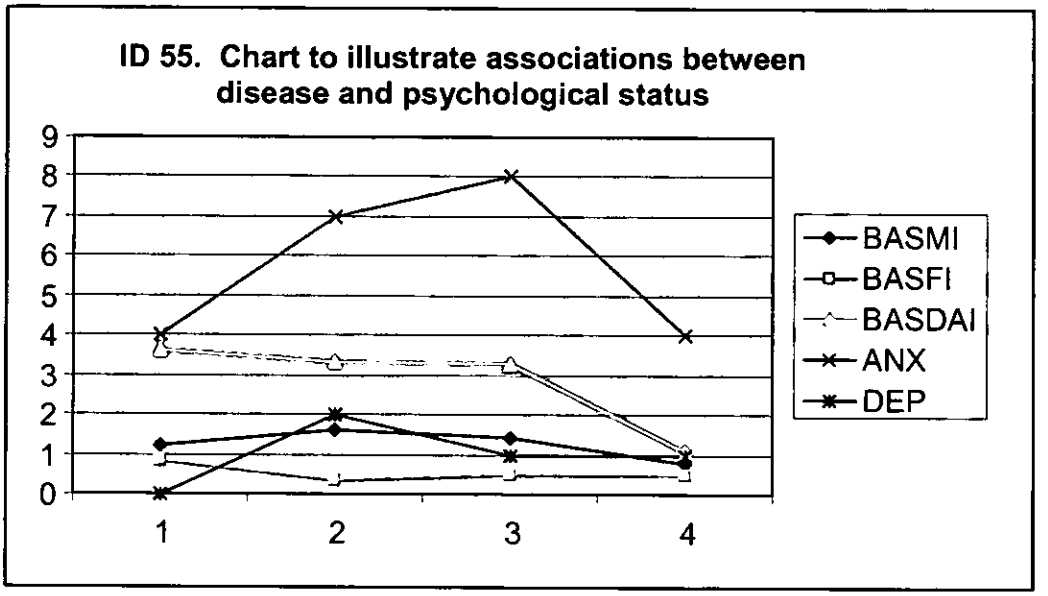
Individual 71

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
71	BASMI Anxiety r = 0.97	3.0 6	200% 200%	1.4 to 4.6 3 to 9
	BASFI Anxiety r = 0.94	4.1 6	120% 200%	3.4 to 9.3 3 to 9
	BASMI Depression r = 0.74	3.0 10	214% 250%	1.4 to 4.6 4 to 14
	BASFI Depression r = 0.69	4.1 10	121% 250%	3.4 to 9.3 4 to 14



Individual 55

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
55	BASMI Anxiety r = 0.78	0.6 4	75% 100%	0.8 to 1.6 4 to 8


ID 55. Chart to illustrate associations between disease and psychological status
9
8
7
6
5
4
3
2
1
0
1
2
3
4
BASMI
BASFI
BASDAI
ANX
DEP

Disease and psychological scores for individuals who qualified for but did not enter the qualitative study

The tables for each of the 5 individuals who qualified for but did not proceed to the qualitative study are shown. Each table shows strengths of correlations between disease and psychological scores. The highest change, which occurred for both the disease and psychological score, are also shown, together with the percentage change, which this reflects. The range of scores for the individual recorded over the course of the study has also been included to demonstrate the extent of variation which occurred.

Individual 37

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
37	BASMI Anxiety r = 0.96	1.4 6	41% 300%	3.4 to 4.8 2 to 8
	BASFI Anxiety r = 0.99	2.9 6	46% 300%	6.3 to 9.2 2 to 8
	BASDAI Anxiety r = 0.92	4.0 6	184% 300%	2.2 to 7.0 2 to 8
	BASDAI Depression r = 0.69	4.0 6	184% 150%	2.2 to 7.0 4 to 10

Individual 92

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
92	BASDAI Anxiety r = 0.73	0.8 6	115% 600%	0.7 to 1.4 1 to 7
	BASMI Depression r = 0.94	0.4 4	66% 400%	0.4 to 1.0 0 to 4

Individual 45

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
45	BASFI Anxiety r = 0.88	1.7 5	26% 71%	6.6 to 9.2 7 to 12
	BASMI Depression r = 0.99	1.0 6	23% 150%	4.4 to 5.4 2 to 10
	BASFI Anxiety r = 0.87	1.7 6	26% 150%	6.2 to 9.2 2 to 10
	BASDAI Depression r = 0.69	2.5 6	40% 150%	6.3 to 8.8 2 to 10

Individual 60

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
60	BASDAI Anxiety r = 0.67	3.2 4	55% 200%	8.9 to 5.8 8 to 2
	BASFI Depression r = 0.68	0.7 7	18% 266%	2.8 to 3.8 11 to 3
	BASDAI Depression r = 0.74	3.2 7	55% 266%	5.8 to 9.0 11 to 3

Individual 48

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
48	BASMI Anxiety r = 0.95	2.2 6	61% 46%	2.8 to 5.8 12 to 19
	BASFI Anxiety r = 0.99	2.0 6	47% 46%	4.2 to 6.1 12 to 19
	BASDAI Anxiety r = 0.82	2.2 6	43% 46%	5.0 to 7.7 13 to 19
	BASMI Depression r = 0.82	2.2 3	61% 100%	2.8 to 5.8 2 to 6
	BASFI Depression r = 0.57	2.0 3	40% 100%	4.2 to 6.1 2 to 6

Summary data for individuals who did not meet full inclusion criteria for entry into the qualitative study

For these 11 individuals, although the r values indicating strength of associations between disease and psychological status are high, the level of change in disease and psychological status scores was too low to suggest dynamic and concurrent change in the relationship between the two scores.

Data for individuals in whom associations were high but percentage change in scores were low

ID	Correlation	Highest change between two consecutive points	Percentage change	Range of scores
4	BASMI Anxiety r = 0.77	0.4 3	10% 23%	4.4 to 4.0 13 to 16
	BASDAI Anxiety r = 0.57	0.5 3	9% 23%	6.3 to 7.4 13 to 16
6	BASFI Anxiety r = 0.96	0.9 3	18% 25%	4.9 to 5.8 12 to 15
	BASDAI Depression r = 0.83	0.9 4	18% 50%	4.9 to 5.8 4 to 8
12	BASDAI Anxiety r = 0.91	1.8 3	56% 60%	3.1 to 4.9 5 to 8
	BASMI Depression r = 0.51	1.0 1	27% 11%	3.6 to 4.6 8 to 10

	BASFI Depression r = 0.99	1.2 1	17% 11%	5.3 to 7.8 8 to 10
26	BASMI Anxiety r = 0.64	1.0 2	28% 16%	3.6 to 4.6 10 to 14
	BASFI Anxiety r = 0.59	0.9 2	14% 16%	6.4 to 7.3 10 to 14
	BASDAI Anxiety r = 0.80	0.7 2	10% 16%	6.2 to 7.6 10 to 14
	BASMI Depression r = 0.50	1.0 4	28% 26%	3.6 to 4.6 13 to 19
	BASDAI Depression r = 0.78	0.7 4	10% 26%	6.2 to 7.6 13 to 19
47	BASDAI Anxiety r = 0.98	1.9 3	35% 27%	5.4 to 7.2 11 to 14
	BASFI Depression r = 0.63	1.0 4	15% 40%	6.4 to 7.3 10 to 14
58	BASFI Anxiety r = 0.98	0.8 2	21% 18%	3.8 to 5.0 11 to 14

	BASDAI Anxiety r = 0.80	0.9 2	15% 18%	5.9 to 6.9 11 to 14
	BASMI Depression r = 0.75	1.2 6	27% 85%	4.4 to 5.6 7 to 14
	BASFI Depression r = 0.87	0.8 6	21% 85%	3.8 to 5.0 7 to 14
	BASDAI Depression r = 0.98	0.9 6	15% 85%	6.0 to 7.0 7 to 14
70	BASFI Anxiety r = 0.77	1.4 3	21% 43%	6.1 to 7.8 7 to 10
	BASDAI Anxiety r = 0.99	1.3 3	27% 43%	4.8 to 6.1 7 to 10
	BASMI Depression r = 0.94	0.6 2	9% 20%	6.4 to 7.2 9 to 12
88	BASDAI Depression r = 0.57	1.7 5	29% 41%	5.9 to 7.6 12 to 17
95	BASMI Anxiety r = 0.68	0.2 7	4% 140%	4.8 to 5.0 5 to 12
	BASDAI Anxiety r = 0.79	1.2 7	16% 140%	6.4 to 8.3 5 to 12

95	BASFI Depression r = 0.85	4.4 2	136% 25%	3.2 to 7.6 8 to 11
	BASDAI Depression r = 0.51	1.2 2	16% 25%	6.4 to 8.3 8 to 11
107	BASMI Anxiety r = 0.67	0.4 3	8% 30%	4.8 to 5.2 7 to 11
	BASMI Depression r = 0.92	0.4 5	8% 42%	4.8 to 5.2 7 to 12
	BASFI Depression r = 0.93	2.8 5	103% 42%	2.7 to 5.6 7 to 12

Individuals' descriptions

13

Individual 1 (ID29)

Before the initial study

Male aged 57.

Disease duration – 34 years with age of onset aged 21.

Has concurrent Iritis and skin involvement (minimal).

Working full time in a high powered job. He describes coming home from work and falling asleep immediately due to mental exhaustion.

He is a Lay preacher.

Happily married and has 2 children and grandchildren.

His daughter also has AS which was diagnosed several years before the study.

During the initial study

Developed atrial fibrillation accompanied with an irritating cough towards the end of the study.

His physical measurement range was good but there was a significant change in this and the self report measures during the initial study.

Anxiety and depression scores are not significant.

However there were associations for both anxiety and depression and all disease status assessments over the 18 month period.

After the initial study

Job became less demanding.

Atrial fibrillation seemed to worsen and medical tests were frightening.

Increased concern over chest pains which were a new symptom.

What was talked about

His wife read his diary and was surprised and somewhat alarmed that she had not realised the amount of pain and discomfort that he was feeling.

His father was an above knee amputee. He openly talks about his father's acceptance of his disability and his ability to 'just get on with it'. This he feels has influenced his ability to accept and deal with his AS. He is anxious not to disclose that he 'has a bad back' to others.

Now that he is less responsible at work however, he had presumed that he would have more energy in the evenings to enjoy a more active social life. He is disappointed that this is not the case as he finds that he still needs to rest when he comes home and

therefore feels that his 'enjoyment side' of life is still curtailed. As a journalist he has witnessed a lot of traumatic events and was never offered counselling. This he compares to the Emergency Services reliance on this.

He enjoys Police type programmes on the TV. He enjoys having his grandchildren around but is disappointed that he cannot physically play with them as he did with his own children due to his physical limitations. They enjoy caravanning holidays but he discloses that it is becoming more difficult to set up the site. He 'can't be bothered' with the hastle and preparation aspects anymore and yet after making the effort can immediately relax and enjoy the time when there. He is becoming more inpatient, as he is getting older. He describes however a part of his personality that when there he cannot wait to get back home on the last one or two days.

He enjoys driving but now feels more frustrated that he cannot drive for long distances as he used to do because of discomfort. He now has 'given in' and delegated driving longer distances to his wife.

He is a lay Reader and has noticed that from formerly being very organised, he now writes his sermons on the last minute. He described his lack of methodical working. He finds it more difficult to concentrate and easily forgets things now. He also finds DIY tasks a lot hard which makes him frustrated.

Atrial Fibrillation has dominated his life recently. He is extremely anxious about this and is dreading further medical tests. He has an irritating cough and is very embarrassed about this as he says 'people can hear him coming'. He experiences a great deal of confusion with this condition and a recent episode of chest wall pain, which was a new area of involvement for him. He openly talks about his anxiety around this issue.

The diary for him was the first time that he had really been asked to focus on his psychological state and he was beginning to feel that his condition was beginning to get him down.

Individual 2 (ID51)

Before the initial study

Male aged 66.

Disease duration – 21 years with age of onset aged 42.

Co-morbidity includes Osteoporosis, depression.

Medically retired for many years.

Son who was living with them died from drugs over dose. They had not been aware of the drug problem. Other family live near by.

During the initial study

His wife died towards the end of the study.

His physical measurement range was moderately affected and there was a significant change in this during the initial study. Scoring for the self report measures were constantly high.

Anxiety and depression scores indicate clinical anxiety and depression throughout the study period.

There were associations for both anxiety and depression with the physical assessment score only.

After the initial study

His dog died and he felt unable to replace her.

He was awaiting a hernia repair over which he is very anxious as a blood disorder was found as part of the pre operative screening. He is very anxious that he may not wake after the anaesthetic.

He was unable to complete a diary and gave no reason for this.

What was talked about

He blames all his back problems on a physical trauma at work. He really does attribute his AS to this. He had previously been a miner and had been forced to 'go down the pit'. His father had died when he was 14 and he had to support the family. He changed to a physical council Services job and when the doctor said he would never work again, he had cried as he was unsure of how he could pay the mortgage and survive. He regrets the way that his life has turned out.

He describes how his wife was terribly depressed at the trauma of loosing their son and that she never fully recovered. Their son had died of a drugs overdose in their own home. They were not aware of his drugs problem and had said goodnight. They heard a bang upstairs but had not investigated. The following morning, they had found him and could not come to terms with the fact that they had not 'looked in on him'. His wife's illness had been very traumatic and following investigations she was transferred to a hospital in Birmingham where she died. The trauma and the travelling had been a

lot to deal with at the time. He described how he still has her clothes at home and how he should get rid of these but he has not been able to do so.

He also enjoyed his dog who he says really helped to keep him active. He was able to get out of the house and socialise as he walked her. Tragically she also died and he cannot bring himself to replace her. His other son has children and they visit from time to time.

Playing darts had been 'the only thing that I was ever any good at'. He became increasingly worried about excess alcohol abuse and the expense this would cause. These were some of the reasons for stopping this hobby along with the fact that other people 'felt sorry for him' and picked up his darts was also a factor.

He relies heavily on two friends. One friend does have a drink problem and he tries to avoid visiting too often. His other friend has been his 'rod' and they help one another considerably. He is very proud and doesn't want people helping him in the house. He openly talks about feeling depressed and isolated. He expresses fear of falling, as there will be no one there to get help. He has great difficulty sleeping and becomes very afraid of moving when his pain becomes more severe.

Individual 3 (ID 25)

Before the initial study

Male aged 44.

Disease duration – 24 years with age of onset aged 18.

He has concurrent skin involvement.

Co-morbidity includes: depression, panic attacks, claustrophobia.

He has been receiving incapacity benefit for many years.

He is married and lives in a council house in an area that he does not like. He has three children, the eldest aged 21 (has Autism), daughter aged 17, and youngest son ages 13 (has ADH). They had been forced to move because of the eldest son's autism. This is his second marriage.

His mother in law has schizophrenia and they look after her. She has both tablet and alcohol abuse problems.

His father died in 1996 and this had a devastating affect on him. Matters were made worse because at the time his sister in law was in intensive care and this was hidden from their father.

He has many issues around this very traumatic time in his life and has received counselling. He remains psychologically scarred and is very much aware of this.

During the initial study

His physical measurement range is good but there was a significant change in this and the self-report measure of disease activity during the initial study.

Anxiety scores indicated clinical anxiety throughout the study and depression scores were bordering on clinical depression ranges.

There were associations with anxiety and movement assessment and self report functional assessment during the study.

After the initial study

He was awaiting ulna nerve decompression surgery.

His mother was knocked down and has become depressed as a result of this. He is currently caring for her also.

What was talked about

He had been a motorbike mechanic but had not worked since diagnosis. He still has three motorbikes but he is unable to ride these due to physical problems. He hides his pain and discomfort from others. He also acknowledges his reliance on mobility not only physically but his reliance on transport. In the car he feels he has freedom.

He talked freely about being depressed and anxious but sees the fact that he has so many other people to support that he has very little time to concentrate on his physical treatment for his AS.

The recent onset of the arm pain and loss of function in his arm has been difficult to deal with as he finds it hard to determine if this has affected him emotionally more so than the AS.

He describes claustrophobia feelings and a traumatic incident with his daughter but very little else about AS specifically.

Individual 4 (ID 74)

Before the initial study

Male aged 38.

Disease duration – 18 years with age of onset aged 18.

Has concurrent skin involvement.

Co-morbidity includes: perceived RA (peripheral joint involvement as first symtomology).

He lives with his partner

He also has a 14-year-old daughter from his previous marriage.

During the initial study

His stomach ulcer and abdominal hernia were becoming a problem towards the end of the study.

His physical measurement range was good and there was a significant change in the self report measure of disease activity during the initial study.

Anxiety scores bordered on clinical anxiety at some points during the study although depression scores did not.

There were associations with anxiety and movement assessment and self report functional assessment during the study.

After the initial study

He was awaiting surgery to repair abdominal hernia. He and his partner had just had a baby.

He was given news about possible redundancy.

Unfortunately he has now become unemployed and has financial worries to contend with.

What was talked about

He was very physically active at work and chose this type of work purposefully to remain active as he saw this as a way of coping with his symptomology. He finds it physically demanding to pick up his baby daughter and fears falling especially when

coming down stairs because of knee pain. He talks about how he has to exercise to relieve stiffness and has several coping strategies including diet and going against medical advice as in riding motorbikes and seeing Chiropractors in the past. He is more of a 'rebel'. He sees how AS has changed him as he is now more angry and irritable and easily wound up. He is able to say that AS makes him depressed and he is very much in tune with his own feelings about this and feels that he is able to cope. He feels a need for 'release' at times and usually 'gets drunk' about once every six months. His friends call him 'Stiffy' because of his neck but he seems to accept this.

Having the hernia has been a significant problem as it has curtailed a lot of his exercise and therefore coping strategies and therefore feels that he is grumpier. The peptic ulcer has also limited him lying flat in bed at night and has added to sleep disturbance along with the baby. He recognises these things as being factors in the way that he is feeling emotionally. He also attributes his getting a bit older as making things a bit more difficult for him to deal with. He is very much aware of medication and his reliance on it. Doctor's for him can be inept as he knows his own mind on what works for him and what doesn't.

Individual 5 (ID 85)

Before the initial study

Male aged 60.

Disease duration – 42 years with age of onset aged 15.

Has concurrent skin involvement.

Co-morbidity includes: significant peripheral joint involvement. high blood pressure.

Retired – took voluntary early retirement from a career in engineering.

His wife has RA and he is her carer.

During the initial study

High blood pressure was diagnosed.

The spinal problem progresses to leg weakness and loss of muscle bulk.

His wife's health was deteriorating. Her knee replacement becomes infected.

His physical measurement range is reduced and self reported disease status is high throughout the study.

Anxiety scores bordered on clinical anxiety during the study and depression scores were clinically significant throughout.

There were associations with anxiety and movement assessment and self report functional assessment during the study.

After the initial study

He is awaiting surgery for spinal stenosis. There was rapid deterioration and legs give way without warning.

His wife now has a heart problems and requires heart surgery.

What was talked about

He cares for his wife and they are considering moving into a bungalow as the stairs are a problem for both of them. He is extremely distressed about his deteriorating condition with leg weakness increasing. His father had AS and was almost bed ridden for 17 years. He witnessed the muscle wastage and was very concerned that he would be the same. He had fears about the spinal operation and was reluctant to have this although he saw that he would not get any better. He expresses fears of ending up in a wheelchair and the loss of independence and having to rely on others. An epidural performed whilst writing the diary makes it evident that he enjoyed the nursing attention. He has a great reliance on the medical profession and expresses exasperation at what he sees as declining medical services. Their daughter had recently moved to be near them although he was very reticent to let her help more.

He was very angry that now that they were retired that they should be able to enjoy themselves after working all their lives. He is extremely unhappy that their lives are restricted by their medical conditions and the constant round of hospital appointments. This anger and frustration is also manifest when describing how he can no longer go to the gym and that he had really enjoyed exercise. He compared himself to his son and there was a degree of envy in his son's appearance.

He felt that because of his condition he was loosing the ability to protect his wife in a physical way. He felt vulnerable in a way that he hated having been proud of his previous strength and physical prowess. He has issues over his age with a wish to be younger and fitter.

He describes himself as enjoying socialising and having the 'crack' with their friends. He acknowledges that he is very short tempered and that this does not help his blood pressure. When driving he 'cannot suffer idiots'. He loves driving but hates other forms of transport where he is not in control. He tends to get up very early in the morning and driving to Blackpool where they will have breakfast and a walk if they are able. By the afternoon he usually has to rest and sees this as a waste of time. He feels that the enjoyment that he has in his life has been severely restricted by his medical condition – not the AS but the spinal stenosis. The uncertainty of the leg weakness has led to falls and dangerous situations. He is loosing control and is obviously very frightened although he unable to admit this.

Individual 6 (ID 81)

Before the initial study

Female aged 59.

Disease duration – 29 years with age of onset aged 29.

She has concurrent iritis.

She lives with her husband and they have been married for over 30 years.

He was a Chief Fire Officer and now teaches First Aid on a part time basis.

She was a Staff Nurse but took early retirement on medical grounds shortly after being diagnosed. She describes that because of the iritis she felt useless in the clinic when she was unable to see the amount of fluid in a syringe and felt that she would be dangerous.

They have 2 sons.

During the initial study

There were no flares of iritis.

Her physical measurement range were extremely good and there were no significant changes in the self report measure of disease activity during the initial study.

Anxiety and depression scores were extremely low throughout.

There was an association with anxiety and self report disease activity only.

After the initial study

Co-morbidity – OA hand involvement

One son lost his eye and she feels somewhat guilty about this as his problem was diagnosed as iritis due to her condition when in fact it was a severe infection.

Her other son and family including their only grandchildren, recently emigrated to Australia

She is extremely distressed about this and admits that this causes her more emotional distress than her condition.

What was talked about

They enjoy caravan holidays and although she finds the preparation tedious and harder to do when she is in pain she is very anxious to hide her discomfort from her husband. However, she describes how he will purposefully limit her physical activity if he perceives that it will make her worse. She enjoys gardening but finds it irritating that her back pain can limit her activities although she describes how her husband will have a hot bath ready for her.

Her coping mechanisms revolve around heat and hot baths. She feels guilty at resting on bad days as she feels that she achieves nothing from her day. She enjoys dog walking and perceives that she is better in the summer as she gardens more and walks the dog much more. They also enjoy ballroom dancing but she will rest through the day in order to be able to enjoy the activity in the evening. If she has a disturbed sleep it is due to menopausal sweating and she is very irritable when she looses sleep. She is aware of fatigue as being a problem for her but tends to refer to it as tiredness and yawning at embarrassing times. However, there are no confines on her time and she often lies in and recuperates in that way. She has a good network of friends but she tends to hide any pain and discomfort from them. She hates her limitations preventing others from enjoying themselves.

Prior to diagnosis she describes the hip pain as being so severe that she feared that she would need a wheelchair and that she would loose her independence. She was extremely distressed at his time. Ititis has been her main concern. She has had many attacks and still recalls the distress and inconvenience when she was younger and her children were young.

Recent shoulder problems had led to some anxiety as this was a new area of involvement. She takes a great deal of care with her personal appearance and the thought of being unable to style her hair due to the pain when holding her hairdryer was quite worrying for her.

Her perception of her AS was that it was a very mild case and that she had been extremely lucky. Her iritis caused her far more concern but her knowledge of this was extensive and psychological distress caused by an attack she describes as transient.

Individual 7 (ID 53)

Before the initial study

Male aged 63.

Disease duration – 27 years with age of onset aged 33.

Has no concurrent condition.

His diagnosis was delayed for over 20 years.

As a result of his medical condition prior to diagnosis he had volunteered for early retirement.

He had started an Open University degree in history. Unfortunately this was before the diagnosis and pain levels prevented him from concentrating and he had to give this up. This was a decision, which he regretted.

He has three daughters from his first marriage.

He did feel however that the break up of his first marriage may have been attributable to his irritability caused by his unexplained pain during those years.

During the initial study

A heart condition was diagnosed. He was recommended to increased his exercise levels and now walks his dog and enjoys this.

His physical measurement range is limited and the self-report measures were reasonably stable over the study period at moderate levels.

Anxiety scores bordered on clinical anxiety during the study although depression scores did not.

There was an association with anxiety and movement assessment only.

After the initial study

He was diagnosed with prostrate cancer.

Just prior to starting his diary, he was married for the second time. He had been with his partner for several years and she is currently in full time employment.

What was talked about

The delay in diagnosis was extremely traumatic. After diagnosis the improvement in pain and stiffness from simple anti-inflammatory medication had changed his life completely. He describes an anorexic state and feelings of 'black dog' and severe depression prior to this. He acknowledges that his symptoms made him very grumpy and difficult to live with at that time. He was easily irritated and bad tempered.

He describes his management position as making him very unsympathetic to staff with 'glass backs' as he was aware of how much pain he was suffering and judged them against himself. In retrospect he sees himself as being too hard. A recently diagnosed heart condition, which occurred during the initial study, has modified his life style and dog walking now plays a large part of his daily exercise.

Early retirement is regretted now that he is feeling so much better from not only knowing and accepting his AS but also being able to control the pain. He acknowledges the importance of self-discipline when retired. He is aware that he cannot do 'jobs' in the time scales that he would like although he now has the time to do this.

The interview coincided with investigations for prostrate cancer. He had just been told that it was quite severe and that the next two years would be critical for him. The sense that his ability to cope with his AS, and how much better he is now has been a life changing event. He has no worries about his AS only the acknowledgement that it comes back every now and again and makes him grumpy. This is transient. His concerns for the future hinge now on the treatment for the cancer.

Individual 8 (ID 73)

Before the initial study

Male aged 69.

Disease duration – 47 years with age of onset aged 22.

No concurrent disease.

Co-morbidity includes: Osteoarthritis.

Blames onset of AS on the trauma caused by a car crash.

He has been retired for several years.

He is divorced and lives alone although he does have a lady friend.
He had a daughter who died in her early teens and he was happy to participate in this research in order to help others.

During the initial study

He had bilateral knee replacement surgery during the study.
His physical measurement range is reasonable and there were significant ranges in the self report measure of disease activity and function during the initial study suggesting more significant disease.
Anxiety and depression scores were not suggestive of clinical anxiety or depression.
There were associations with anxiety and function and depression and disease activity.

After the initial study

He under went spinal surgery for spinal stenosis. His lady friend has offered care and support in the recent post operative convalesce.
Prostrate cancer has been suspected and he was commencing investigations.

What was talked about

He enjoys his freedom and hates to be fussed over. He loves the outdoor life of walking his Gun dog, shooting and rearing pheasants. He fears losing his independence and not being able to fish or enjoy his country pursuits. He now lives in a flat and his dog lives with a friend.

Co-morbidity has become an increasing problem. He became more limited in mobility due to needing knee replacement surgery. The need for spinal surgery had been a further distressing event. Investigations for prostrate cancer had been distressing and embarrassing and he is beginning to wonder where it will all end. He still feels '21' in the head but his 'body is breaking down'. The fear of needing to live in a nursing home is distressing.

Motivation since retirement has been a problem. He recognises the problems of sleep disturbance and fatigue. When he feels 'low' even to go out for a newspaper is difficult. He recognises that if he stays in, he does very little and then begins to focus on the pain and that is when he admits to feeling depressed. There is a great deal of understanding

associated with emotional changes and symptomology. He acknowledges the unpredictability of the condition.

He was in the Merchant Navy and was an engineer when first diagnosed and went on to work as an engineer after this until retirement. He was a supervisor and as a result had to walk all day. He believes that the exercise and keeping mobile at this stage in his life helped him to cope with his AS.

Individual 9 (ID 91)

Before the initial study

Male aged 35.

Disease duration – 15 years with age of onset aged 18.

No concurrent disease.

No co-morbidity.

He is a full time deputy manager at a Job Centre. He finds his job demanding and stressful.

His mother had RA and died before the initial study due to a perforated ulcer caused by medication.

He has a sister who has children and he lives with a partner who he says very little about.

During the initial study

His physical measurement range was excellent. There was a variation in range with disease activity reporting during the study however functional scores were extremely low.

Anxiety scores at one point bordered on clinical anxiety although depression scores remained extremely low.

There were associations with anxiety and self report disease activity assessment during the study. There was also association between depression and physical assessment.

After the initial study

Nothing of note occurred.

What was talked about

He is a full time deputy manager at a Job Centre. He finds his job demanding and stressful. His manager delegates a lot of work and is unsupportive. She has issues with accepting his AS although he hates to have time off work and finds that he compares other members of staff to himself and judges them by his standards. He hides his condition and emotions from the staff always trying to be bubbly and approachable. Sleep disturbance and fatigue are major issues and can interfere with his mood considerably although he would not admit this to the staff and would refuse to go home early.

His mother's death and the fact that she had RA has significantly affected his reliance on medication to the extent that he hates taking the back pain tablets and will avoid them at all costs. He becomes very worried if he has symptoms in new areas especially peripheral joints as he fears that he may be starting to develop RA like his mother and grandfather.

As a family they recently took their father on his first holiday since his wife's death. He is a very caring person and worried about how others were coping on the holiday. Even after a long day at work, he weekly sees his Aunt and all she seems to talk about are her ailments. He does a lot of DIY for friends and family and finds it difficult to say no even though he may be in pain and he is exhausted. He is an on the go all the time type of person and it is only when he is on holiday when he will actually relax.

He perceives his disease to be very mild but does worry about the future and if there will be deterioration. He compares each flare up to the first. This was an extremely distressing period in his life having to be lifted out of bed by his father if he needed to go on the toilet and taking 30 minutes to walk a few yards into work with tears rolling down his face. He admits that he does fear that it may be as bad again.

Individual 10 (ID 71)

Before the initial study

Male aged 54.

Disease duration – 15 years with age of onset aged 37.

No concurrent disease.

Co-morbidity includes: previous alcohol abuse, kidney problems, depression (on medication states to help him sleep only).
Father has had a disability all his life and he 'always hides it.'
He took redundancy from BNFL although his work's doctor had wanted him to retire on medical grounds. He finds it boring being at home but although he has felt better recently does not feel that he can go back to work.
He lives with his second wife (previously divorced – **no details of dates for this**) and frequently has his daughters with their children visiting.

During the initial study
Nothing of note occurred.

After the initial study
Diabetes was diagnosed.

What was talked about
He finds it boring being at home but although he has felt better recently does not feel that he can go back to work.

He says that the house is never empty. He enjoys watching TV and sports. He supports the local football team but if he 'is bad' finds that he cannot go. He helps his wife around the house if he is able to do so. He relies very heavily on medication. At times he can be in so much pain that she has to almost lift him out of bed. He tends to stay in the bedroom and isolate himself from the family if he is a lot of pain.

He recognises that the house needs redecoration but he is afraid of the pain that he could be in if he attempts it. He now is unable to enjoy a social life as he was forced to stop drinking due to an alcohol problem (**no details of exact dates but not recent**). He is the driver and seems annoyed and resentful when his wife and daughters are getting drunk and he can't.

He finds that he cannot play football with his grandchildren as much as he would like to do. His life revolves around the 'ups' – washing up, cleaning up. He admits it is a dull existence. He does however perceive that the AS is not as bad as it used to.

Individual 11(ID 55)

Before the initial study

Male aged 30.

Disease duration – 8 years with age of onset aged 22.

Concurrent disease includes inflammatory bowel disease and iritis.

Co-morbidity - nil.

He is married with two young boys and works part time as a music teacher in schools teaching piano and brass. He was previously a builder but found this too difficult to continue due to health limitations.

During the initial study

His physical measurement range was excellent. Self-report disease activity and functional status remained very low throughout the study.

Anxiety scores at one point bordered on clinical anxiety although depression scores remained extremely low.

There were associations with anxiety and physical measurement instrument only during the study.

After the initial study

Nothing of note occurred.

What was talked about

Initially in 1997 there was a considerable delay in diagnosis and he describes vividly the pain and suffering at that time. He had just begun his relationship with his wife at that time and feels that she supported him a great deal during that time. He describes sleeping with a coffee table between his legs on the floor as he had to keep his legs open. He acknowledges being more grumpy and irritable when his sleep is disturbed or he is in more pain than usual.

When his Chrons is active he is limited in the amount that he can play with the boys as they usually wrestle a lot and he cannot tolerate pressing on his abdomen at that time. He enjoys bike riding with them but also becomes aware of the limitations on that activity as he can suffer from knee pain afterwards. This knowledge prevented him from going mountain biking when his friends from the pub invited him. He suffers

from foot pain from time to time and yet refuses to sit down in the pub as he doesn't want his friends to think that he has anything wrong with him.

Being a musician, his recent wrist pain has been problematical. He does talk about all his pains being very transient and in that respect it doesn't really worry him.
However he was asked to play a more complicated piece for the piano recently and his hands did become painful. He was confused as to whether it had been a long time since he had played a lot or whether it had exacerbated the arthritis. He has his own coping mechanisms and describes wanting to be quiet early in the morning as he knows that when he is in more discomfort he can be more anti social and he doesn't want the family to suffer from that. Once he 'comes round' then he feels he has no problems. He doesn't openly discuss how he is feeling with his wife as he 'winds her up' by saying talking about emotion is a weakness. He will however tell her if he is in more pain and ask her to 'rub his neck'.

Diary transcripts

Diary Participant 1

Entry 1

Day after night before1 Election Day! Woke up stiff and tired after a late night. Difficult to get motivated. Hands stiff in joints.

2

Had day at the office! Spent 10hours at computer. Back stiff after long spells sitting down. Quite motivated. Plenty work but OK. Came up with few ideas. No problems.

3

Quite fatalistic. Restless night- mind wandering all over the place. Difficult to get comfortable. Tiring day-shattered. No energy. Holiday Saturday! Also pain in left leg (knee?).

4

Holiday. Sore start-anxious. Back, knees sore. Neck ache after three hour drive. Arrived: inpatient. Awning hard work- took longer than usual. Sore back from bending. But when all erected manage to relax. Wine helped but will have effect in morning.

5

Sore from wine! Good day. Sun's out. Relaxing. Did little walking. Hips aching. Knees sore. But all in all good day.

6

Is it AS or AF. Nothing to think about everything to worry about. On holiday bet always wanting to do something. Finding it hard to relax today. Want to be out and about. Can't concentrate on anything.

7

Suppose I'm in a routine. Everything I feel feels normal because I have felt it so long.

Usual pains and problems but just getting on with it. Going home.

8

Couldn't relax-know I have to drive home. Agitated and irritable. Difficult concentrating. Home – everything will be OK. Tried to relax but still couldn't.

9

Pain, pain go away. Don't know what's causing it but it is worse. Started talking to myself. So Barbara says, complaining about the condition. Did I feel like this before I kept the diary? Yes but it was at the back of my mind. Aggravated and unable to concentrate for long periods. Start DIY jobs but don't think about them carefully enough. Just plough in.

10

Happy day – Zoe's birthday. Still in pain (back). Decided that I would go to the doctor. Enjoyed break in Carlisle. Relaxed pretty well although worried about journey back home -weather and distance. (forgot to write yesterday: must have been relaxed or tired but nearly fell asleep in middle of shopping centre while sat on bench!

11
Jane phoned. Got to finish diary. Never written a diary before-kept everything in my head: how I felt, what I could do to make AS better. This week AS, or at least my back pain has been much, much worse. What is causing it? Worry it's something to do with AF or the medication. Tried not to grumble. Hope it helps Jane. Most days you just get on with life but it has stated to get me down. Fed-up but it wont be like this every day.

Diary Participant 6

1
I have not had a good sleep last night, could not get into a comfortable position, turned over many times, during the first four hours. Awoke this morning 8.30 am did not feel like doing anything at all, I just wanted to laze about but forced myself to do my chores.
2
Had a good night's sleep and I feel rather happy today got up early 7.30am looking forward to the day.
3
Another good night, feeling happy, going to pick some pheasant chicks up today.
4
I went out for a couple of pints last night; and I had a lousy night, lots of pain, I think alcohol affects my back pain, I don't feel like doing anything today.
5
A better night's sleep, I feel like doing some shopping and cleaning the flat up. Finished off the chores, had a hot bath and went to see the pheasant chicks with the Banthem hen.
6
Poor sleep last night awake most of the night with back pain. I feel a bit low today, I can't seem to motivate myself to do anything. I just watched TV and read the papers.
7
Lousy night's sleep, could not get any comfort in any position, got up rather late 10.30 am had a very hot bath to try to eleviate the pain. Feel much better, I feel a bit more perky so I went to see a friend in hospital, made plans for an Irish holiday in September, so that gives me a boost.
8
My back pain has been playing up today for no reason, I feel a bit low in myself.
9
A good night's sleep, I feel good in myself up early, cleaned up, showered and went shopping.
10 Not a good night constant pain in the back. Feeling rather low, can't be bothered to do anything, I can't get comfortable at all sat down or walking about.

11 A lousy night back ache all night, don't feel happy at all today but I have to motivate myself to clean up and make breakfast. I feel real lazy but I made myself go out for a walk and meet people.

12

Not too bad last night, but could not sleep well, mind too active, did not feel like going out just watched TV and did some reading could not be bothered to go out at all.

13

Not a good night sleep, thinking of some tests at the hospital I have to have, woke up very stiff in the joints, difficult walking today, resting up, never went out, have just worried about the tests.

14

Good nights sleep but could not get this feeling of apprehension about these tests at the hospital.

15

a lousy nights sleep, I have to go to the hospital today for the testsa on my bladder with the camera to see if the problem is with stones or anything.

16

Spondylitis quiet but mind racing all night after hospital test, the y found a growth on my bladder now waiting for operation.

17

Back ache all night now thinking about op, I feel like I am falling apart at the seems, back op five weeks ago, now bladder problems, I don't seem to be able to win.

18

Back ache all night but I have other things on my mind than spondylitis, so tonight I will go out and have a couple of pints with mates and see if that helps the depression.

19

A fitful night waking up every hour or so I had a couple of drinks with friends so that disturbed my sleep, feel fine today I am going out to do a spot of fishing looking forward to it.

20

Had a good nights sleep and feel much better in my mind today. I am going out to dinner tonight so I feel quite good about it.

21

A good sleep, very relaxed had a nice evening out and feel well with world today I feel like giving my flat a good once over and change curtains etc.

22

Sleep would not come easy a lot of aches and pains in the back and the joints knees, hips etc. I think I did too much yesterday, today I am taking it easy watching TV and a book, but still feel a bit like a caged cat: I have been out, took the dog up the canal for a walk I feel better being out I am now tired out I will have an early night to night.

23

A good sleep very little pain, I had a nice lie in 10.00 showered, breakfast and out again with the dog, I went for a drive to Lytham took the dog on the

sea shore and then went for a pub lunch, very relaxing came home about 5pm bathed changed and I'm going out with a friend.
24
Another good sleep, but feeling a bit low as I have a letter from the Preston Royal hospital giving me a date for a pre op, I feel like things are getting worse, Ankylosing, new knees, op on a trapped nerve in the spine, now a small growth in the bladder op due on the 24th 7 05 I wonder when it will end.
25
Not a good night mind racing like hell and very hot I will be glad when I have had the op, today has been a funny day I sat in the garden reading then went inside could not keep still plenty of aches and pains back and joints can not settle down in comfort I had a lie down on my back for a while but that did no good I just don't seem to get with it perhaps tomorrow will be better.
26
Not as bad as yesterday took two Volterol instead of one it seems to have worked, I slept much batter and feel better in myself today. I went to Fleetwood with a lady friend I really enjoyed it, she drove the car so I could look round at everything we had a nice meal and a good walk on the front it gave me a bit of backache but was worth it.
27
I don't think the pain is Spons as the back ache is where I had the op on the spine, today I feel good, I am going out again today to the Lakes with my friend, she is driving.
28
Slept well, very little pain, had a great day out at the Lakes we had a very nice lunch in Bowness, a sail on the lake and dinner at night in Morecombe. I feel really good no depression about this forth coming op feel really relaxed I wish I could feel this good every day.

Diary Participant 7

1
No real problems
2
Feeling very stiff and uncomfortable. Some pain in rib cage. Suspect reaction to MRI scan yesterday.
3
Again still feeling a lot of discomfort.
4
Everything seems back to normal.
5
Frustrated at the length of time that it takes to do normal domestic jobs.
6
Bone scan yesterday. No problems.
7
Quite sore. Very depressed.

Diary Participant 9

1. Check up at Wrightington. Saw a guy walking in very stopped and could see it took him all his effort to look forward with his eyes straining to look up. Wondered if that could be me in some years. Thought about the pain, could see it in his face. Felt upset for him and a little worried. I AM grateful that I am not like him and value my health whilst I can.

2. Keep thinking about the 'arched men' at hospital. Lucky that I am stood upright.

3. Woke up at 2am with hot weather. Back was aching and had restless night. Felt tired at work all day. Had a stressful day at work with a lot of pressure. Thought my brain would explode at 5pm. My managers on leave and I'm in charge of the office with constant queue of staff. Not easy to deal with when tired. Keep smiling.

4. Friday! Last day as boss! Although I feel fine writing this brings light to the fact that I have backache in middle of spine. I seem to block out the pain normally and feel fine but know the pain is still there.

5. Stayed at sister's over night on her Z bed. Always get back ache and restless nights so got up early. Came home, cut the grass, weeded and did odd jobs. Felt fine. On the go all day. Can't sit still. Think I'm hyperactive!

6. Felt good today. Sun shining, sky blue. Spent the day sunbathing in the garden and doing odd errands. Fell I cant lay in the sun for long periods need to be on the go. Best friends came over for tea. A happy, enjoyable evening.

7. Got an aching pain in left big toe. I can tolerate it but it is annoying me. A bit like toothache. Again keep arching back to confirm pain is still there. Back is sore but feel I have got used to the pain. Thought back to a couple of years ago when I couldn't get out of bed to go to the toilet. Had to be carried. Had to sleep upright with 6 pillows. That was pain! This is just an ache. Thought that some of my staff would be off sick with it but I carry on.

8. Still aching big toe! Worried about big meeting at work, top boss but it went fine. Feel good today. Weather still hot! Got a medical report back for girl who's constantly off sick and advised to be lenient with her. Don't think she is as bad as she says. I've never had a day off in three years and dragged myself in some days when had no sleep and a lot of pain. Feel frustrated that some people can just get away with it.

9. Limped in work all morning. Pain in toe moved to side of foot. Don't know if I have twisted foot or whether it's part of AS. Feel confused what to blame as AS and what not too. Very stressful day. Queue of staff at my desk. Feel my head is going to explode.

10. Busy day at work but pay day. Felt happy that it is nearly weekend. Went to view a job for my sister's friend and agreed to tile her bathroom. She has no money so feel good with myself that I will save her over £500. My Mum a giving hand never wants. So I am happy to do the work for her.

11. Work went well, not as busy. Felt relaxed and calm all day. Got on with jobs I wanted to do for months. Went to visit Auntie in evening. Listened to her moans and groans of her aching foot. Told her about this diary and she was very interested. All in all feel happy today. Felt I had achieved a lot at work and am pleased.

12. Running errands all day getting stuff for hols. Looking forward to it but bothered that Dad will be OK. Not too hot for him. Went to sister's last night and we had a pre holiday get together 10 of us without my Dad. Got some ground rules for holiday so it made everyone feel better. Stayed over but dreaded the morning after. Always wake up in pain with as best is very uncomfortable.

13. Woke up with backache but it eased off by lunchtime. Came home and spent afternoon in garden, mowing lawns etc felt ok. Garden looks great and I feel proud that it is down to my efforts. Thought back too earlier in year when spent days taking the lawn up and reshaping it. All these blisters were worth it.

14. Boss left early so I did too. Started the tiling job. Realised how much hard work I have let myself in for and regret offering to do it a little. Sister's friend is so grateful that it made me feel happier. Walls very uneven so had to push the tiles to line them up with all my strength. It worried me that I could end up in agony but will have to see.

15. Woke up at 2am in absolute pain. Dozed off again around 6.30 and got up at 7.30am. Was tired in work all day. Went to carry on tiling that night as I knew how much it meant to her. Only did 2 hours as I was starting to feel grumpy. Back was aching and walls seemed worse. Didn't want to take it out on my sister's friend so I made my excuses and left for the evening. I was worried that if I did too much I would be in pain again. Feel like this is a barrier and restricting my ability to do the job.

16. Woke up at 5am in pain. Work was ok. Again by 2pm felt tired but went at 5pm to finish tiling. Told my sister's friend of pain and she said to leave it for a few days. My thoughts were that it would trigger off in a few days so might as well get it over with. She was telling me

some funny stories about her Mum and we laughed. I measured tiles to be cut and she cut them and I stick them. Team work. This seemed to relieve some pressure and I was happy to stay for a few hours. Left at 9pm exhausted and tired. Went straight to bed.

17. Better night's sleep. Just normal aching but used to that. Work was ok but one of my staff told me her father had cancer and had only days/weeks to live. I sent him home on special leave for 2 days. Was upset by this and thought of time I had off when Mum was poorly. Glad I had 3 weeks off just before she died. I valued the precious time. Was a little upset. 5pm again left work and carried on with tiling. Felt pleased that I ran out of tiles so left early. Had tea, watched a little TV and another early night.

18. My boss was off today and I did my job and her's. Didn't get paid to do her job but ended up with all the crap. 3 customers to interview who wanted to see the manager. 3 unhappy staff (her staff not mine) feel like whenever she is off all staff come to me with their moans. Felt mad and annoyed that I was doing all her work and not being paid for it. By 3pm my head was spinning but did not show this in front of the staff. Left by 5.30pm and thought my head would explode. Went and tiled but happy as it was the last 8 tiles. Finished the walls! Felt great and really pleased of finished result. Sister's friend over the moon so felt happy. Finishing seemed to release all of the day's pressures. Just opened a bottle of wine!

19. Walls done but floor to do. Got up early and traveled to friends. Was there for 9am and started. By 11an was getting annoyed with adhesive so went to buy some more. Wonderful buy and finished by 2pm. Felt like the icing on the cake. Felt proud, happy, relieved that it is all done. She felt the same. Spent the rest of the day chilling in the garden and relaxing. Another job done, less pressure. Got a call off my sister, her friend called to say how pleased she was. I felt all the pain was worth it.

20. Busy day shopping for the hols, ironing and general jobs around the house. This time next week will be in sunny Spain. First relaxing day in weeks and felt bored a little. Need to get a life! Again did the garden, watched telly. Nothing exciting today. Foot started to ache at 9pmish. Think it's AS related.

21. Had no sleep!!! Ankle killing me and back feels like a pack of wild horses has trodden over me. Couldn't walk on foot and got to work shaking with the pain. Went to casualty and damaged ligament in ankle. Worried that it might affect my holiday on Saturday. Still not taken my back 'pain pills'! Should do but my pride won't let me. I feel like it would be throwing in the towel after not having any for 18 months.

22. 1st day sick in 5 years!!! Don't want to stay off, foot is sore, can't walk on it. Phoned in sick and felt manager didn't believe me. When I put the phone down, I felt pissed off (excuse language). I come into work with colds, flu, back pain, no sleep, aches. She told me not to do any decorating jobs (I do these in my spare time for my friends) and think she thinks I am off to do a job. Just her tone. Anyway weather was great so sat in garden. Calmed down and thought tough! Need to rest feet for holidays.

23. 2nd day off sick. Still in pain but backache as well. I feel really guilty as I hate being off sick and such a busy time at work. Feel I am letting the team down. Spoke to my sister who made me feel better saying that they will manage. Weather is nice so sitting in garden writing this.

24. Went into work with bandage and flip flops on as can't get shoe on. I put my sock over bandage. 1st thing my boss said was to take sock off so everyone could see bandage. Very annoyed!!!! Not how are you or how's your foot. She still didn't believe me. Hobbled round work all day. Toes a little sore. Is it part of AS or due to foot? Don't know. Had to deal with a customer who was 'kicking off'. Had no patience and wanted to tell him where to go. Bit my tongue and dealt with him. Feel angry and cheated with what boss said. Keep doubting myself all day.

25. Still at work. Still in flip flops. Decided that I will do what I have to do and no more. Still annoyed with boss. Can put heel down now so feel better. Worried it won't be right for hols.

26. Holiday!!! Up at 2am. Very red itchy eyes. Thought it was because I was tired. Got here and 40 degrees+ spent afternoon in swimming pool. Eyes now very bloodshot. Think it is due to chlorine and tired. Feel happy that we have brought my Dad to Spain but wished we could have brought my Mum as well. She loved the sun! Felt proud of bringing Dad. Had mixed emotions today. Was looking forward to hols but dreading it at the same time. Usually go for quite, relaxing holidays but aim to keep everyone happy (even me).

27. Eyes very sore. Worried it is AS. Very conscious of red eyes. Everybody asking if they are ok. Been to pharmacy. Got eye drops, hope they are ok. Was told to go to Doctor if still red in 2 days. Other wise very happy, with family, beer and sun!

28. Eyes a bit better. Feel great. No back pain. Foot ok. Suns been shining. Concerned that Dad is enjoying his holiday. Can't just think about me but 11 of us.

29. Good nights sleep. Hot today. Walked for over 2 miles. Eyes better, feel relieved and happy that it will not spoil my holiday. Played in pool all afternoon with children. Everyone on top note.

30. Woke up with stiff back. Think it's with throwing kids into pool. Got better after a few hours. Carrying on as normal. A little pain does no one any harm! 10pm was very tired but kept awake for rest of party. Usually quite a lively sole and everyone was asking me if I'm alright. Got annoyed a little. Just tired! Last day for this diary and can't believe how much pain I have had over month. Writing this diary makes me think about it more and normally I would have ignored some of it as I feel I get used to it. Still proud I have not taken any 'back pain pills'.

AIM: To seek to understand how Ankylosing Spondylitis influences a person's emotions.

1. **Can you tell me a little about yourself?**

   Age, socially, family, job.

2. **Tell me about your AS**

   How long have you lived with it?
   Are you aware of any changes it has made on you?

3. **What does having AS mean to you?**

4. **Having lived with AS for some time, does it worry you?**

5. **When you have a 'flare', can you describe what happens?**

6. **When you have a flare, does it ever affect your mood?**

   Got you down?
   Do you worry more?
   Does it make you anxious?

7. **Whilst you kept your diary, how did you feel during that month?**

8. **Go through diary.....**

9. **Would you say that you find it difficult to share your feelings with others?**

10. **I have covered all that I wanted to, is there anything further that we haven't said that you would like to tell me?**

15 b

AIM: To seek to understand how Ankylosing Spondylitis influences a person's emotions.

1. **Can you tell me a little about yourself?**

   Age, socially, hobbies, commitments.

2. **Tell me about your AS**

   - **How long have you lived with it?**
   - **What is it like to live with AS?**
   - **What does having AS mean to you?**

3. **There is a lot written about the physical effects of having AS but far less about how it affects people's mood. I would be interested to know if you think it affects your mood and the way that you feel?**

4. **When you have a 'flare', can you describe how it affects you?**

   a. **What happens physically to you?**
   b. **As it changes how do you feel it affects your mood?**

5. **Does the unpredictability of AS affect your feelings?**

6. **Has the way that you cope with your AS changed as you have got older?**

7. **Do you think that having AS stops you doing what you want to do?**

8. **Would you say that you find it difficult to share your feelings with others?**

I have covered all that I wanted to, is there anything further that we haven't said that you would like to tell me?
[1]

[1] Interview schedule ver 4 July 05

DISSEMINATION OF FINDINGS	Date
A poster and three-minute oral presentation describing the retrospective study was presented at the BSR: **British society for Rheumatology XVIIIth Annual General Meeting 2001, April 24-27, The Edinburgh International Conference Centre, UK.** **'A five year study of clinical and psychological measures in 95 patients with ankylosing spondylitis.'** J. Martindale, J. Smith , C. Sutton, D. Swinson and J. Goodacre Rheumatology, 2001, Vol 40. Abstracts supplement 1, No 116	April 2001
Presented at AGM – Chronic disease and Rehab research and Training Group – UCLan	May 2001
Presented at Research Student Conference UCLan	April 2002
Presented at Research Student Conference UCLan	April 2003
A poster presenting preliminary findings from the prospective study was presented at **The American College of Rheumatology Annual Scientific Meeting 2003, October 24-28, Orange County Convention Centre, Orlando, Florida, USA.** **'Associations between disease and psychological status in ankylosing spondylitis.'** J. Martindale, J. Smith , C. Sutton, D. Swinson and J. Goodacre	October 2003

Presented at Research Student Conference UCLan	April 2004
Presented at WWL Research Symposium – Won 2nd prize	May 2004
Presented at Interdisciplinary Research and education Meeting – Blackpool Post Grad Centre	July 2004
Poster Presentation – PRISM Conference –Liverpool University and Post Grad Education Meeting	June 2004
Presented at WWL Research Symposium	18/03/05
Presented at Research Student Conference UCLan	April 2004
A poster and three-minute oral presentation describing the results from the study was presented at the BSR in 2005: **British society for Rheumatology Annual General Meeting 2005, April 19-22, Birmingham, UK.** **'A longitudinal study of clinical and psychological status in ankylosing spondyltitis.'** J. Martindale, J. Smith , C. Sutton, D. Swinson and J. Goodacre Rheumatology, 2005, Vol 4. Abstracts supplement 1, No 116	April 2005

Oral Presentation North West Rheumatology Club – won Mike Chalk Trophy for best oral presentation.	May 2005
Poster Presentation – PRISM Conference – UCLan and Post Graduate Education Meeting	July 2005
Presented at ALWPCT 1st Research Symposium	June 2005
A poster describing the results from the study was presented at the British Psychology Society, DHP Annual Conference – Coventry September 2005: **'A longitudinal study of clinical and psychological status in ankylosing spondyltitis.'** J. Martindale, J. Smith , C. Sutton, D. Swinson and J. Goodacre	September 2005
Oral and Poster Presentations – Combined Research Meeting between ALWPCT and WWL – won best poster	October 2005
Publication in 'Rheumatology' 2006; 45:1288-93 **'Disease and psychological status in ankylosing spondylitis.'** J. Martindale, J. Smith , C. Sutton, D. Swinson and J. Goodacre	September 2006
Presented at Research Student Conference UCLan – Disease and psychological status in AS: A qualitative study	April 2006

Won 'Gold Award' for best research in ALWPCT Trust	May 2006
A poster presentation describing the results from the study was presented at the BSR in 2005: **'An investigation of the associations patients make between changes in disease status and the impact of change on their psychological health.'** J. Martindale, J. Smith , C. Sutton, D. Swinson and J. Goodacre Rheumatology, 2007, Vol 46. Abstracts supplement 1, No 430	May 2007
Oral Presentation North West Rheumatology Club – Liverpool Postgraduate Medical Centre	October 2007

An oral presentation in the concurrent abstract session for Spondyloathropathies and Psoriatic arthritis: Treatment 1; ACR in 2007: **American College of Rheumatology Annual Scientific Meeting 2007, November 6-11, Boston, Massachusetts, USA.** **'Sustained Disease Activity in AS. A prospective Study.'** J. Martindale[1], J. Smith [2], D.Grennan[1] , D. Swinson[1] and J.A. Goodacre [2], Arthritis and Rheumatism. Vol 56, No 9 (supplement) Sept 2007. S320, Abstract 752	November 2007

Rheumatology 2006;45:1288–1293
Advance Access publication 4 April 2006
doi:10.1093/rheumatology/kel115

Disease and psychological status in ankylosing spondylitis

J. Martindale, J. Smith[1], C. J. Sutton[1], D. Grennan[2], L. Goodacre[1] and J. A. Goodacre[1]

Objectives. **Psychological factors may be important in the assessment and management of ankylosing spondylitis (AS). Our primary objective was to describe associations between disease and psychological status in AS, using AS-specific assessment tools and questionnaires. Our secondary objectives were to identify patient subgroups based on such associations and to determine the stability of the measures over time.**

Methods. **A total of 110 patients were assessed at 6-monthly intervals up to four times using tools to measure disease [Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), Bath Ankylosing Spondylitis Functional Index (BASFI) and the Bath Ankylosing Spondylitis Metrology Index (BASMI)], psychological [Hospital Anxiety and Depression Questionnaire (HADS), Health Locus of Control—Form C Questionnaire (HLC-C)] and generic health [Short form (SF)-36] status.**

Results. **Eighty-nine participants completed all four assessments. Throughout the study, BASDAI, BASFI and BASMI scores correlated significantly with anxiety, depression, internality and health status, but not with levels of belief in chance or powerful others. Clinically anxious or depressed subgroups had significantly worse BASDAI and BASFI, but not BASMI, scores. BASMI scores were the least closely linked to psychological status. Mean scores for disease, psychological and health status were clinically stable over the 18 months period.**

Conclusions. **Disease status scores in AS correlated significantly with anxiety, depression, internality and health status. Interpretation of AS disease scores should take an account of psychological status and the choice of measures used. These findings have important potential applications in AS management and monitoring, including the identification of patients for biological therapies.**

KEY WORDS: Ankylosing spondylitis, Psychological status, Disease assessment, Clinical monitoring.

Introduction

Ankylosing spondylitis (AS) is a chronic inflammatory disease that characteristically affects the sacroiliac joints and spine. Key features include enthesitis, fibrosis, bony ankylosis [1] and genetic susceptibility determined predominantly by the HLA B27 allele [2]. Clinical management focuses upon symptom relief and maintenance of posture and function, although recent trials of anti-TNFα therapy [3–6] have demonstrated strong potential for significantly improving the efficacy of medical treatment.

The major impact of AS on overall health and activity raises the possibility that psychological factors may influence disease status and outcome. If true, this would have important implications for both assessment and management of AS. The potential relevance of this to clinical practice is suggested by studies in other chronic diseases, including back pain [7–9], as well as by previous studies in AS. For example, Barlow *et al.* [10] found that about one-third of AS patients reported symptoms of depression and that features of depression, high internal locus of control and low reliance on powerful others were common amongst AS patients attending a UK self-help group [11]. Gunther *et al.* [12] characterized coping behaviour of AS males as 'playing down' stressful situations, and found that use of such coping strategies was independent of disease duration, whilst Hidding *et al.* [13] found that self-reported health status was more strongly related to personality traits, particularly neuroticism, than to levels of disability. Such findings highlight the need to determine the relationships between disease and psychological status in AS in order to inform clinical assessment and management, as well as to inform selection and monitoring of AS patients for biological therapy.

The primary objective of the study reported here was to describe associations between disease and psychological status in a large group of AS patients. The secondary objectives were to identify patient subgroups based on such associations and to determine the stability of disease and psychological scores in this group over 18 months. This is the first study to utilize a longitudinal approach to address this issue, thereby enabling the consistency of the measures and associations over time to be determined.

Patients and methods

Study participants

Patients with AS, diagnosed according to the Modified New York criteria [14], who were regularly attending the AS Review Group

Ashton, Wigan and Leigh Primary Care Trust, Lancashire, [1]Interdisciplinary Research and Teaching Group for Chronic Disease and Rehabilitation, University of Central Lancashire, Preston and [2]Wrightington, Wigan and Leigh NHS Trust, Lancashire, UK.

Submitted 5 January 2006; revised version accepted 28 February 2006.

Correspondence to: John Goodacre, MD, PhD, Director of Clinical Research, Lancashire School of Health and Postgraduate Medicine, University of Central Lancashire, Preston PR1 2HE, UK. E-mail: jagoodacre@uclan.ac.uk

at Wrightington Hospital, Lancashire, UK were invited to participate. Patients with recent serious illness or pregnancy were excluded from the study. From April 2002, appointments for routine review were sent out according to established practice and included an invitation to participate in the study. Consent to participate was sought until 110 patients were recruited. Patients' written consent was obtained according to the Declaration of Helsinki. Ethical approval was obtained both from the Wrightington, Wigan and Leigh Local Research Ethics Committee and the University of Central Lancashire Ethics Committee.

Study design

Baseline assessment of clinical and psychological measurements was completed at recruitment. Patients were then sequentially reassessed at 6-monthly intervals until three further assessments had been completed. Other demographic data, such as current work status including retirement on medical grounds and marital status, were also collected at baseline via a self-completion questionnaire. Co-existent disease (including iritis, psoriasis and inflammatory bowel disease), date of birth, age of onset and age of diagnosis were retrieved from the patients' records. If age of disease onset was not available from the records, this was obtained via patient self-report at baseline. Disease duration was obtained by subtracting age of onset from the age at recruitment into the study.

Assessment tools for clinical status

Measurements of disease status were conducted using the Bath Ankylosing Spondylitis Functional Index (BASFI) [15], the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) [16] and the Bath Ankylosing Spondylitis Metrology Index (BASMI) [17]. The BASDAI is scored using a 10 cm visual analogue scale (VAS) for each of five major symptoms over the past week. The individual scores are averaged to form a 0–10 scale, with lower scores indicating less active disease. The BASFI comprises 10 items on ability to perform and cope with activities of daily living, each scored on a 10 cm VAS reflecting status over the past month. The mean of the 10 scales generates the score, with 10 denoting worst possible functional status. The BASDAI and BASFI assessment tools were all self-completed in the clinic without significant assistance from staff. BASMI assessments were performed by two senior physiotherapists rigorously-trained in this method and working closely together on this project. The BASMI assesses cervical rotation, tragus to wall distance, lumbar side flexion, lumbar flexion (modified Schober's test) and intermalleolar distance. Measurements for the five domains are integrated to provide an overall score between 0 and 10, with lower scores indicating better range of spinal movement.

Assessment tools for psychological and health status

Psychological status was measured using three questionnaires, all presented within a booklet. The Hospital Anxiety and Depression Scale (HADS) [18] is a 14-item self-report measure of anxiety and depression. Seven questions assess anxiety and seven questions assess depression. All items are scored on a four point scale from 0 to 3. Each domain is scored separately with a possible maximum score of 21, and the higher the score, the higher the level of either anxiety or depression, respectively. The Health Locus of Control—Form C Questionnaire (HLC-C) [19] is a questionnaire relating to beliefs concerning back problems. It provides a measure of the level of perceived control that people have over their health, their beliefs about external control of health by powerful others (for example, health professionals) and their beliefs about the influence of chance, luck or fate over health. The score is calculated according to the levels of agreement (1 = strongly disagree; 6 = strongly agree) with 24 statements about belief in chance, belief in powerful others and internality. The scores obtained from the statements relevant to each of these three areas are summed to form domain totals with a possible range of 8–48.

Generic health status was measured using the Short Form (SF)-36 questionnaire [20], which measures eight multi-item dimensions: physical functioning (10 items), role limitations due to physical problems (four items), role limitations due to emotional problems (three items, social functioning (two items), mental health (five items), energy/vitality (four items), pain (two items) and general health perception (five items). For each dimension item scores are coded, summed and transformed on a scale from 0 (worst possible health state measured by the questionnaire) to 100 (best possible health state).

Statistical analysis

Data were stored and analysed in SPSS (Release 12), with further analysis performed in Stata (Release 6). Analysis was performed on those completing all four assessments. The stability of each outcome measure over time was investigated using repeated measures analysis of variance (ANOVA) [21]. The Huynh–Feldt correction for non-sphericity [22] was used to obtain *P*-values. Relationships between pairs of measures of disease (BASDAI, BASFI and BASMI), psychological and generic health status, age and disease duration were assessed using Spearman's rank correlation coefficients. Partial Spearman's rank correlations were also computed to assess whether any relationships found between disease or psychological status and age (disease duration) still existed when controlled for disease duration (age). Based on data collected at enrollment, subgroups were defined by presence/absence of iritis and presence/absence of psoriasis. Subgroups were also formed at each assessment point based on anxiety and depression scores. Based both on previous work [23] and on current use of the HADS in clinical settings, scores of 11 were used as a threshold to define clinically anxious and depressed subgroups. The between-group differences in outcomes on interval scales were analysed using independent-samples *t*-tests, using its approximate form when group variances appeared different. Characteristics potentially associated with non-completion of study were assessed using independent-samples *t*-tests for characteristics measured on an interval scale and the Fisher's exact test otherwise. Tests resulting in *P*-values <0.05 were grouped as statistically significant. The sensitivity of findings to parametric assumptions was assessed when these were in doubt. The sensitivity to exclusion of those not completing all assessments was also investigated.

Results

Characteristics of the study participants

Eighty-nine (74 men, 15 women) of the 110 participants (80.9%) completed all four assessments. Reasons for non-completion were: non-attendance (13), myocardial infarction (2), incomplete fulfilment of AS diagnostic criteria (3) and incomplete data recording (3). Among the 89 study completers, median age was 50 yrs [inter-quartile range (IQR) 38.5–55.5, range 18–77], median age of reported disease onset was 25 yrs (IQR 18–33, range 9–58), giving median duration of disease as 18 yrs (IQR 13–27, range 2–50) and median age of diagnosis was 35 yrs (IQR 25.3–43, range 12–59). Eight people had co-existent inflammatory bowel disease, 41 had a history of iritis and 14 had clinically mild or moderate psoriasis. Forty-eight participants worked full or part-time, 41 were unable to work or unemployed. Seventy participants were married, four divorced and 15 single, of whom six were living alone.

Disease, psychological and health status over the study period

Mean (S.D.) scores for each measure for the 89 study completers are shown in Table 1. Overall, mean scores for disease and psychological parameters over the study period were relatively stable, although there was a statistically significant ($P=0.002$) effect of time on mean anxiety score. This effect was due to a lower mean anxiety score at assessment 1, with mean scores at assessments 2–4 being very similar to each other, and the significance of this finding is therefore unclear. The mean (S.D.) scores for each SF-36 domain for the first assessment were: physical functioning 57.6 (31.2); role limitation due to physical function 34.4 (26.8); role limitation due to emotional problems 25.0 (27.7); social functioning 58.9 (26.2); mental health 54.5 (18.4); energy and vitality 36.4 (19.5); pain 47.2 (26.2); general health perception 45.9 (26.2) and change in health 47.9 (15.5). Scores for most SF-36 domains were stable throughout the study (results not shown), although scores of physical functioning declined approximately linear ($P=0.017$) to 53.5 (32.1) by the end of the study.

Disease status associations with anxiety and depression

BASDAI, BASFI and BASMI scores correlated quite strongly with anxiety scores at all assessment points, although for BASMI scores the levels of correlation were lower than for BASDAI and BASFI (Table 2). Using HADS scores of 11 or more as a threshold, mean BASDAI and BASFI, but not BASMI, scores were significantly higher in anxious subgroups (Table 3). Higher levels of depression were quite strongly associated with worse disease status, with correlations lowest for BASMI compared with BASDAI and BASFI scores (Table 2). Using HADS scores of 11 or higher to identify clinically depressed subgroups, mean BASDAI and BASFI, but not BASMI, scores were significantly higher than in non-depressed subgroups (Table 3).

Disease status associations with internality, belief in chance and belief in powerful others

BASDAI scores consistently showed a negative, albeit relatively weak, correlation with internality and the same generally applied to BASFI and BASMI scores, showing that worse disease activity, function and movement were associated with lower levels of perceived control over health (Table 2). At each of the four time points, internality showed similarly significant, but relatively weak correlations with anxiety (r_s ranging from -0.27 to -0.41; all $P<0.015$) and with depression (r_s ranging from -0.26 to -0.33; all $P<0.015$). There was no consistent correlation between strengths of belief in chance or powerful others and any of the disease status scores (Table 2), and there was no significant correlation between these parameters and either anxiety or depression scores (results not shown).

Disease status and generic health status

BASDAI, BASFI and BASMI scores correlated significantly with all SF-36 domain scores except change in health throughout the course of the study (results not shown).

Effects of co-existent iritis or psoriasis

There were no significant differences in disease or psychological scores between those with ($n=41$) and those without ($n=48$) a history of iritis, and anxiety and depression scores correlated significantly and moderately strongly with BASDAI, BASFI and BASMI scores in both subgroups (results not shown). Likewise, although analysis of the effects of co-existent psoriasis was limited because there were only 14 people in the psoriatic subgroup, all of whom had clinically mild or moderate psoriasis, no significant differences in either disease or psychological status between subgroups with or without psoriasis were found (results not shown).

Effects of age, disease duration and gender

BASMI and BASFI scores were significantly, but relatively weakly, correlated with age, whereas no consistent correlation was observed between age and any of BASDAI, anxiety, depression and internality (results not shown). Furthermore, correlations

TABLE 1a. Disease score at each assessment ($n=89$)

Assessment	1	2	3	4	*P
BASDAI	4.89 (2.25)	4.91 (2.40)	5.00 (2.36)	4.85 (2.40)	0.78
BASFI	4.48 (2.61)	4.64 (2.71)	4.74 (2.75)	4.73 (2.81)	0.12
BASMI	3.37 (1.74)	3.49 (1.71)	3.41 (1.66)	3.45 (1.73)	0.43

TABLE 1b. Psychological status at each assessment ($n=89$)

Assessment	1	2	3	4	*P
Anxiety	6.76 (4.48)	7.69 (4.51)	7.51 (4.58)	7.57 (4.50)	0.002
Depression	5.35 (4.32)	6.07 (4.93)	5.76 (4.31)	5.84 (4.56)	0.10
Internality	30.13 (6.81)	29.42 (7.18)	28.90 (6.51)	29.43 (6.62)	0.15
Belief in chance	23.49 (6.65)	23.84 (6.48)	24.15 (6.49)	24.85 (6.26)	0.13
Belief in powerful others	26.31 (6.49)	26.07 (6.58)	26.30 (6.11)	26.58 (5.51)	0.79

The table shows mean (S.D.) scores for each measure of disease and psychological status at assessments 1–4. Differences in disease and psychological scores over time were tested using repeated measures ANOVA. *P-values are shown for each measurement tool.

TABLE 2. Correlations between disease and psychological scores at each assessment ($n=89$)

	Assessment (r_s)			
	1	2	3	4
BASDAI				
Anxiety	0.58**	0.63**	0.67**	0.61**
Depression	0.64**	0.65**	0.66**	0.67**
Internality	−0.35**	−0.33**	−0.26*	−0.24*
Belief in powerful others	−0.02	0.09	0.18	0.08
Belief in chance	0.05	0.07	0.04	0.11
BASFI				
Anxiety	0.60**	0.55**	0.57**	0.67**
Depression	0.61**	0.71**	0.62**	0.68**
Internality	−0.25*	−0.25*	−0.18	−0.22*
Belief in powerful others	0.09	0.19	0.21*	0.18
Belief in chance	−0.03	0.04	0.01	0.08
BASMI				
Anxiety	0.43**	0.33**	0.46**	0.38**
Depression	0.43**	0.53**	0.46**	0.43**
Internality	−0.25*	−0.23*	−0.23*	−0.13
Belief in powerful others	0.18	0.21*	0.23*	0.26*
Bbelief in chance	−0.12	0.09	0.05	0.06

The table shows correlations between each psychological and disease measure at assessments 1–4. Correlations between variables were assessed using Spearman's rank correlations (r_s). *$P<0.05$, **$P<0.001$.

of these patients satisfied current criteria for persistently active disease and would therefore be eligible for treatment with anti-TNF-α therapy if this option were available. Regarding the group's psychological status, normative data for anxiety and depression scores among healthy UK residents show mean (S.D.) HADS scores of 6.14 (3.76) for anxiety and 3.68 (3.07) for depression [40], and the reported incidence of clinical anxiety in otherwise healthy people is 7%, rising to 33% among those with health complaints and 36% of people with back pain [23]. Similarly, clinical depression has been reported in 5, 13 and 29%, respectively of these groups. In our group, about 25% were clinically anxious and 15% clinically depressed, suggesting that, within the inherent limitations of comparing different groups in this way, there was no substantive bias in our assessment of psychological status.

We used a longitudinal study design in order to determine whether associations between disease and psychological status were consistent over time. Our results show not only that the associations between these measures were stable over the 18 month study period, but also that the mean scores for the study group as a whole were relatively consistent throughout the study. The analysis of the data presented here does not attempt to address variation in disease status over time at the level of individual patients, but we are currently exploring this issue by analysing data from patients identified within the study group who showed demonstrable change in one or more disease measure over this time. A longitudinal approach was also used by others to annually monitor 74 patients attending an AS specialist clinic over 5 yrs [30]. Although mean BASDAI scores were not significantly different at the beginning compared with the end of their study, final mean BASFI score was significantly higher than the initial score. However, this change did not necessarily result from progressive deterioration, since some scores actually improved from one year to the next. In contrast, we monitored patients only for 18 months and would need to considerably extend this time in order to fully compare findings from the two studies and to determine whether the disease and psychological scores remain stable over a longer period.

In summary, we found that BASDAI, BASFI and BASMI scores correlated significantly with anxiety, depression, internality and generic health status, but not with levels of belief in chance or powerful others, over 18 months. BASMI scores were the least closely linked to psychological status. Interpretation of disease status scores in AS may therefore need to take account of psychological status. These findings have important potential applications in the clinical management and monitoring of AS patients. They also have important implications for patient assessment in the context of selection for and responses to biological therapies. Such assessments depend heavily upon the use of tools such as BASDAI and BASFI, and our findings suggest that the effects of psychological status on these scales should be taken into account when interpreting and utilizing the data obtained both in clinical trials and clinical practice.

Rheumatology	Key messages
	• There are significant associations between disease and psychological status in AS. • Among AS-disease-specific tools, there are important differences in strength of association with scores for psychological status. • Interpretation of AS-specific disease scores should take account of both psychological status and choice of assessment tool.

Acknowledgements

The authors gratefully acknowledge Dr David Swinson and Ms Sarah Inman for their help and support with this study. The authors also wish to thank Dr Kateryna McDonald for her valuable help in preparing this manuscript.

The authors have declared no conflicts of interest.

References

1. Calin A. Ankylosing spondylitis. In: Maddison PJ, Isenberg D, Woo P, Glass D, eds. Oxford Textbook of Rheumatology. 2nd edn. Oxford Medical Publications, USA, Oxford University Press 1998:1058–60.
2. Khan MA. HLA-B27 and its subtypes in world populations. Curr Opin Rheumatol 1995;7:263–9.
3. Braun J, Brandt J, Listing J *et al.* Treatment of active ankylosing spondylitis with infliximab: a randomised controlled multicentre trial. Lancet 2002;359:1187–93.
4. Braun J, Sieper J. Therapy of ankylosing spondylitis and other spondyloarthropathies: established medical treatment, anti-TNF-alpha therapy and other novel approaches. Arthritis Res 2002;4: 307–21.
5. Van der Heijde D, Dijkmans B, Geusens P *et al.* Efficacy and safety of infliximab in patients with ankylosing spondylitis: results on the randomised, placebo-controlled trial (ASSERT). Arthritis Rheum 2005;52:582–91.
6. Van der Heijde D, Baraf HS, Ramos-Remus C *et al.* Evaluation of the efficacy of etoricoxib in ankylosing spondylitis: results of a fifty-two week, randomised, controlled study. Arthritis Rheum 2005;52: 1205–15.
7. Burton AK, Tillotson M, Main CJ, Hollis S. Psychosocial predictors of outcome in acute and sub-acute low back trouble. Spine 1995;20:722–8.
8. Picavet S, Vlaeyen J, Schouten J. Pain catastrophizing and kinesiophobia: predictors of chronic low back pain. Am J Epidemiol 2002;156:1028–34.
9. Roberts L, Chapman J, Sheldon F. Perceptions of control in people with acute low back pain. Physiotherapy 2002;88:543–8.
10. Barlow JH, Macey SJ, Struthers GR. Gender, depression and ankylosing spondylitis. Arthritis Care Res 1993;6:45–51.
11. Barlow JH, Macey SJ, Struthers GR. Health locus of control, self-help and treatment adherence in relation to ankylosing spondylitis patients. Patient Educ Couns 1993;20:153–66.
12. Gunther V, Mur E, Traweger C, Hawel R. Stress coping of patients with ankylosing spondylitis. J Psychosom Res 1994;38: 419–27.
13. Hidding A, de Witte L, Van der Linden S. Determinants of self-reported health status in ankylosing spondylitis. J Rheumatol 1994;21:275–8.
14. Van der Linden S, Valkenburg HA, Cats A. Evaluation of diagnosis criteria for ankylosing spondylitis. A proposal for modification of the New York criteria. Arthritis Rheum 1984;27:361–8.
15. Calin A, Garrett S, Whitelock H *et al.* New approach to defining functional ability in ankylosing spondylitis: the development of the Bath Ankylosing Spondylitis Functional Index (BASFI). J Rheumatol 1994;21:2281–5.
16. Garrett S, Jenkinson T, Kennedy LG, Whitelock H, Gaisford P, Calin A. A new approach to defining disease status in ankylosing spondylitis: the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI). J Rheumatol 1994;21:2286–91.
17. Jenkinson TR, Mallorie PA, Whitelock H, Kennedy LG, Garrett SL, Calin A. Defining spinal mobility in ankylosing spondylitis: the Bath Ankylosing Spondylitis Metrology Index. J Rheumatol 1994; 21:1694–8.
18. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67:361–70.

19. Wallston KA, Stein MJ, Smith CA. Form C of the MHLC Scales: a condition-specific measure of locus of control. J Pers Assess 1994;63:534–53.
20. Ware JE, Sherbourne CD. The MOS 36-item short form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992;30:473–83.
21. Diggle PJ, Liang KY, Zeger SL. The analysis of longitudinal data. Oxford Science Publications; USA, Oxford University Press 1994.
22. Huynh H, Feldt LS. Estimation of the Box correction for degrees of freedom from sample data in randomized block and split-plot designs. J Educ Stat 1976;1:69–82.
23. Herrmann C. International experiences with the hospital anxiety and depression scale – a review of validation data and clinical results. J Psychosom Res 1997;42:17–41.
24. Haywood KL, Garratt AM, Dawes PT. Patient-assessed health in ankylosing spondylitis: a structured review. Rheumatology 2005;44:577–86.
25. Van der Heijde D, Dougados M, Davis J *et al*. Assessment in Ankylosing Spondylitis International Working Group/Spondylitis Association of America recommendations for conducting clinical trials in ankylosing spondylitis. Arthritis Rheum 2005;52:386–94.
26. Harkapaa K, Jarvikoski A, Mellin G, Hurri H, Luoma J. Health locus of control beliefs and psychological distress as predictors for treatment outcome in low-back patients: results of a 3-month follow-up of a controlled intervention study. Pain 1991;41:35–41.
27. Harkapaa K, Jarvikoski A, Vakkari T. Associations of locus of control beliefs with pain coping strategies and other pain-related cognitions in back pain patients. Br J Health Psychol 1996;1:51–63.
28. Pincus T, Burton K, Vogel S, Field A. A systemic review of psychological factors as predictors of chronicity/disability in prospective cohorts of low back pain. Spine 2002;27:109–20.
29. Kennedy LG, Edmunds L, Calin A. The natural history of ankylosing spondylitis. Does it burn out? J Rheumatol 1993;20:688–92.
30. Robertson LP, Davis MJ. A longitudinal study of disease activity and functional status in a hospital cohort of patients with ankylosing spondylitis. Rheumatology 2004;43:1565–8.
31. Taylor AL, Balakrishnan C, Calin A. Reference centile charts for disease activity, functional impairment and metrology in ankylosing spondylitis. Arthritis Rheum 1998;41:1119–25.
32. Gran JT, Skomsvoll JF. The outcome of ankylosing spondylitis. Br J Rheumatol 1997;36:766–71.
33. Falkenbach A, Franke A, Van-der-Linden S. Factors associated with body function and disability in patients with ankylosing spondylitis: a cross-sectional study. Rheumatology 2003;30:2186–92.
34. Claudepierre P, Sibilia J, Chevalier X *et al*. Factors linked to disease activity in a French cohort of patients with spondyloarthropathy. J Rheumatol 1998;25:1927–31.
35. Band D, Jones S, Kennedy G *et al*. Which patients with ankylosing spondylitis derive most benefit from an inpatient management program? J Rheumatol 1997;24:2381–4.
36. Auleley G, Benbouazza K, Spoorenberg A *et al*. Evaluation of the smallest detectable difference in outcome or process variables in ankylosing spondylitis. Arthritis Rheum 2002;47:582–7.
37. Sweeney S, Taylor G, Calin A. The effect of a home based exercise intervention package on outcome in ankylosing spondylitis: a randomised controlled trial. J Rheumatol 2002;29:763–6.
38. Brandt J, Khariouzov A, Listing J *et al*. Six-month results of a double blind, placebo-controlled trial of Etanercept treatment in patients with ankylosing spondylitis. Arthritis Rheum 2003;48:1667–75.
39. Maksymowych W, Jhangri G, Lambert RG *et al*. Infliximab in ankylosing spondylitis: a prospective observational inception cohort analysis of efficacy and safety. J Rheumatol 2002;29:959–65.
40. Crawford JR, Henry JD, Crombie C, Taylor EP. Normative data for the HADS from a large non-clinical sample. Br J Clin Psychol 2001;40:429–34.