Psoriatic Arthritis and Psoriasis: The Role and Impact of Psychosocial Factors

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Abstract

This thesis is concerned with the psychosocial impact of psoriatic arthritis (PsA) – an inflammatory arthritis associated with psoriasis.

Although an extensive literature exists on the nature and impact of psoriasis, little is known about the effect that psoriatic arthritis can have on an individual, and the bearing it may have on their quality of life. In order to address this gap in the literature, this study utilised a mixed methods research design, employing a qualitative study with semi-structured interviews, followed by a quantitative, cross-sectional postal survey.

In the qualitative study, interviews were conducted with ten people living with psoriatic arthritis. Analysis of the data, using Interpretative Phenomenological Approach (IPA; Smith, 2003) resulted in five emerging themes; pain, functionality (including fatigue), emotions (including depression), coping and treatment experience/management.

The quantitative study used a postal survey to measure the variables of interest and explore the associations between them. Survey respondents consisted of a sample (n = 313) drawn from The Psoriasis Association membership and also 44 from a hospital rheumatology clinic. AA participants completed a piloted questionnaire containing questions about their demographic characteristics and validated measures of quality of life.

Analysis confirmed that the group with PsA fared less well on all measures of quality of life, than those with just psoriasis. Correlations identified highly significant relationships between most study variables, however of note were the relationships between fatigue and current pain (r = .547) and depression (r = .670). Within the Psoriasis Group correlations of interest included those between anxiety and social functioning (r = -.606) and DLQI and social functioning (r = -.546). Comparison of the correlations identified 18 that were significantly different between the groups. Of these, relationships between physical functioning, pain, fatigue and self efficacy were of particular interest, whilst in the psoriasis group the

associations between self efficacy, social functioning and psychological health were noteworthy.

This research provides some evidence that different psychosocial variables appear to be involved in the reductions in quality of life experienced by the two clinical populations in this study.

The results suggest that in rheumatology and dermatology clinics, the routine measurement of fatigue, self efficacy and psychological health could be used to inform the prescribing of therapies, psychosocial interventions and drugs to improve emotional functioning, so impacting on health-related quality of life.

Furthermore, these findings have highlighted the need to elucidate the symptom of fatigue in PsA and position it as an appropriate target not only for clinical management, but also psychological management. By advocating fatigue as a legitimate concern, this may offer patients the chance to discuss fatigue explicitly and obtain appropriate health advice.

CHAPTER 1

INTRODUCTION TO THESIS

1.1   Background

Although an extensive literature exists on the nature and impact of psoriasis, little is known about the effect that psoriatic arthritis can have on an individual and the bearing it may have on their quality of life.

This thesis is concerned with the psychosocial impact of psoriatic arthritis (PsA) – an inflammatory arthritis associated with psoriasis. Whilst both these chronic conditions warrant exploration, the focus of this research is PsA, however given that the conditions are linked, the role of psoriasis is, by necessity, reviewed.

In summary, research examining the psychosocial aspects of PsA has been historically under-investigated with the vast majority of the published literature consisting of clinical reports and a limited number of prevalence studies. It is clear that there are substantial gaps in the literature, and that basic questions about the scope, nature and impact of psychosocial issues among individuals with PsA, remain largely unanswered.

1.2   Research Questions

In order to address these deficiencies and provide a valid and detailed assessment of the impact of psychosocial issues related to PsA, several research questions are addressed in the present study:

(1) What is the prevalence and nature of the psychosocial issuess experienced by people with PsA?

(2) What is the impact of these issues on the quality of life in people with PsA?

(3) To what extent do physical and psychosocial issues influence how people with PsA cope with the disease?

Given that there is a paucity of research concerning the psychological impact of living with PsA, no specific hypotheses were formulated. Rather, exploratory analyses were conducted to determine which psychosocial issues were viewed as pertinent by patients, before using quantitative instruments to measure the impact and determine the presence of any associations.

1.3   Methodology

The methodology adopted, in turn, reflected the nature of these research questions. The present study utilised a mixed methods research design involving semi-structured interviews (Study 1) and a cross-sectional postal survey (Study 2).

Study 1: Interviews were conducted with ten people living with psoriatic arthritis. Study participants were a purposive sample drawn from a hospital rheumatology clinic located in Liverpool, UK. The inclusion criteria were three-fold: participants had to be aged between 18 and 65; had a new or existing diagnosis of PsA, and spoke English as their first language. The sessions were audiotaped and tapes transcribed verbatim and, in order to identify emerging themes, were interpreted using Interpretative Phenomenological Approach (IPA) as described by Smith (2003).

Study 2: Survey respondents consisted of a sample (n = 313) drawn from The Psoriasis Association membership and also 44 from a hospital rheumatology clinic. All participants completed a piloted questionnaire containing questions about their demographic characteristics and validated measures of quality of life.

1.4   Structure of thesis

Chapter 2 considers, in broad terms, the impact of chronic illness with particular reference to inflammatory arthritis and more specifically, psoriatic arthritis. A critical review of the

existing literature concerning PsA-related psychosocial issues is discussed. However, given the shortage of published papers in this area, psychosocial functioning in people with rheumatoid arthritis (RA) and ankylosing spondylitis (AS) is explored with implications for the current study.

A discussion and justification of the methodology adopted to meet the aims of the current study is presented in Chapter 3. The design and sampling methods for the research in Study 1 and 2 are described, as is the rationale for using qualitative interviews, rather than focus groups.

Chapter 4 presents the research design and sampling methods for Study 1. It reports the results and discusses the findings and their implications for the choice of quantitative measures used in Study 2.

Chapter 5 reviews the instruments available to measure the psychosocial variables that Study 1 determined were of interest. The chapter concludes with justification for the final choice of measures to be used in Study 2.

Chapter 6 considers the aims and objectives of Study 2. The research design, sampling method and results are presented, along with a discussion that interprets the findings.

Chapter 7 considers the findings of both Study 1 and 2 and examines the results in the context of the current literature concerning PsA and psoriasis. It summarises the major findings of the study and how they integrate with previous research. The thesis concludes with an overview of the research process utilised to address the research problem and the methodological strengths and limitations of the study are also considered. The implications arising from the findings with respect to clinical practice are discussed along with possible directions for future research.

CHAPTER 2

LITERATURE REVIEW

2.1   Chronic Illness

The latter half of the twentieth century and the dawn of the new millennium has been a period in which life expectancy in the United Kingdom has increased as modern medicine and improved sanitation has eradicated many communicable diseases like cholera, while acute illnesses such as pneumonia are no longer an automatic death sentence.

However, this greater longevity has resulted in the health services having to adapt to meet the challenges of the increasing burden of conditions such as heart disease, stroke, cancer, diabetes and arthritis, due to the predominant disease pattern in the UK, and most other developed countries, now being one of long-term, or chronic, illness rather than acute disease. This change has created a significant economic cost to the UK health service as 80% of GP consultations now relate to chronic illness and 60% of hospital bed days result from chronic illness and related complications (Office of National Statistics, 2008).

The challenges faced by the 17.5 million people in the UK living with a chronic illness are many, because not only are they required to contend with physical pain, prolonged medical treatment, increasing restrictions on their daily activities and psychological distress, but they face the possibility of making significant changes in their employment status and social and family relations, all of which has the potential to significantly reduce their quality of life (Department of Health, 2004)

The impact on quality of life extends to those family members who provide care for the chronically ill who face an increased financial, physical and emotional responsibility. Research shows that carers who are employed reported missing work, taking days off, and even retiring early in order to provide care (Lim & Zebrack, 2004). Given that many patients

may be unable to continue in employment, chronic illness frequently leads to financial hardship for patients and their families.

Chronic illnesses are one of the most prevalent and escalating health concerns facing not only the health service, but also organisations and employers nationwide. With an estimated third of the workforce managing a chronic illness, the need to find innovative management strategies that can improve a patient's ability to cope with a long-term condition and manage symptoms, so as to remain productive at work, is becoming increasingly important.

A chronic illness is a disease that has a prolonged course, does not resolve spontaneously, and rarely is completely cured. According to the World Health Organisation (2006), they are diseases that are defined by being permanent, caused by non-reversible pathological alteration, leave residual disability, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care.

Individuals with a chronic illness experience a permanent alteration in their way of life and a reappraisal of functional abilities that introduces significant psychosocial stressors and adaptive demands. Such illness-induced disruptions to lifestyle, activities, and interests have been shown to compromise psychosocial well-being and contribute to emotional distress in chronic disease (Devins, 1994).

The most common long-term condition in the UK is arthritis followed by heart conditions (British Household Panel Survey, 2001). One in four of all GP consultations in the UK relates to a musculoskeletal problem with arthritis affecting one in five adults (McCormick, Fleming & Charlton, 1995; Parroy, 2005). This equates to approximately 9 million people with some form of arthritis, which, according to The Health and Safety Executive, costs the economy £5.7 billion per year.

Arthritis is a stressful chronic illness which results in persistent pain, joint damage and joint stiffness, that may not only produce substantial physical disability, but also negatively influences individuals' lives as it is detrimental to functional ability, family and social

relationships, employment, and psychological status (Escalante & Del Rincon, 1999; Yellin & Callahan, 1995; Katz, 1998). The subsequent loss or reduced independence, role changes and uncertainty that can result, are compounded by the economic burden that confront many sufferers as maintaining employment becomes a challenge (Melanson & Downe-Wamboldt, 2003)

There are 200 types of arthritis that are classified into three categories: Inflammatory arthritis (e.g. rheumatoid arthritis), Non-Inflammatory Arthritis (e.g. osteoarthritis) and Connective Tissue Disease (e.g. Lupus).

Inflammatory arthritis is the term used to describe a range of conditions including rheumatoid arthritis (RA), psoriatic arthritis (PsA), ankylosing spondylitis (AS) and juvenile idiopathic arthritis (JIA). These are autoimmune diseases in which the body's immune system attacks the joints causing them to become inflamed, and whilst the cause is not exactly known various factors are thought to play a role, including infection, the environment, trauma and a person's genetic make-up (Svendsen et al., 2002).

2.2   Inflammatory Arthritis – the size of the problem

The most common form of inflammatory arthritis is rheumatoid arthritis. Approximately 387,000 adults in the UK have RA, a figure that represents 0.8% of the adult population (Symmons et al, 2002). Each year there are approximately 12,000 newly diagnosed cases of this condition that affects three times as many women as men (Arthritis Research Campaign, 2002).

Annually, 200,000 people visit their GP with ankylosing spondylitis (Arthritis Research Campaign, 2002), whilst estimates for those with psoriatic arthritis vary between 84,000 and 177,000 (Kay et al, 1999). A further 250,000 people have gout, (McCormick et al, 1995) whilst 12,000 children in the UK have Juvenile Idiopathic Arthritis (Silman, 2001).

Whilst these figures serve to demonstrate the human cost of inflammatory arthritis in the UK, they do not present the complete picture. These are progressive diseases, but are unpredictable as their pattern and progression varies greatly between individuals. Many people will experience severe and disabling pain, stiffness and reduced joint function, other organs can be affected and severe inflammatory arthritis, particularly RA, can shorten life expectancy by approximately 6-10 years, which is similar to the impact of diabetes, Hodgkin's disease, strokes and triple coronary artery disease (Arthritis Research Campaign, 2002; Scott et al, 1998).

2.3   Economic Cost of Inflammatory Arthritis

Whilst the costs of the disease are high for the individuals affected and their families, so too is the cost to the NHS. For example, in 2000, there were 1.9 million GP consultations for inflammatory arthritis, with almost 46,000 hospital admissions (Arthritis Research Campaign, 2002).

The annual NHS spend for managing RA and complications arising from its treatment is estimated to be £240 million (Arthritis Care, 2000), whilst the total annual cost of treating RA, including health costs and lost working days, is estimated to be £1.3 billion (van Jaarsveld et al, 2000).

2.4   Psoriatic Arthritis (PsA)

Associated with psoriasis, psoriatic arthritis is a chronic, inflammatory disease of the joints and connective tissue with potential for significant joint destruction contributing to pain and disability. The disease affects men and women almost equally, with a mean age at onset of 36 years.

Although probably first described by Alibert in 1818, the association between inflammatory arthritis and psoriasis was only formally recognised in 1964 when the American Rheumatism Association classified PsA as distinct from other rheumatic conditions (Moll & Wright, 1973;

Blumberg et al., 1964) and included it in the group of seronegative spondyloarthropathies - a family of inflammatory rheumatic diseases that affect the spine, joints, ligaments and tendons. Other diseases in this group include ankylosing spondylitis (AS), enteropathic arthritis (e.g. associated with Crohn's disease or ulcerative colitis) and reactive arthritis or Reiter's disease.

2.4.1   Epidemiology

There are few universally agreed diagnostic criteria for PsA, so prevalence is difficult to estimate, however a study, based on a population of 413,421 patients in the Norwich area, reported prevalence rates of 3.5 per 100,000 for males and 3.4 per 100,000 for females (Harrison et al, 1997). In other studies the reported incidence has varied from 3.4 to 8 per 100,000 (Bruce, 2003: Savolainan, 2000; Soderlin, 2002). One Swedish study suggested that 30% of patients with psoriasis had PsA (Zachariae, 2003) whilst another study of patients attending a psoriasis clinic found 31% to have PsA (Brockbank, 2001). These findings suggest that prevalence rates for PsA in the general population would be $\approx 1\%$.

Occurrence of PsA increases with severity and duration of psoriasis. In 70% of patients, psoriasis usually precedes onset of PsA by an average of ten years, but PsA can precede the appearance of the skin condition in up to 20% of cases, by as much as fifteen years. The onset is contemporaneous in approximately 20% of cases (Mease & Goffe, 2005; Veale et. al, 1994).

2.4.2   Clinical Features of PsA

Given there is no specific diagnostic test for PsA, diagnosis is made primarily on the basis of history, physical examination, the usual absence of Rheumatoid Factor, and radiographic features.

The physical examination includes assessment of number, location and distribution of joints involved, along with the presence of psoriatic skin lesions (Barth, 1997). Key signs indicative of PsA include asymmetric joint involvement, enthesitis (inflammation at the site of insertion of the tendons and ligaments to bone), dactylitis (inflammation of an entire digit, sometimes

referred to as 'sausage fingers'), distal interphalangeal involvement and spinal inflammation. Extra-articular manifestations include nail lesions, iritis, mouth ulcers, urethritis, and heel pain (Mease & Goffe, 2005). Nail involvement occurs in 80% of patients with PsA, causing pitting, thickening, separation of the subungual bed, and ridging of the nail plate (Bennet, 2001).

2.4.3   Treatments

Drugs for the treatment of psoriatic arthritis can be divided into several categories: nonsteroidal anti-inflammatory drugs (NSAIDs), disease-modifying anti-rheumatic drugs (DMARDs) and biologics, which are also considered DMARDs.

NSAIDs help to decrease inflammation, joint pain and stiffness and include over-the-counter medications such as aspirin and ibuprofen, as well as prescription products.

Disease-modifying antirheumatic drugs (DMARDs) may relieve more severe symptoms and attempt to slow or stop joint and tissue damage and progression of psoriatic arthritis. Biologics, such as Enbrel®, Humira® and Remicade®, are highly selective agents that target specific internal events in the body that trigger the inflammatory response in psoriasis and psoriatic arthritis.

Despite the advances in treating PsA, the disease remains incurable and one that can result in substantial deformities of the affected joints, as demonstrated by the following images:

Images showing PsA

Figure 1: Swelling and deformity of the metacarpophalangeal and distal interphalangeal
Joints in a patient with psoriatic arthritis (www.emedicine.com)

Figure 2: Severe psoriatic arthritis involving the distal and proximal interphalangeal joints (www.emedicine.com).

Figure 3: Arthritis mutilans, a typically psoriatic pattern of arthritis, which is associated with a characteristic "pencil-in-cup" radiographic appearance of digits (www.emedicine.com)

2.5 Psoriasis

Psoriasis is a chronic, recurrent, immune mediated, inflammatory skin condition that can result in a significant negative impact on a patient's physical, emotional and psychosocial functioning (British Association of Dermatologists, 2005).

2.5.1 Prevalence

Epidemiologic studies from around the world have estimated the prevalence of psoriasis to be 0.6% to 4.8%, however, The British Association of Dermatologists estimate the UK incidence to be 2% (2004), although UK studies typically report rates of 1.5%, whilst in the USA a 2005 population-based survey estimated the lifetime prevalence of self-reported psoriasis in people 18 years or older to be 2.2% (Rapp et al., 1999).

It is a very diverse skin disease that may present in one of five forms, although approximately 80% of those with the condition are diagnosed with Plaque Psoriasis (scientific name being Psoriasis Vulgaris). This form is characterised by raised, inflamed, red lesions, covered by a silvery white scale and is typically found on the elbows, knees, scalp and lower back (see Figure 4).

Inverse psoriasis (see Figure 5) first shows as very red lesions that usually lack the scale associated with plaque psoriasis and appears smooth and shiny. As it is located in the armpits, groin, under the breasts, and in other skin folds around the genitals and the buttocks, it is particularly subject to irritation from rubbing and sweating and tends to be more common and troublesome in overweight people and people with deep skin folds.

Erythrodermic Psoriasis is a particularly inflammatory form of psoriasis that often affects most of the body surface and is characterized by periodic, widespread, fiery redness of the skin (see Figure 6). The erythema (reddening) and exfoliation (shedding) of the skin are often accompanied by severe itching and pain. Erythrodermic psoriasis causes protein and fluid loss that can lead to severe illness. Edema (swelling from fluid retention), especially around the ankles, may also develop along with infection. The body's temperature regulation is often disrupted, producing shivering episodes. People with severe cases of this condition often require hospitalisation as infection, pneumonia and congestive heart failure brought on by erythrodermic psoriasis can be life threatening.

Guttate psoriasis is a form of psoriasis that often starts in childhood or young adulthood. This form of psoriasis resembles small, red, individual spots on the skin. Guttate lesions usually appear on the trunk and limbs, although the spots are not usually as thick as plaque lesions (see Figure 7). Guttate psoriasis often comes on quite suddenly and a variety of conditions have been known to bring on an attack, including upper respiratory infections, streptoccocal infections, tonsillitis, stress, injury to the skin and the administration of certain drugs (including antimalarials and beta-blockers). A streptococcal infection of the throat (strep throat) is a common guttate psoriasis trigger.

Pustular psoriasis, primarily seen in adults, is characterized by white pustules (blisters of non-infectious pus) surrounded by red skin (see Figure 8). It tends to go in a cycle, with reddening of the skin followed by formation of pustules and scaling. The pus consists of white blood cells. It is not an infection, nor is it contagious. Whilst it may be localized to certain areas of the body, for example, the hands and feet, this form can also be generalized, covering most of the body. Pustular psoriasis reportedly may be triggered by internal medications, irritating topical agents, overexposure to UV light, pregnancy, systemic steroids, infections, emotional stress and sudden withdrawal of systemic medications or potent topical steroids.

2.5.2   Treatments

There are a variety of different treatments available to help control psoriasis, including topical creams, phototherapy and systemic medications.

Topical treatments refer to medications that are applied to the skin and are usually the first line of defence. They include products available over the counter, such as tar and salicylic acid, as well as prescription topicals such as Dovonex cream and topical steroid creams.

Light therapy, involves exposing the skin to wavelengths of ultraviolet light under medical supervision. There are three types of treatment, UVB phototherapy, PUVA and lasers. UVB involves exposing the skin to an artificial UVB light source. PUVA is an acronym for psoralen (a light-sensitising medication) combined with exposure to ultraviolet light A (UVA). UVA, like UVB, is found in sunlight. However, UVA alone is relatively ineffective unless used with a light-sensitising medication such as psoralen.   Targeted UVB treatment and pulsed dye lasers can be used to treat chronic, localised plaque lesions.

Systemic medications, such as cyclosporine and methotrexate, are prescribed medications that affect the entire body and are reserved for patients with moderate to severe psoriasis who are not responsive to conventional topical medications or UV light treatments.

Biologics are a fairly new type of systemic medication, and whilst seemingly very effective, they are still being evaluated, as their long-term effects are not fully known. Biologics are developed from living sources, such as cells, rather than the combination of chemicals found in traditional drugs. To date, there are several available to treat psoriasis (National Psoriasis Foundation).

Images of Psoriasis

Figure 4: Plaque Psoriasis

Figure 5: Inverse Psoriasis

Figure 6: Erythrodermic Psoriasis

Figure 7: Guttate Psoriasis

Figure 8: Pustular Psoriasis

(All images courtesy of www.emedicine.com)

2.6   The Psychosocial Impact of Psoriasis

Most chronic rheumatological disorders require some form of adaptation, both physical and psychological, by the patient in order that they may come to terms with a painful, disabling condition that often has an unpredictable course and no cure.

Psoriasis and psoriatic arthritis are inflammatory, immune-mediated skin and joint conditions with significant visible manifestations such as thickened, scaly plaques, local or widespread lesions, significant joint deformities and permanent disability, all of which may not only contribute to decrements in patients' physical functioning, but may cause a distorted perception of their self image and embarrassment about their appearance, with the cumulative effects impacting negatively on their health related quality of life.

Although associated with deformities and joint destruction, PsA had been considered a milder disease in terms of articular erosions, when compared to RA, however, it is now thought to be much more aggressive than previously believed and is considered as severe as other arthropathies, with one study of PsA patients reporting that 57% of participants had erosive arthritis and 19% had pronounced physical limitations (Torre Alonso et al., 1991).

The course of PsA is unpredictable with periods of relapse and remission, and because severity fluctuates over time, so does the impact of the disease. However, given that the symptoms of PsA, such as joint pain, pain at insertions of tendons and ligaments, stiffness and fatigue combine with visible physical signs of disease such as joint swelling, 'sausage digits' and joint deformities, the psychological burden of the disease may always be present. The skin component of this condition contributes to this burden, as patients may have to endure the physical discomfort and disfigurement that can occur as a result of psoriasis (Rapp et al., 1999).

Traditionally, research has tended to focus on the physical aspects of these diseases, however, in recent years there has been a growing interest in the psychosocial impact, as evidenced by

an increasing number of researchers adopting a biopsychosocial approach as they strive to explore the interaction between physical, psychological and social factors.

Such an approach was adopted for the purpose of the current study, as it aims to identify and explore, in patients with PsA and psoriasis, the role of psychosocial factors.

Given that the majority of individuals with PsA also endure the legacy of living with psoriasis, it is appropriate to briefly examine the experience that those with psoriasis undergo – an experience that, research findings suggest, is detrimental to physical, social and psychological health.

2.6.1   Psoriasis and Psychosocial Issues

Various studies have documented the impact that physical symptoms associated with psoriasis can have. For example, Fleisher et al. (1996) surveyed 317 patients with a diagnosis of Psoriasis Vulgaris and reported that 95% experienced pruritus, 86% sore skin and 81% burning skin and that the average time spent in daily psoriasis care was 68 minutes. In addition, 69% (219 participants) reported joint pain, over half the respondents, 163, stated they had arthritis, whist 64 (20%) reported they had PsA. The prevalence of PsA in this group mirrors that cited by Stern (1985), and Zanolli & Winkle (1992). It is of note that arthritis in general was a common condition in this group, however the authors do not elucidate to the possibility that a portion of these had undiagnosed PsA.

Physical symptoms, such as pruritus, were found in a study by Koo (1996) to be the worst or second worst aspect about having psoriasis – a finding that supported the results of a survey by Gupta et al. (1988), in which psoriasis patients reported pruritus as one of the most distressing symptoms. This study further reported that increased pruritus was associated with increased severity of depression, whilst Rapp et al. (1999) concluded that pruritus and skin soreness were the symptoms associated with a decrease in the mental component of health related quality of life, as measured by a non-disease specific instrument.

In 1998, in order to better understand how psoriasis affects the quality of life of individuals, the National Psoriasis Foundation (NPF), the largest organisation of psoriasis patients in the United States, undertook a two-part survey of their patient membership. They aimed to explore patients' perspectives of the impact of psoriasis on their lifestyle, emotional well-being, employment and social conditions (Krueger et al, 2001).

Surveys were mailed to 40,350 members and a response rate of 43% (17,488) was achieved. Those respondents meeting the criterion for severe psoriasis (6,194) were entered into a database, and once a representative sample had been created, 502 telephone interviews were conducted.

Findings from the mail survey clearly demonstrate the psychosocial impact of psoriasis across all age ranges (18-34y; 35-54 and ≥ 55y). A total of 43% reported difficulties in the workplace, 36% believed psoriasis affected their interaction with family and friends and 20% had contemplated suicide. Obtaining a job (12%) and exclusion from a public facility (21%) also accounted for some of the difficulties faced by this patient group. Many activities of daily living were affected such as walking and performing job duties, but the greatest impact was on sleeping (64%) and sexual activities (67%).

The results of the follow-up telephone survey in the NPF study lend further weight to these findings as 79% of respondents reported that severe psoriasis had an overall negative impact on their lives. In addition to the practical implications of living and managing the disease, serious emotional issues were noted with 54% of the sample feeling depressed.

The NPF study undoubtedly provides compelling evidence that individuals with psoriasis believe that the disease has a profound emotional, social and physical impact on their quality of life.

This finding was re-enforced by the results of a large Italian study that explored the prevalence of depressive symptomatology among Italian patients with the most common form of psoriasis, psoriasis vulgaris, more commonly referred to as plaque psoriasis (Esposito et al., 2006). In

this study, the researchers mailed five thousand patients the Centre for Epidemiological Studies Depression Scale (CES-D) questionnaire, a 20-item instrument developed for use in epidemiological studies of depressive symptomolgy in the general population. Of the 2,391 that were returned completed and usable, 63.9% (1,528) were from men. Overall, depressive symptoms were observed in 62% of the respondents, a figure that represented 61% of the males and 63% of the females, however, it was males under the age of forty who were significantly more likely to report depressive symptoms.

The Italian study serves to support numerous findings that report a high prevalence of depressive symptoms among patients with dermatological conditions, but notably, psoriasis. Comparison studies invariably highlight that a higher percentage of psoriasis patients exhibit general psychiatric morbidity, compared with patients suffering with other types of skin diseases. For example, a study by Sharma et al., (2001) that used the General Health Questionnaire to assess the psychiatric morbidity of psoriasis and vitiligo patients found that 53.3% of psoriasis patients recorded scores indicating the presence of psychiatric illnesses, such as depression, anxiety and sleep disturbance. Furthermore, a study exploring life events and psychological distress in three dermatological disorders, specifically, psoriasis, chronic urticaria and fungal infections, reported that patients with psoriasis and urticaria had higher depression, anxiety, and inadequacy scores than patients with fungal infections (Fava et al., 1980).

The literature indicates that researchers comparing psoriasis patients with general population norms consistently report higher degrees of depression in psoriasis patients than controls. For example, a Turkish study comprising fifty psoriasis patients and fifty healthy controls, with no history of skin and psychiatric disease, were matched for sex, age and education and were administered various measurement instruments, including the Beck Depression Inventory (BDI). It was found that significantly higher levels of depression were present in psoriasis patients than the healthy controls (Mean BDI score of 16.96 and 5.48 respectively), and that the BDI scores were strongly correlated with the severity of the psoriasis symptoms. Interestingly the researchers also noted that the length of illness was inversely related to the

BDI score and they suggest that this may be due to individuals adapting and learning to cope with the psychosocial effects of the disease (Devrimci-Ozguven et al., 2000).

Disease severity in psoriasis is traditionally assessed in terms of the physical appearance of the lesions and total body surface area involved. However, it is clear that, using these measures, the clinical severity as determined by a physician, does not necessarily bear any relationship with the patient reported degree of impairment. With this in mind, Krueger et al. (2000), in a position paper, argued that severity of psoriasis is predominantly a quality of life issue, and that conflicts between clinical severity ratings and the actual disability experienced by the patient can be reconciled, if both the physical and psychosocial effects of psoriasis are taken into account.

There is evidence that both joint and skin (psoriasis) manifestations contribute to psychosocial and physical disability and take a substantial physical and emotional toll on patients. Indeed, Rapp et al. (1999) measured health-related quality of life in patients with psoriasis and found that not only did the impact on physical function correlate with joint pain, but also that patients experienced significant reductions in physical and mental function (compared with healthy adults) similar to patients with cancer, diabetes, hypertension, heart disease and depression. Furthermore, another study found that in those people with psoriasis, quality of life was impaired in terms of bodily pain and social functioning (Heydendael et al., 2004),

The significant psychosocial morbidity and decreased health-related quality of life found in psoriasis patients was highlighted by Gupta et al, (1993) when they explored depression and suicidal ideation in dermatology patients. They found a 9.7% prevalence of a death wish and a 5.5% prevalence of acute suicidal ideation in those individuals with psoriasis, both of which were associated with higher depression scores and higher patient self-ratings of psoriasis severity. These rates are more than double that found in the general community (Olfson et al, 2002). A later study by Gupta & Gupta (1998) found that psoriasis patients recorded depression scores that were in the range for clinical depression and the rate of suicidal ideation among 79 outpatients being treated for psoriasis was 2.5% - a figure consistent with that seen in other populations with chronic illness (Cooper-Patrick, 1994).

Substance abuse is known to be an independent risk factor for suicide so it is of some note that a further study by Gupta & Gupta (1996) reported an 18% prevalence of alcoholism among patients with psoriasis, compared with 2% among patients with other dermatological conditions.

Indeed, research has shown that simply receiving a diagnosis of psoriasis can result in significant psychological sequelae, with one study by Fried et al. (1995) reporting that half of the participants were depressed and anxious following a diagnosis of psoriasis.

Whilst the clinical implications of psoriasis and psoriatic arthritis are well documented, research into the psychosocial impact of these conditions is heavily biased towards psoriasis, a disease which, as the evidence above demonstrated, impacts negatively on quality of life.

2.6.2   PsA and Psychosocial Issues

When considering the psychosocial impact of living with PsA, it is apparent that compared with the plethora of psoriasis studies, the literature exploring PsA is less well developed, as much of the research has been undertaken using a medical model which utilises clinical measures, such as counting the number of tender and swollen joints in a patient, inflammation markers and physician assessed global health (Mease et al., 2005). These outcome measures have primarily been borrowed from the assessment of RA and AS and are used in clinical trials and with clinical registries of PsA patients. Yet, where much of the research examining RA, AS and psoriasis includes measures for quality of life, fatigue, function, depression and mood, this is not the case with PsA, as these have not yet been established as core domains in PsA research.

In his paper 'Psoriatic Arthritis Update' (2006), Mease argues that 'a challenge of PsA therapy is addressing the multiple clinical domains involved in the disease: arthritis, enthesitis, dactylitis, spine disease, skin, and the significant impairment of function and quality of life that may occur'. If therapies are to target these domains, then outcome measures need to be

used in clinics to allow for the assessment of psychosocial domains in order to establish the efficacy of treatments.

Given the paucity of studies exploring and measuring the psychosocial impact of living with PsA, it is difficult to ascertain which factors, if any, may play a role in the lives of those affected by the disease. However, some understanding of the consequences that may result from living with other chronic, rheumatoid conditions may be obtained by examining studies undertaken with RA and AS patients.

The following sections outline and explore various psychosocial factors and are considered in the light of research relating to RA, AS, and where available, PsA.

2.6.3 Quality of Life

One way of capturing the personal and social context of patients is to use quality of life measures. Increasingly in the field of health, and in particular, chronic, disabling conditions, quality of life measures are used to supplement objective clinical or biological measures of disease severity. Whilst no definitive definition of quality of life has been agreed upon it is usually regarded as existing relative to individual or cultural expectations and goals (Carr & Higginson, 2001). In an attempt to clarify the position, the World Health Organisation (WHO), described quality of life as:

> *'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment'.*

In the health care literature, quality of life is associated with function and health status, and is invariably referred to as health related quality of life (HRQOL). Functional status is not just concerned with physical ability, but considers the degree to which an individual can perform chosen roles without limitation in three key areas – physical, social and psychocognitive function. Seemingly, quality of life is a broad concept, indeed Mount and Scott (1983) likened the assessment of it to assessing the beauty of a rose: no matter how many measurements are made (for example of colour, smell and height), the full beauty of the rose is never captured.

Given that a substantial body of research supports the view that physical findings and disease severity do not always correlate with patient self-report about quality of life, it is becoming progressively more important to assess health using multi-dimensional outcome measures (Corinsky, 1999).

In one of the very few studies to explore PsA-related quality of life, a study undertaken in Canada by Husted and colleagues (2001), compared the health-related quality of life of patients with PsA and RA and, as would be expected, both patient populations experienced lower physical health when compared with that of a general population. Based on the emerging belief that PsA is more aggressive than previously thought, Husted expected to find that PsA affects quality of life to a similar extent as RA.

From two outpatient clinics of the University of Toronto Rheumatic Disease Unit, the researchers recruited 107 PsA patients and 43 with RA. In addition to a number of clinical measures, all the participants completed the Health Assessment Questionnaire (HAQ) and the SF-36 in order that particular dimensions of health-related quality of life could be assessed. Although the RA patients had more active inflammatory disease at the time of the assessments, the PsA patients, even after adjustments were made for differences in demographic and clinical characteristics, recorded higher levels of vitality. The researchers suggested this result might relate to fibromyalgia as in a previous study they had found patients with RA had higher frequency of fibromyalgia with more tender points than PsA patients. After adjusting for the observed difference in vitality, it was the PsA patients who reported more role limitations due to emotional problems and more bodily pain, a result that supports the researchers' earlier

work, in which they found approximately 47% of a sample of 118 PsA patients described mood disturbances or low self-esteem related to changes in appearance due to psoriasis (Husted et al., 1995).

The 2001 study by Husted and her colleagues revealed meaningful differences in quality of life between PsA and RA. The higher vitality reported by those with PsA may indicate that PsA is a less disabling arthropathy than RA, although it is of note that those with PsA experienced greater bodily pain and role limitations due to emotional problems, a result the researchers suggest may be due to unique disabilities associated with the psoriasis dimension of PsA.

In 2001 Sokoll and Helliwell also reported the findings of their study that compared severity, disability, and quality of life in patients with PsA and RA matched primarily for disease duration. Forty-seven patients were matched for disease duration with the Median duration for those with PsA being five years, and those with RA seven years. Function and QOL data was gathered using the Health Assessment Questionnaire (HAQ) and the EuroQol-5D, respectively, whilst recent radiographs of hands and feet were read blinded to diagnosis in order to establish the extent and severity of disease. The researchers found that peripheral joint damage was significantly greater in RA than in PsA, but that function and quality of life scores were the same for both groups and they concluded that this result may reflect the additional burden of skin disease in those with PsA.

Similarly, another study that explored quality of life and the prevalence of arthritis in Nordic psoriasis patients concluded that those with arthritis exhibited reduced psoriasis-related quality of life, longer disease duration and greater self-reported disease severity for psoriasis, with important predictors for arthritis-related quality of life being pain, number of affected joints and restriction of joint mobility. Interestingly, this research also indicated that the prevalence of arthritis in patients with psoriasis might be far higher than the previously accepted average of 7%, as in their study of 5,795 members of the Nordic Psoriasis Associations, the prevalence was found to be 30% (Zachariae et al, 2002).

2.6.4   Depression

The World Health Organisation defines depression as 'a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration'.

Different forms of depression exist and can manifest in different grades of severity. Tamminen (1993) observed that throughout the history of psychiatry a number of different classifications have existed, however contemporary epidemiological surveys conceptualise depression as a diagnosis based on the criteria of diagnostic systems such as the DSM-IV (edition four of the Diagnostic and Statistic Manual of Mental Disorders) and ICD-10 (International Classification of Diseases) as endorsed by the WHO.

Evidence in the chronic pain literature suggests that symptoms of depression, and indeed clinical depression, often develop secondary to pain (Fishbain et al., 1997).

The incidence of depression has been found to be higher among those with rheumatological disorders than in the general population, with a rate similar to that found in individuals with other chronic conditions (De Vellis, 1993). Although the reasons for the elevated incidence of depression and depressed mood may be multi-faceted, research with RA patients indicates that pain is associated with depression (Hawley & Wolfe, 1988) although the direction of causality between the two is debatable (Brown, 1990; Parker et al., 1992). Depression has been found to have an effect on disability, with one study reporting that RA patients were more impaired than those who were not depressed (Katz & Yelin, 1993) whilst another found that psychological factors were a better predictor of disability than traditional measures of disease activity (McFarlane & Brooks, 1988).

In a meta-analysis of 12 studies, Dickens et al. (2002) found that depression was significantly more common among RA patients than healthy individuals and the levels of pain influenced this.

These findings support earlier studies that conclude, even when careful methods of assessment are applied, major depressive disorder affects between 13% and 17% of patients with RA (Frank et al., 1988; Murphy et al., 1988; Creed, 1990).

Although much of the research relates to patient samples with chronic RA, there are a number of studies that have documented rates of depression that are at least as high for patients recently diagnosed with RA compared to those with chronic RA. In one study considering the clinical and health status of patients with recent-onset RA, the scores on all clinical and health status measures indicated substantial disease effects in the group with recent-onset RA, with an effect size similar in magnitude to those with more established disease (Meenan et al., 1991).

Interestingly, evidence suggests that RA patients who are depressed early in the disease rarely adjust with medical intervention alone. Evers and colleagues (1997) reported that depression and anxiety measured at Time 1 were highly predictive of subsequent deterioration in those measures, suggesting that patients showed little evidence of adaptation to their disease. Their findings also suggested that social support networks were predictive of positive changes in depressed mood.

In a study of 110 patients with ankylosing spondylitis that examined the associations between disease and psychological status, the authors reported that anxiety, depression, internality and health status all correlated significantly with disease status scores. Indeed, 25% of the group were clinically anxious and 15% clinically depressed (Martindale et al., 2006), figures that reflect those reported in an earlier study by Barlow et al. (1993), who found one third of AS patients revealed symptoms of depression.

2.6.5 Pain

The International Association for the Study of Pain describes pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage' (IASP, 1994).

Pain is usually experienced as an unwanted physical stimulus located in a specific anatomical region and was, up until about 1895, considered a direct consequence of physical injury with the intensity generally believed to be proportional to the degree of tissue damage (Brannon & Feist, 2000). However, towards the end of the nineteenth century, a different view of pain began to emerge as Strong (1895) hypothesised that two factors were implicated in the experience of pain – the sensation and the person's reaction. The suggestion that psychological factors and organic causes may be of equal importance has lead researchers to suggest pain is a psychological and physical phenomenon that is mediated by personal perception.

Increased knowledge regarding the physiology of the brain and spinal cord supports the notion that the experience of pain includes a psychological element and has paved the way for researchers to employ a biopsychosocial approach in which the role of factors such as anxiety, depression, social support, self efficacy and functionality, to name but a few, can be assessed and their impact on a person's perception of pain, evaluated.

Given that pain is the most prominent symptom in people with musculoskeletal disorders and the most common reason for patients to seek medical help (Kazis et al., 1983), the literature contains a broad array of studies which contemplates how pain may be perceived, affected or mediated by factors such as depression, coping, fatigue, personality traits and catastrophising (a set of negative emotional and cognitive processes), to name but a few.

Indeed catastrophising, with its construct that incorporates magnification of pain-related symptoms, feelings of helplessness, rumination about pain, and pessimism about pain-related outcomes, has been increasingly implicated in the experience of pain and associated with various adverse outcomes such as pain severity, depression, and disability (Edwards et al., 2006). Among patients with RA, cross-sectionally, higher pain severity has been found to relate to catastrophising (Covic et al, 2000) whilst several prospective studies have reported the longitudinal association of catastrophing with pain – using daily diaries studies, RA patients who exhibited greater catastrophising reported more day-to-day pain and also attention to pain than low catastrophisers (Lefebvre et al., 2002). Other RA studies have established that catastrophising predicts disability even after controlling for pain severity

(Covic et al, 2000; Thastum et al., 2005) suggesting that the degree of physical disability experienced by patients in not just a function of pain intensity or frequency, but also of the degree of catastrophising.

Much of the literature examining pain in individuals with PsA utilises clinical outcome measures and generally fails to include any psychosocial assessment of pain. Traditionally researchers measure pain in this patient group with a view to establishing the efficacy of various treatments. For example, Chenglong and colleagues (2007), employed the SF36 to compare the health-related quality of life (HRQoL) of patients with moderate-to-severe RA, PsA and AS, and then compared the effect of treatment with Infliximab (a biologic Anti-Tumour Necrosis Factor agent) or a placebo on the HRQoL of these patients. After adjustment for age, sex and disease duration, at baseline, the physical HRQoL, which includes physical functioning, role physical and bodily pain, was similar for all three groups. After treatment with Infliximab, all three showed significantly greater improvement from baseline to the first assessment time point in all physical scales of the SF-36, compared with patients who received the placebo. In each of the three diseases, the greatest improvements were observed in bodily pain and role physical. Whilst the study clearly shows the beneficial affect of such treatment, the possible impact or mediating role of psychosocial factors on pain was not assessed.

Whilst there may be dearth of studies exploring PsA using a biopsychosocial approach, lessons may be learnt from RA and AS, given that many of their physical characteristics are shared with PsA. Research has shown that pain and functional limitation associated with RA negatively affects a patient's ability to engage in everyday activities (MacKinnon et al., 1994) and results in diminished levels of physical activity (Eurenius et al., 2005). Furthermore, other studies, for example, Katz 1998, have concluded that patients with RA report pain, fatigue unpredictability of symptoms, functional impairment and changes in joint appearance as having a significant impact on their lives.

Although not the case for psoriatic arthritis, numerous studies have documented the contribution of emotion and cognitive processes to the experience of chronic pain (Keefe et al., 1992; Turner & Romano, 1985). Indeed, research investigating chronic pain and emotion

typically conclude that chronic pain is highly associated with depressive mood (Mikail & Fisher, 1992; Turner & Romano, 1985)

A prospective study investigating the course of depression for patients recently diagnosed (less than two years) with RA assessed twenty-two patients on a variety of measures at six different time points over twenty-one months. The researchers found that the patients became significantly more depressed over time and that a set of five factors - initial level of depression, pain, disability, coping strategies and consequences of arthritis - consistently predicted depression at the following assessment. Although only a small sample size was used, these results support much of the previous literature that suggests complex interrelationships exist between pain, depression and other psychosocial factors (Sharpe et al., 2001). For example, a five month, weekly study of 188 older women with RA and osteoarthritis reported that levels of pain and reactivity to perceived stress were affected by depression (Zautra & Smith, 2001), whilst a study by Covic et al. (2000) concluded that both pain and depression were predicted by physical disability and that the relationship was mediated by passive coping and helplessness.

In 2003, Covic et al. hypothesised a biopsychosocial model that used physical disability, helplessness and passive coping to predict pain and depression in RA. The results indicated that physical disability, helplessness and passive coping were significant contributors to the levels of pain and depression experienced in RA and interestingly, that helplessness was a stronger predictor of pain than passive coping – a finding which suggests that the perception that one has no control over one's disease can affect the levels of pain.

In a survey of 295 AS patients, 65% rated fatigue as a major symptom and in these patients, pain, functional disability and stiffness were significantly associated with the level of fatigue (Jones et al., 1996). Similarly, studies using RA patients have shown that pain severity may be a significant predictor of subsequent sleep disturbances and this in turn may impact on levels of fatigue (Drewes et al., 1998, 2000). An investigation by Pollard et al (2006) explored the amount of fatigue experienced by patients with RA, and its relationship to pain, synovitis and other common clinical features. They reported that pain is strongly associated with fatigue

and that patients with active RA had high levels of fatigue, however multiple regression analyses showed this relationship was less important than the association with pain.

2.6.6   Fatigue

In healthy people, fatigue occurs as a normal and temporary phenomenon resulting from identifiable events such as physical exercise, emotional tension or lack of sleep. It is generally considered to play a purposeful and protective role, as it is self-limiting and relieved by sleep or rest (Mayoux-Benhamou, 2006). However, in people living with a chronic condition, fatigue may become a disabling, life-and activity-limiting experience impacting on quality of life, as it is a poorly managed symptom for which there are few pharmacological solutions.

Fatigue is not simply a general symptom of disease activity, but is a complex, disruptive stressful and subjective personal experience (Repping-Wuts et al, 2007) and whilst there is little consensus regarding its definition, Piper (1993) suggested that it is an abnormal experience that has negative effects on bodily function and daily life. Rather than being a temporary phenomenon, fatigue may have a gradual onset, is cumulative and persists over time (Ream & Richardson, 1996) unlike the fatigue which most people experience in their daily lives which is usually related to some form of short-duration exertion that is relieved by a good night's sleep.

Although incidence of fatigue is unknown, Pawlikowska et al. (1994) studied a population they assessed as being without chronic conditions and reported a prevalence of 18.3%, whilst a later American study by Addington et al (2001) reported lifetime prevalence in the community of 20%. However, these may be conservative estimates given that fatigue is a chronic symptom that manifests itself in a multitude of chronic and somatic disorders, including multiple sclerosis, cancer, Parkinson's disease and rheumatic diseases, to name but a few (Bol et al., 2008; Goldstein et al., 2006; Friedman & Chou, 2004; Wolfe et al., 1996).

Common in many major diseases, fatigue is especially prevalent in pain disorders such as osteoarthritis (Fishbain et al., 2003), fibromyalgia syndrome (Wolfe, 1999) and rheumatoid arthritis (Sing et al., 2003), with pain patients rating fatigue as a key factor leading to

decreased quality of life (Swain, 2000). Indeed, in 1996, a study by Wolfe et al. reported that clinically significant fatigue has been reported by over 40% of patients with osteoarthritis (OA) and rheumatoid arthritis (RA), and by 76% of patients with fibromyalgia syndrome (FMS). Although their report was essentially a psychometric analysis, van Tubergen et al. (2002) assessed fatigue in patients with ankylosing spondylitis (AS) and concluded that it is a major symptom that negatively influences different aspects of quality of life and appears to be associated with the level of disease activity, functional ability, global well-being and mental health status. Its emerging role as a major symptom was highlighted in an earlier study when 57% of RA patients reported that fatigue was the most problematic aspect of their disease (Tack, 1990), whilst a study by Hendriksson et al. (1992) exploring pain and daily fatigue among FMS patients, concluded that fatigue constituted a greater impediment to the accomplishment of daily tasks than did pain.

In their paper, Zautra et al. (2007) examined reports of fatigue among American patients with chronic pain, all of who had a diagnosis of OA, RA and FMS. They found considerable variance in levels of fatigue both between patients and over time and comparison of the three chronic pain conditions revealed group differences in both the average level of fatigue and also extent of day-to-day variability. Pain was among the strongest predictors of fatigue, with those individuals with higher average levels of pain reporting greater fatigue, with daily increases in pain related to daily increases in fatigue and elevated fatigue levels the next day. The researchers concluded that as a symptom, fatigue is central to all three conditions, although the fatigue response observed in the participants' diaries suggests that the actual type of chronic pain condition is implicated. Given the different etiologies of OA, RA and FMS, it seems the underlying causes of fatigue may also be distinct across disorders.

Research by Krupp et al (1990) concluded that fatigue is one of the most frequently reported and often the most disabling symptom experienced by individuals with systemic lupus erythematosus (SLE) – an autoimmune disease which falls under the umbrella of rheumatic diseases. Krupp reported that up to 80% of this patient group report fatigue, yet the cause remains largely unknown. However, findings from various studies suggest it is likely that fatigue results from a combination of factors such as disease activity (Zonana-Nacach et al,

2000), mood disorder (Wysenbeek et al, 1993) and associated fibromyalgia (Taylor et al, 2000).

Qualitative research by Hewlett et al., (2005) explored the experience of fatigue in patients with RA in the United Kingdom. RA fatigue was viewed as different from normal tiredness because it is extreme, often not earned, and unresolving and participants attributed it to inflammation, working the joints harder and unrefreshing sleep. Physical, cognitive and emotional components were described along with the far-reaching effects on physical activities, emotions, relationships and social and family roles. Whilst clearly highlighting that RA fatigue is an important, intrusive and overwhelming symptom, this study revealed that participants perceive that fatigue is dismissed by professionals and assume it cannot be treated, so do not raise the issue in clinic. Such reluctance supports an earlier study of the general population that found 74% of women attending their family practice had fatigue, but only 22% discussed it (De Rijk et al., 2000).

In 2005, a study by Kralik, Telford, Price and Kock, exploring women's experiences of fatigue in chronic illness, reported the finding of data which were generated via email group conversations between the researchers and thirty women with diverse chronic diseases such as psoriatic arthritis, osteoarthritis and fibromyalgia. Common themes emerged as participants described extreme fluctuations in their levels of fatigue throughout each day and from day to day. They also reported how the severity and unpredictable nature of fatigue disrupted their lives and caused them to re-evaluate the way in which they related to family, friends and the community. Despite the consequences of living with fatigue, the issue was rarely raised when attending appointments, as there was a general belief that health care professionals fail to acknowledge or recognise fatigue as a legitimate concern.

It seems clear from the literature that whilst there is no 'gold-standard' definition of fatigue, there is consensus that it is a complex, stressful and disruptive subjective personal experience.

2.6.7 Coping

Coping, according to Lazarus and Folkman (1984), consists of cognitive and behavioural efforts to manage stressors, and is an ongoing, dynamic process concerned with what an individual actually thinks or does in a specific context, as well as changes in these thoughts and actions across encounters.

Most people use various forms of coping in stressful situations, however, problem-focused and emotion focused coping are the two major functions. Problem-focused coping involves activities that aim to change elements of the stressful situation, whereas emotion-focused coping involves activities that modify one's emotional reactions that result from the stressful situation and make life bearable by avoiding situations that, if confronted directly, can be overwhelming (Lazarus & Folkman, 1984).

Whilst different forms of coping are effective for different people and situations, Lazarus suggests that there is a greater association between unsuccessful coping and the use of emotion-based strategies such as avoidance, self-blame and wishful thinking (Lazarus, 1990).

The Transactional Model of Stress and Coping developed by Lazarus & Folkman (1984) considered appraisal and coping as processes but failed to allow for the importance of social support on coping. Researchers, in order to address these limitations, have combined other models with the original in order to achieve a more rounded framework. Most notably, Schwarzer (1998) suggested perceived self-efficacy was a personal coping resource for managing a stressful event and incorporated this into the model, maintaining that having the belief that one can master difficult scenarios by means of adaptive action, and an optimistic view of one's capacity to deal with stress, plays a vital role in determining both how an individual is motivated to act and how they cope. Furthermore, Social Support is included in the model as researchers view it as a resource that affects an individual's appraisal of stressors.

Various definitions exist for social support, however it is generally considered to be a generic construct that includes social networks and social interactions (Schreurs & Ridder, 1997).

Cohen and Syme (1985) suggest that it comprises the resources provided by informal supports, such as that provided by family, extended family, friends, relatives, work acquaintances, and neighbours, whilst formal support refers to that which is paid for or provided by the health care system (Chappell, 1992).

The mechanisms through which social support and self-efficacy influence coping and psychological well-being have been explored by researchers, and both self-efficacy and social support have been found to affect patients' appraisals of their situations and in turn, their coping behaviours in various chronic illnesses (Hagger & Orbell, 2003; Manne & Zautra, 1989; Merluzzi & Martinez-Sanchez, 1997; Ptacek et al., 2002; Shaw, 1999).

Cognitive appraisal, personal (e.g., self-efficacy), and situational (e.g., social support) variables are identified in the literature as predictors of coping and HRQOL in individuals with chronic illness, such as cancer, multiple sclerosis, and rheumatoid arthritis (Weber et al., 2007; Riazi et al., 2004; Cross et al., 2006).

Using a cross-sectional study to analyse the extent to which coping strategies and illness perceptions were associated with levels of daily functioning (that is, physical, social and role functioning), Scharloo et al. (1998) recruited patients with RA (n=84), psoriasis (n=80) and chronic obstructive lung disease (n=80) and found that coping by seeking social support, and beliefs in controllability and curability of the disease, were significantly related to better functioning.

Quite how social support affects psychological adjustment is still not fully understood, although two theoretical models have been proposed. The stress-buffering model that Cohen and Willis (1985) proposed, suggests social support has a beneficial effect on adaptation to chronic illness by acting as a buffer against a stressful situation, so reducing the negative effects of the illness. In the case of chronic rheumatoid diseases, this theory suggests that social support, in the form of family and friends would protect the patient against stressors such as pain and disability, so reducing the patient's distress. Alternatively, the direct effects model maintains that support is beneficial regardless of the level of stress experienced.

Several studies have compared these two models among RA patients. Brown et al. (1989) found evidence for both models – the existence of a direct effects model was underpinned as greater support was associated with lower depression for people at all levels of pain, whilst the stress-buffering model was given credence as psychological depression was greatest in those patients with high levels of pain and low satisfaction with emotional support received from family and friends. Affleck et al. (1988) also reported modest evidence of a stress-buffering effect in 129 RA patients – the researchers found psychological adjustment was lowest among individuals with functional disability who also reported dissatisfaction with support. However, a number of studies report only evidence for the direct effects model, such as Fitzpatrick et al. (1998) who found that regardless of disability, greater social support was related to lower depression and greater self-esteem. Similarly, another study of 101 recently diagnosed RA patients concluded that the more support patients received, the less depression they experienced, regardless of physician-rated disease severity (Revenson et al., 1991).

Whilst evidence to support these different models would lead us to conclude that overall, social support is beneficial for individuals coping with varying amounts and types of arthritis-related stress, it should be noted that some researchers maintain that receiving, using or requesting social support has costs as well as benefits and that it is important to understand how support can both help and hinder adjustment to rheumatic disease (Revenson, 1990). A small number of studies in RA have concluded that social support is not always conducive to health. Dissatisfaction with support may have a negative impact on psychological well-being, as demonstrated by Newsome and Schulz (1998) who found that distress was the response to being helped by a family caregiver. Such findings may be due to the individual feeling that the support is unwanted, excessive, inconsistent with their needs, or coming from the 'wrong' support providers (Lanza et al., 1995).

The evidence does suggest that social support and coping are inextricably linked, but the mechanism by which they interact and impact on psychological health in those individuals with chronic disease is still not fully understood, although it may be that support is effective in enhancing an individual's well-being because it acts as coping assistance. It is possible that when a person is faced with a stressful situation, such as chronic illness, social support may

help them alter the meaning of the situation, their emotional or behavioural response to the situation, or even the situation itself (Holtzman et al., 2004).

A brief review of the coping literature suggests that emotion-focused coping strategies (that is, avoidant or passive) are linked to poorer outcomes when compared with active and adoptive problem-focused coping techniques. For example, Evers et al. (1998) undertook a study examining the psychosocial predictors of functional change in 91 recently diagnosed RA patients and found that a decrease in all measures of functional status within the first year after diagnosis could be predicted by the initially more frequent use of the passive pain-coping strategies of resting and worrying. In addition, the researchers also found that a decrease in mobility could be predicted by an initially smaller social network, independent of what could be explained by the initial functional status, demographic variables or by the disease itself.

Conversely, individuals who engage in more active coping, such as the use of positive statements or ignoring symptoms, report better outcomes as effective coping strategies have been found to reduce pain and emotional distress. Keefe et al. (1991) examined pain in RA patients and concluded that patients who were active copers had the ability to control and decrease the pain, rarely engaged in catastrophising, and experienced low levels of psychological distress.

Efficacy beliefs in those with a rheumatic condition impact on appraisals regarding the potential ability and success of coping efforts, and may play a pivotal role in determining the level of adjustment to stressful events surrounding the illness (Affleck & Tennen, 1996). Smith and Wallson (1996) undertook an analysis of coping profiles and adjustment in 171 RA patients to establish whether any particular group of coping strategies influenced psychological adjustment. Patients were grouped as active, passive, self-blaming or minimal copers depending on the techniques they typically used to manage their arthritis. The active and passive groups reported similar levels of pain, the self-blamers reported more pain than the overall sample, whilst the minimal copers, who had relatively little use of the various coping strategies, reported lower pain levels than the rest of the sample.

The results infer that the four groups differed in psychological adjustment to their RA, with greater levels of negative affect and depressive symptoms and lower levels of positive affect and life satisfaction reported by the passive copers and self-blamers. The contrast in adjustment profiles of the active and passive copers is of note, given both groups reported similar levels of pain and disability, this, the researchers suggest, is evidence for the hypothesised role of pain coping as an influential mediator of the relationship between pain and adjustment in rheumatic conditions. In addition, Smith and Wallson argue that the positive psychological adjustment found in the active copers group lends support to the proposition that an active approach to coping with pain is often adaptive, whereas a more passive approach is maladaptive.

2.7   Summary

Despite evidence demonstrating that those with PsA may experience reduced health-related quality of life resulting in role limitations and reduced physical functioning (Husted et al., 1997) there remains a lack of consensus with regard to the role and impact of various psychological factors. Indeed, the limitations of many existing studies are their failure to include measurements for psychosocial factors that have been shown to have good predictive value in other conditions. It is surprising that to date, the role of such factors and their potential impact has been largely ignored in PsA.

The evidence from previous studies exploring the role of psychosocial issues and psoriasis, suggests the landscape emerging is somewhat blurred. Studies have focussed on quality of life issues, but generally have not been patient driven, at a time when there is a move in the Health Service to include the opinions of service users. Eminent dermatologist and researcher, Professor Chris Griffiths has suggested that 'involvement of patient groups and an understanding of the psychosocial aspects of psoriasis, particularly its significant impairment of quality of life, are keys to progress' (Griffiths, 2004).

In their report, 'The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century', the Department of Health acknowledges that chronic disease and its effects are

now a major challenge. Due recognition is given to the physical and psychological difficulties, socio-economic problems, reduced quality of life and possible social exclusion that those with a chronic condition are faced with, but they also suggest that although people have problems specific to their individual illness, there is also a core of common needs, including developing strategies to deal with the psychological consequences of the illness.

Given the lack of such research and paucity of patient driven studies relating to PsA, the aim of the first phase of this research was to explore, from the patients' perspective, the impact that PsA and psoriasis has on an individual's quality of life. By identifying and establishing which psychosocial issues impact on this patient group, it may be possible to improve the management of the condition and contribute to the future development of strategies that lead to improved functioning and inform the content of interventions to lead to improved quality of life.

The following chapter outlines the rationale for the methodology employed in the current study.

CHAPTER 3

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RATIONALE FOR METHODOLOGY FOR STUDY 1

3.1   Introduction

A review of the literature relating to PsA failed to identify any robust studies that clearly demonstrate the psychosocial impact experienced by individuals who live with this disease. As a result, there is limited understanding within the health system and wider society on how best to support these patients.

In order improve understanding and gain deeper insight or a new perspective of a phenomenon about which little is known, Strauss & Corbin (1999) suggested that qualitative methods may offer a way of discovering new information that would otherwise be difficult to capture using quantitative methods.

3.2   A Qualitative Approach

Qualitative research is concerned with the nature of the phenomenon, rather than producing aggregate data and is aimed at discovering the meaning that events have for the individuals who experience them. As a consequence, the results deal with the emotional and contextual aspects of human response, rather than with objective measurable behaviours and attitudes.

The goal of qualitative research is to discover patterns that emerge after close observation, careful documentation and detailed analysis of the research topic. Researchers collect qualitative data from the individual by means of several techniques – typically interviews with participants, either on an individual basis or in a focus group, diaries (audio, written or video) and various forms of writing. The data can then be analysed in different ways, such as discourse analysis, narrative analysis, grounded theory and interpretative phenomenological analysis (IPA).

3.3   Justification for use

Unlike quantitative research, a qualitative approach offers the researcher an opportunity to obtain depth and detail and see the worldview of those people that are studied. It allows for an openness that can generate new theories and recognise phenomena that have been ignored by previous researchers and literature. A qualitative approach is undoubtedly the preferred choice where the goal is to try and present people on their own terms and from their own perspective and to give the participant a voice.

Despite its strengths, it must be acknowledged that fewer participants are usually studied when a qualitative approach is utilised, meaning that the results are less easily generalised to the wider population and, because it is difficult to aggregate data, systematic comparisons may not be possible. It may also be argued that qualitative data collection is dependent upon a researcher's personal attributes and skills, although this is also true when a quantitative method is used, although it may not be as easy to evaluate their skills.

Given that the initial research aim of the current study was to explore the nature of psychosocial issues experienced by people with PsA, a qualitative approach was appropriate.

A qualitative method particularly suited to understanding the lived experiences of an individual is Interpretative Phenomenological Analysis (IPA), a framework developed and described by Smith et al. (1995, 1997, 1999), that is concerned with trying to understand lived experience and how individuals make sense of their experiences, particularly with regard to living with a medical condition. Although a relatively new approach, it is now being widely used by researchers in various disciplines, including health, clinical and social psychology.

IPA has its origins in health psychology (Smith et al, 1995) and is theoretically rooted in critical realism (Bhaskar, 1978) and the social cognition paradigm (Fiske & Taylor, 1991). Critical realism accepts there are stable and enduring features of reality that exist independently of human conceptualisation and that differences in the meanings individuals attach to experiences are possible because they experience different parts of reality.

Meanwhile, the social cognition paradigm suggests human speech and behaviour reflects these differences in meaning either directly or indirectly, thus explaining why the analysis of interview data is considered an appropriate method of accessing and developing an understanding of such differences.

Concerned with human understanding, the concept of Phenomenology was put forward in 1936 by Edmund Husserl (Husserl, 1970) as he rejected the view that empirical science is the basis for gaining an understanding of the world, instead stressing the importance of lived experience. He posited that what is really there in the world, can be understood by perceiving it in a manner that is uncontaminated by an individual's past experiences and viewpoints.

Traditionally researchers undertaking phenomenological research attempt to 'bracket out' their preconceptions (Moustakas, 1994) using formal reflexive techniques (Duck, 1992), however, Caelli (2001) argued that respondents too, should engage with such reflexive techniques in order to give a more accurate representation of the way in which they see the world pre-cognitively. This viewpoint could imply that IPA has been incorrectly labelled as 'phenomenological', however Smith et al (1999) stress that the aim of IPA is to attempt to gain an insider perspective of the phenomenon being studied, whilst acknowledging that the researcher is the primary analytical tool and that the researcher's beliefs are not to be viewed as biases to be eliminated, but rather as being necessary for making sense of the experiences of others. To this end, reflexivity is not viewed as an essential technique for removing bias, but as an optional tool, enabling the researcher to formally acknowledge their interpretive role. Smith et al (1999) maintain that IPA is phenomenological as it seeks an insider perspective on the lived experiences of individuals and it is interpretive in that it acknowledges the researcher's personal beliefs and encompasses the view that understanding requires interpretation.

In the current study, the researcher chose to use IPA as it aims to capture and explore experiences of the individual without testing hypotheses or making assumptions about the meaning of the topic being studied (Reid, Flowers & Larkin, 2005). It was anticipated that by giving the patients 'a voice' and gaining an understanding of their experience of living with

psoriasis and PsA, various themes would emerge during analysis that would drive the choice of quantitative measures that could be used in a second study.

The following chapter outlines, in detail, Study 1.

CHAPTER 4

STUDY 1

4.1   Introduction

In broad terms, this study aims to explore the lived experience of individuals with PsA and psoriasis and whilst no specific hypothesis were formulated, the objective was to identify the nature of any psychosocial issues that patients perceive as impacting on their daily lives.

Given the exploratory quality of this initial study, semi-structured interviews and subsequent Interpretative Phenomenological Analysis (IPA) were utilised in order to achieve this aim

4.2   Design

Semi-structured interviews were conducted with ten individuals who had a diagnosis of psoriasis and psoriatic arthritis.

The previous chapter detailed the rationale for the qualitative design employed, however, to summarise, semi-structured interviews were chosen as they allow for the interviewer to probe and explore, and they offer flexibility that enables the participant to change the direction of the interview as issues arise that the researcher may not have thought of when designing the interview schedule (Smith & Osborn, 2003). They also make good use of interview time and make interviewing multiple participants more systematic and comprehensive.

4.3   Participants

A purposive sampling strategy was employed to ensure that views were represented from individuals of different age and gender. The criteria for inclusion into the study was that participants be aged between 18 and 65, have a new or existing diagnosis of psoriatic arthritis and/or psoriasis and that English was their first language – the clinical staff who were

identifying potential participants for the study checked and confirmed that participants fulfilled these criteria before passing their contact details to the researcher.

Smith, Jarman & Osborn (1999) suggest ten participants is the higher end of the desired sample size for IPA studies. The sample for the current study is within the recommended sample size and consisted of ten adults - five women with ages ranging between 37 and 65 years ($M = 48.2$ years) and five men aged between 30 and 64 ($M = 46.0$ years). Participant characteristics are summarised in Table 4.1.

Table 4.1: Characteristics of participants who were interviewed

(n=10) Alias	Gender	Age	Married	Employed	PsA Duration (yrs)	Psoriasis Duration (yrs)
Annie	F	37	Y	N	19	20
Beryl	F	65	Y	N	40	43
Chris	F	49	Y	N	8	10
Debbie	F	38	N	Y	11	11
Ellie	F	52	Y	N	16	17
Frank	M	30	N	N	6	10
Gary	M	46	Y	Y	10	12
Henry	M	64	Y	N	15	16
Ian	M	39	Y	Y	5	5
Jack	M	51	Y	N	20	20

4.4 Ethical Approval

Approval was sought and granted from Liverpool John Moores University and Liverpool NHS ethics committees. Research Governance was granted by Aintree University Hospitals (see Appendix 8)

4.5   Procedure

Participants were recruited from a local NHS University Teaching Hospital. Following ethical approval the researcher had briefed the clinical staff about the nature of the study and provided them with information sheets that were to be given to potential participants.

Initially, clinical staff in the rheumatology out-patients department identified patients attending the PsA clinic and, after confirming that they had a diagnosis of PsA, provided them with an information sheet (see Appendix 1) and explained the nature of the study. Verbal and written information was given to all eligible parties stating that their participation was not mandatory to receive health care within the clinic. Participants were also informed that declining participation would not have any deleterious effect on the receipt of their care. Any patients who expressed interest in taking part in the study gave verbal consent for their contact details to be given to the researcher and were advised that the researcher would contact them within the next fourteen days.

The clinical staff provided patient names, date of birth and contact details to the researcher, who then contacted the patients by telephone in order to further explain the study and arrange a convenient time and place to conduct an interview.

Before the interview commenced, the researcher explained the purpose of the study and ensured participants were fully aware of their right to withdraw from the study at any time. They were given the opportunity to ask questions about the study before the researcher obtained their informed, written consent to take part in the study and also to allow for the interview to be recorded and transcribed. Participants were given a copy of their signed consent form and an information sheet that included a contact telephone number and email address for the researcher (see Appendix 1-3).

The audio-taped interviews were transcribed and analysed. Following ten interviews, no further themes were being generated and the analysis was deemed to have reached saturation.

4.6 Interviews

All interviews were conducted in participants' own homes. The interviews were audio-taped and ranged in duration between forty-five and eight-five minutes. The interviews were semi-structured with the researcher utilising a basic interview schedule (see Appendix 5) to ensure that relevant topics were covered, such as effects on everyday function, pain, and ability to work. The questions were asked in no prescribed order, but were included at appropriate points within the dialogue. This allowed for flexibility within the interview and an opportunity for the participant to introduce aspects of living with the disease that held importance for them and enabled the researcher to explore any of these in greater depth.

4.7 Analysis

The tapes were transcribed verbatim and analysed using Interpretive Phenomenological Analysis (IPA) as described by Smith (2003). This method strives to fully preserve people's perceptions of the world and ensure their unique view is reflected, so capturing the quality of individual experience.

IPA identifies subordinate and overarching themes within and across transcripts through a process of reading and re-reading the texts. In order to obtain the richest representation of the transcripts the following steps were followed:

1. The first interview transcript was read several times and brief notes made of any associations or early interpretations.
2. Emergent themes were identified from the transcript and researcher's notes and were assigned appropriate labels.
3. These themes were then reordered and organised into groups. Connected themes were clustered together to create superordinate themes, which were then included in a preliminary table of themes (see Table 4.3).
4. This process was then repeated with each of the remaining transcripts. New examples of each of the already identified themes were noted and any new emergent themes

identified. Previous transcripts were re-read to check for instances of the new themes. All the themes were reviewed and any not well represented, were excluded.

5. Finally all the cluster themes were integrated across transcripts in order to identify shared themes that captured the essence of the participants' experience of living with PsA and psoriasis. A table of quotes from across all interviews was constructed to illustrate each theme and demonstrate that the themes were supported verbatim within the texts. An example of a quote table for a theme is provided in Appendix 6.

In order to increase validity and reliability of the analysis, the first and third transcripts were reviewed independently by the researcher's supervisor. Both discussed the transcripts and concurred on the emerging themes and categories. In addition, 40% (four) of the transcripts were analysed by a researcher familiar with the topic area, which again supported the validity of the analysis. Osborn & Smith (1998) suggest that such a process serves to ensure that analysis is systematic and provides results that are supported by the data (see Appendix 7 for an example of a participant transcript).

4.8   Results

Given the epidemiology of PsA, is it is generally the case that people with PsA invariably have psoriasis, so it was not unexpected that all 10 participants had both conditions. However, it is also the case that some of the treatments for PsA improve psoriasis to such an extent that the skin manifestations completely clear. At the time of the interviews, it was apparent the impact of PsA was far greater than that of psoriasis, with participants having very little to say about the effects of living with psoriasis. In three instances this was due to the fact the psoriasis had cleared as a result of treatment for PsA, but in others it was simply the case that PsA was viewed as far more detrimental to quality of life.

Analysis of the data revealed various themes that were concordant across the sample. That is not to say that every participant gave evidence of every theme, but that common patterns of meaning emerged both within and across the transcripts. A brief example of the development of the superordinate theme of pain is shown in Table 4.2.

Pain is comprised of smaller ordinate themes such as pain descriptors, pain intensity, pain measurement and impact of pain. The development of these themes is developed and supported by data from the transcripts.

Table 4.2: Superordinate category of pain comprising four ordinate themes

PAIN	Annie	Jack	Chris
• **Description**	"it's just sharp, constant'	"fizzy pains...like bubble"	"it's like a nagging tooth-ache, it's there all the time"
• **Intensity**	"different day to day..."	"it's there in the background"	"even with pain killers, I don't get relief from it"
• **Measuring**	"you can't put an average on pain"		
• **Impact**	"it's too painful"	"some days I can't even wipe my bottom"	"I've had to ask my husband to cut my food up"

During the analysis, five emergent themes were identified within the transcripts: pain, functionality, emotions, treatment experience/management and coping (see Table 4.3). For ease of presentation these are discussed as separate themes, although it is clear that they are all interlinked and a full appreciation of each can only be achieved through an understanding of the others and their connections.

Table 4.3: Themes supporting development of five superordinate themes

PAIN	EMOTIONS	FUNCTIONALITY	TREATMENT EXPERIENCE/ MANAGEMENT	COPING
Description	Psychopathology	Employment	Regimen	Adaptation
Intensity	Strong feelings	Immobility	Side-effects	Distraction
Measuring	Shame	Planning	Consequences	Help
Impact	Pessimism	Activity	Other sufferers	Alienation
	Optimism	Sleep	Staff	Withdrawing
	Loss	Tired	Desperation	Friends
	Comparing	Fatigue	Clinic	Social
	Normality		Information	
	Futility			

4.8.1 Pain

Given that all the participants interviewed had a chronic musculoskeletal disease, it was, perhaps, to be expected that pain would emerge as a major symptom and key theme.

All of the participants reported experiencing pain and their descriptions of it varied considerably and certainly serve to emphasise that it is a subjective sensation. One said the pain was *"like a pair of tight shoes"*, whilst another characterised it as *"fizzy...like bubbles"* (Jack), whilst another characterised it as *"being stabbed with pins"* (Henry). Whether it was *"sharp and constant"* (Annie) or *"crippling"* (Ian), it's impact shared similarities that were reflected in their reduced ability to perform simple activities due to pain always being *"there in the background"* (Jack). On some days the pain was so bad that Annie, *"couldn't get out of bed"*, whilst Ellie, *"couldn't open a tin of food"* and Gary had to come *"down the stairs on my backside"*. This detrimental effect on mobility was undoubtedly a source of distress for all the participants, for example, Annie commented, *"I can't get on the floor and play with the kids"*, a comment similar in vein to Ian's reflection that, *"I couldn't kick a footy round with my lads"*.

There was a consensus that the pain and its intensity was unpredictable and was *"different day to day"* (Annie). This resulted in participants reflecting on how *"not knowing what it's going to be like one hour to the next"* (Debbie) impacts on the activities they can undertake on any given day. It seems the presence, or possible presence, of pain informs their decisions about going out to the shops or visiting friends. There was a shared view that *"making plans is a waste of time"* (Ellie) because *"you never have an idea of what you're going to be like ...it can be too painful or sore to go out"(Ian)*. This loss of spontaneity was the cause of a great deal of sadness for participants, with typical reflections being, *"cos I'm in pain it makes it difficult to just go and meet up with friends"* (Debbie) and *"I can't just pop out, maybe, like...go for a drink...I need to know I can sit down when I get there"* (Henry).

It was apparent that participants assessed their pain levels each day and used this as a benchmark to determine what their activities would be for the day. Annie reported, *"I can't say I'll go out tomorrow 'cos I don't know what it's going to be like until I get up"*, whilst Ellie commented, *"I never know if I'll manage without a wheelchair...sometimes I just need to be able to sit to help my pain"*. The participants conveyed a deep sense of frustration when discussing their unpredictable pain levels and it was clear that the impact of pain was implicated in every aspect of their lives.

Having talked about varying pain levels, it seemed particularly pertinent that several participants identified pain measurement within the outpatient clinic as a troublesome issue. Annie, looking emotional and angry as she spoke, described her typical visit to clinic,

> *"you go in and it's blah, blah, blah, how are you feeling? It's*
> *like, what really makes me angry, honestly I feel like hitting*
> *them sometimes, they've got this, like a ruler thing, put the*
> *arrow on that to tell me where your pain is over the past week,*
> *that really, really makes me angry that, it's stupid, how can*
> *you describe how your pain is on a ruler"*

This particular participant commented that instead of giving an average rating for her pain, she really wanted to be able to tell the health professionals, *"in the morning it was this way or in the night, on Tuesday I couldn't move...how can you put an average on pain?"*

For most participants, living without pain was a distant memory, illustrated by comments such as, *"...not sure I can remember a time when I didn't feel pain"* (Ellie) and, *"I can't remember not being in pain"*. This sense that pain was an integral part of their lives was further emphasised by one person stating *"pain is part of me...it becomes part of you and part of your life"* (Debbie).

Generally, medication was not a satisfactory solution, *"even with pain-killers I don't get relief from it"* (Chris), meaning the constant presence of pain, *"like a nagging toothache"* (Chris), was a shared experience for all the participants.

Pain appeared to define their emotions for the day and to a large extent dictated whether or not they enjoyed any social interaction. It certainly determined the level of activities they were able to manage and had an undeniable impact on their degree of ability to perform what are best described as everyday activities – opening a bag of cornflakes or a tin of food, playing with their children or walking down the stairs.

4.8.2 Emotions

This category is comprised of various smaller themes that are used to describe the feelings experienced by the participants, including anger, frustration, depression, shame and loss.

Many expressed anger and frustration, often citing their restricted mobility as the reason, with comments such as, *"I'm angry all the time...I can't move easily"* (Ian) and, *"I'm so angry...useless...it frustrates me"* (Chris). Annie remarked that, *"I feel like I'm being punished for something...you feel angry, you need something to blame"*, whilst Jack said, *"I feel I've got some sort of curse"*.

Other participants remarked on feeling anger and believed it was due their disease being misunderstood by others, *"people who haven't got it just have no idea and it makes me mad that they don't understand"* (Debbie), whilst Annie remarked, *"feels like you're the only person with it"* and went on to comment,

> *"I actually feel angry with everyone, don't know why, it's like*
> *you're not getting heard, you feel like shouting, I lose my*
> *temper very quickly, not with the kids or anything, just angry*
> *all the time"*

Individuals reported feeling, *"scared"* (Ian) and *"frightened of losing everything"* (Henry). Whilst others described feeling, *"utterly useless"* (Ellie) saying there was, *"no point to my life anymore"* (Ellie). Most acknowledged feeling depressed at some point, with a typical comment being *"I'd gone into another little dark hole again"* (Jack) and, *"I was going through depression"* (Gary). Chris commented that she had, *"been on depression pills for years"*, whilst Annie said, *"depression...that's the way it makes you feel"*. Indeed, the severity of the low mood experienced by Annie was clearly demonstrated when she remarked that she, *"wanted to go to bed, fall asleep and not wake up"*, a feeling echoed by Frank when he stated, *"I wanted to kill myself"*.

Interestingly, the majority of participants reported feelings of shame, *"I was so ashamed of it (the arthritis)"* (Jack), whilst some associated this with being too young to have a chronic, disabling condition *"feel ashamed, probably because I'm young"* (Annie) and the belief that *"arthritis is an old person's disease"* (Ellie). Others report, *"hanging my face in shame"* (Chris) and being, *"embarrassed"* (Jack).

4.8.2.1 Loss

The theme of loss emerged and comprised four different components as participants talked about their losses in terms of their life, their goals, their identity and their body image.

Living with PsA caused many to view their life as being over, commenting that *"it's just a life no more"* (Annie) and *"...sometimes my life seems pointless 'cos I can't do what I want to do"* (Ian). Annie observed, *"It's ruined my life, that's it now, that is my life"*, whilst Debbie questioned the purpose of her life, *"not sure what I'm supposed to do with my life now"*.

This sense of loss spilled over into a feeling that the participants had lost their future. Annie talked about her future and said, *"I can't see one"*, whilst Chris observed, *"you don't know what's going to happen in the future"*.

It seems the consequences of living with this chronic disease impacted directly on people's goals and ambitions, with remarks such as, *"I gave up on everything"* (Henry) and *"I felt I had just lost it all"* (Ian) reflecting the views of most of the participants. Indeed, for Beryl the ambition to have more children was thwarted as she shared the opinion of her consultant *"I was told I couldn't have anymore because of the state I was in"*.

It seems the impact was so severe that careers were affected, or had to be stopped altogether, *"I couldn't work no more...had to give it all up"* (Henry). In two instances, employment had continued, but the individuals had to change their occupational role, *"I couldn't lift as my hands had lost their strength so they put me in the office...in truth even that was a struggle some days, but at least I had a wage"* (Ian). Participants reflected on their loss of employment, with several stating that it was responsible for creating a void in their lives, *"my work was taken away, I loved my job but just couldn't do it and was left with nothing to fill all that space...I feel I lost a lot"* (Debbie).

The sense of loss was compounded for many participants as they described how they lost their sense of identity, or, as one person reflected, *"You become a different person"* (Jack). Another participant, visibly emotional when speaking, believed her friends thought of her in a completely different light, *"it's not Annie anymore, it's Annie with arthritis"*. Similarly, Frank commented about his friends, *"they knew it's not me"*. This sense of having two identities was conveyed by Debbie as she stated, *"it was like there was the healthy me...that was one identity, and then the unhealthy me...I had become someone else...the old me was lost"*. Whilst Ian

believed, *"I'm treated different by my friends, I think sometimes they don't know what to say to me...I can't play footy with them now, but it's still me on the inside"*.

This image of dual identities was further emphasised by comparisons between their 'old self' and their 'new self' as participants evoked memories of what they used to be able to do, thus highlighting elements of their lives that had been lost, *"I used to play sport"* (Annie) and *"I can't work out anymore, I've lost muscle in my legs...lost my six-pack"* (Frank).

At times there was a great sense of sadness conveyed by participants as they took time to draw comparisons between their old and new self, *"I used to walk miles, I was outgoing...now I spend most of my time sitting"* (Chris), whilst Gary remarked, *"losing my sport affected me...I was on a real downer at the time, with being so fit for my age"*.

It seems that the loss of identity overlapped with the loss of body image. One woman, who previously had a reputation for buying shoes, said, *"I can't wear proper shoes anymore, my feet are too sore, I always used to be the envy of my friends as I bought lovely shoes...but that was the old me...I had to give up buying them"* (Ellie), whilst Jack commented, *"I couldn't put shoes on, so had to change my style"*.

Experiencing loss was undoubtedly an experience shared by all those interviewed, whether the loss related to life, identity, goals or body image, it seemed that, as one male participant succinctly concluded, psoriasis and psoriatic arthritis is *"all about loss"* (Jack).

4.8.3 Functionality

This category was composed of two dimensions, physical impact and social impact.

4.8.3.1 Physical Impact

This theme encompasses various smaller categories that were labelled as immobility, activity, employment, planning, sleep and fatigue, all of which relate to the impact on physical function experienced by the interviewees.

As expected, immobility emerged as a theme and was a problem for all the participants, affecting not only their ability to walk, *"I couldn't walk"* (Jack), but also to perform household tasks - *"on a good day I can do a meal"* (Chris) and be in employment, *"would love to work but there's no chance...days when I can't move my hands properly"* (Chris).

All participants expressed a desire to be able to return to work but were aware that their physical limitations, combined with their need to plan before they do anything, were major obstacles - *"I can't say I'll go out tomorrow, 'cos I don't know what it's going to be like until I get up"* (Annie). Another participant stated wistfully that he would *"love to be out working"* (Henry), whilst Chris mourned the fact that, in order to go out the house, she *"has to wait for a good day, or get all kinds of equipment out to help me"*.

The impact on employment opportunities was clearly demonstrated by one young male participant who *"had the forms filled for a police officer...used to Thai box, run, jog, football, swim...can't do nothing now"* (Frank).

The majority of the interviewees reported severely compromised mobility, some using simple yet stark phrases as descriptors – *"I could hardly walk"* (Gary), *"that stiff I could hardly move"* (Chris) and *"sometimes need help to get out of bed"* (Henry), whilst others explained their lack of mobility within the context of being unable to perform everyday tasks. These ranged from being unable to *"hold the iron"* (Debbie), or prepare food, *"I couldn't open a bag of cornflakes...my little lad did it"* (Frank). Being unable to prepare food was a shared concern, particularly amongst those who had children, *"makes me feel horrible, to watch my daughter, aged nine, doing dinner"* (Frank).

The everyday tasks were often referred to as the, *"normal things"* (Ellie), *"stupid things"* (Debbie) or *"just life's usual kind of things"* (Henry), yet they were all tasks that the participants expressed great difficulty achieving. Annie said she just wanted to be able to walk *"down the street without having to walk next to a wall...so you've got something to grab on to"* and went on to reflect about those tasks she longed to manage, *"opening a tin, turning over in bed without waking up in pain, stupid things"*.

The consequence of the lack of sleep - generally caused as Annie describes, by waking up due to pain, *"I can't sleep, you turn over and you're waking up again"* - was a permanent feeling of being, *"tired all the time"* (Ian). Without exception all participants experienced difficulties sleeping, *"I'm awake a lot through the night"* (Chris). Disrupted sleep was viewed as the norm rather than the exception, *"just let me have one full night's sleep"* (Chris), whilst Ellie commented, *"If I get two hours without waking then that's a good night"*.

However, generally participants reported coping with the tiredness, with one male saying, *"you get used to it and learn to manage"* (Henry), whilst Debbie remarked, *"like most things, you adapt and cope...I cat nap when I can and get by on that"*. However, the lack of sleep inevitably had an affect on psychological status and general feeling of well-being, with several participants admitting to the regular use of alcohol in an attempt to induce sleep, *"I couldn't sleep...I was drinking vodka"* and *"I needed a drink...I was in that much pain* (Gary).

Although disrupted sleep was considered responsible for tiredness, participants remarked on feeling, *"just sheer fatigue"* (Henry) and were able to differentiate between the two experiences, *"I know if I go out shopping, I come back tired, it takes it out of me, but some days I just feel so weary, even when I've not shopped or done things"* (Debbie). Ian described being *"beyond tired"*, whilst Ellie reported having *"no energy to move"*, *"completely drained of everything"* and having a *"need to just sit and not move at all because you feel that you can't"*.

None of the respondents reported having consistent fatigue, but described it as *"something that appears...sometimes from nowhere"* (Henry) and *"sort of comes and goes...bit*

unexpected" (Ian). Although it may be transient in its nature, fatigue undoubtedly has an impact on those that experience it, for as Debbie observed, *"it's so consuming, you can't read, concentrate...I can't even watch telly when it really gets me...I just have to stop everything"*.

4.8.3.2 Social Impact

Living with psoriasis and PsA had negative consequences with regard to enjoying a fulfilling social life, with several participants reporting that they are regularly *"making excuses...to get out of it (parties)"* (Annie), whilst Chris said, *"we don't go out much anyway...I can't be bothered, any excuse"*.

Feelings of isolation and alienation were typical, particularly once the diagnosis had been made, *"you're left to get on with it"* (Jack) and the feeling that, *"everyone wants to help at first, then nothing"* (Annie). However, there was a sense that participants were actively withdrawing from friends and were *"pushing them away"* (Annie) and, *"had difficulty interacting with other people"* (Jack). Ian remarked that, *"I often avoid going out because I'm too tired and can't be bothered"*, whilst Frank said, *"last time I went out was December last year (11 months previously)"*.

Many of the participants held a strong conviction that they would not ask friends for help *"if family don't help, that's it, you either do without or do it yourself"* (Chris), whilst Annie said, *"I won't ask anyone outside the house...I wouldn't lower myself"*. Such views may have been tied up with the perception of some that they were too young to be chronically disabled and would be ashamed to ask for help.

Gary reported being, *"more of a loner than I was"*, and Henry said, *"I think not working causes some isolation because all that contact has gone"*.

4.8.4 Treatment Experience/Management

There was common concern about the long-term effects of the drug treatments, with some participants overwhelmed by the sheer quantity of different medications they were prescribed.

Chris laughingly remarked that, *"some people go in the chemist and get a small paper bag, I go and get a carrier bag!"* although she later expressed concern regarding the volume of medication she required, *"when I get my pills out it seems to be never ending"*.

The regimen of drugs was a source of anxiety for participants as some were worried about the side-effects. Indeed, Annie said,

> *"I wonder what it's doing to my body...what frightened*
> *me more was when all the nurses had to start wearing*
> *glasses and gloves...I thought that's going into my body...*
> *don't want to take tablets no more, fed up...when you've*
> *taken your tablets, you're feeling sick"*.

Jack also commented, *"I feared going on it, the side-effects..."*. However, there was a belief that taking the medications enabled the participants to have, *"a level of control"* over the disease.

Most had experienced the consequences of non-adherence at some time and had come to terms with the realisation that mobility was dependant on their drugs, and so could not contemplate life without their medication - *"if you don't take it...end up in a wheelchair"* (Jack). All participants seemed to appreciate the consequences of not taking their medication, for as Annie said, *"you miss them, you know you've got to pay for it"*, a view endorsed by Frank, *"If I don't take my tablet...couldn't move the next day"*, and Gary, *"I thought I'd miss a couple of days, but I was terrible, had to go back on them"*, adding that currently, *"I stick to all my medication by the book"*.

Regular hospital visits were generally viewed as a part of the treatment plan and as such were tolerated, although Chris commented that she had, *"missed lots of my appointments...I get fed up with them"*, whilst Ellie remarked that, *"sometimes it's such an effort to get there and when I do, parking is bad and I can't walk far, it can be tough"*.

Some participants found being in a clinic with other PsA patients helpful as *"you get understanding there"* (Beryl) and obtain a sense of being, *"in the same club"* (Jack), although Annie had a more negative view of visiting the clinic, stating that she, *"thought I would find someone I could relate to, but I haven't, they are all older than me"*, whilst Chris remarked of the other sufferers, *"I never pay attention to them"*.

These mixed views regarding hospital appointments continued to be reflected as participants talked about the staff. Jack found it was beneficial just chatting about his condition to someone in the clinic, even if it was another patient, *"doesn't have to be a professional, just someone to give you the time"*, whilst Annie believed, *"you don't get enough time...you feel like you're wasting her time"*, a feeling echoed by Gary, *"sometimes I feel, God, I'm wasting their time"*.

Of all the participants it was Gary who experienced the major benefits of treatment as he stated, *"I was like a new man"* (after starting treatment), "the treatment has been great...new tablets...fantastic", but this was tempered with concern about the future, *"I do worry about what my joints are going to be like"*.

Several of the participants, whilst reflecting on appointments at the rheumatology clinic, felt there was more that could be offered by the clinic by way of more informal help. Jack talked about visits to the hydrotherapy pool and acknowledged that because it is a limited resource and always in use, the hospital could, *"organise a venue...so people could go and swim"* and then suggested, that PsA patients, *"should have coffee clubs...a group getting people involved, need to be more active, cope with the disease"*. This view was shared by Debbie, *"I think it would be good to have a get-together with others in the same situation and share what we do to manage...a group or something at the hospital would be good"*.

4.8.5 Coping

This final category encompassed strategies that the participants tried to employ in order to help them cope with their condition. Unsurprisingly, physical adaptation was a common theme as participants, such as Chris, had changed their lifestyle to cope with their condition *("I have*

a wheelchair when I go out"), although the scale of adaptation varied from, *"learning how to move your body"* (Annie) to *"the occupational therapists got my taps changed, shower seat and the rail up the stairs"* (Frank) and *"I've got a car now, I've just learnt to drive, so I've had to change"* (Beryl). What is pertinent, however, is that all reported the requirement for some form of change in order for their daily life to continue.

In order to try and cope with the pain participants used various techniques, including drinking alcohol, *"I had a drink to help me sleep"* (Henry), because as Beryl suggested, *"I was drinking...it helps sometimes...with the pain".* Jack reported trying not to think about his pain *"if I zone in on it, think about it and touch it, I'd go through the roof".* A more extreme form of distraction was demonstrated by Annie as she, *"started getting tattoos 'cos I could control the pain".* It seems for the first time in years Annie was able to experience a feeling other than the pain associated with her PsA, as she commented that even though it was still pain, *"you're concentrating on a different pain...that you know will stop".* As a result she had, at the time of interview, received three tattoos and was contemplating another in the coming weeks. As a method of pain control such action may appear extreme, but it is of note that this participant experienced intense pain that made her, *"want to go to bed, fall asleep and not wake up".*
It was clear that participants had developed their own ways of coping with the restrictions that PsA imposed on them; for example, Jack discussed how he coped with reading a book,

> *"even that's difficult, a simple thing, holding a book*
> *so I tend to prop it up on a couple of cushions, but I can't*
> *sit then, you know how you lose yourself in a book for a*
> *couple of hours? I couldn't, it would have to be in spates*
> *of like half an hour and then put it down 'cos I've stiffened*
> *up again"*

Similarly, Ian commented that he tried, *"to control the condition by changes to how I sit, how I do things, just small changes",* whilst Beryl said, *"if I can keep myself going and keep moving around and when it's bad, stop and rest...find that happy medium".*

4.9 Reliability and Validity of Data

The researcher believes that the aims of this qualitative study (explicitly articulated at the outset as being the exploration of the lived experience of individuals with PsA and psoriasis, and the identification of the nature of any psychosocial issues that patients perceive impact on their daily lives) have indeed been achieved, as the resulting evidence clearly lends some authenticity to claims that the views of the participants are being represented as they describe the impact that the disease has on their lives.

It is imperative that such claims are based on reliable data that has been obtained through the use of a transparent process that can be easily replicated, although there continues to be much debate concerning the most appropriate methods to use when establishing the reliability and validity of data in studies conducted within a qualitative framework (for example, Mays & Pope, 2000; 2005 & Fossey, Harvey et al., 2002).

In order to provide a full demonstration of evidence from the data, the use of quotations, (that is, the participants own words), juxtaposed with the researcher's description and interpretation enables the reader to authenticate the researcher's claims about the data.

Researcher triangulation, that is, the use of several researchers in the analytical process, further enhanced the validity and reliability of the data as this concept allows for a more complex and nuanced understanding of the possible interpretations. The transcripts were analysed by the researcher, whilst a sample were also analysed by the researcher's supervisor and also by a clinical researcher familiar with both the field of rheumatology and dermatology. There was a high level of consensus when all three researchers compared their analysis, which served to corroborate the overall interpretation of the data.

Given that such triangulation enables the themes and categories identified by each researcher to be compared and discussed, there is sound justification for having more than one researcher analyse data, however, Barbour (2001) maintains that what is in fact important in this process,

is not the level of consensus, but the opportunity for discussion among analysts to provide opportunities for developing further coding.

Mays and Pope (2000) advocate that procedural rigour, that is, a clear exposition of the methods of data collection and analysis, is important because it enables the reader to formulate their own judgement as to whether the interpretation offered by the researcher is trustworthy and evidenced by the data.

In the current study, such transparency was demonstrated through descriptions which detail the way in which the research was conducted and the methodological steps which inform the reader about participant recruitment, how data were collected, recorded, transcribed, coded and analysed.

Furthermore, the reflexivity account provided by the researcher acknowledges her own actions and decisions that will inevitably have impacted upon the meaning and context of the experience described by the participants. This self-awareness of potential biases and predispositions enhances the transparency of the overall research process and provides the reader with sufficient information to allow them to identify the foundations upon which the findings of the study have been grounded.

Whilst there is no one method to prevent errors occurring in qualitative research, use of the above criteria facilitates the validity and reliability of the research data. Although other criteria, such as respondent validation or attention to negative cases, may also be employed, Mays and Pope (2000) suggest that researchers should modify their choice of assessment criteria to take account of the distinct goals of the research whilst Rolfe (2006) argues that rather than utilise an overarching set of criteria to judge the validity of qualitative research, each study should be appraised on its own merits.

Due to the voluminous pages of transcripts that result from qualitative interviews, sample sizes of participants are usually small and selection biases proportionately greater. The validity and reliability of the data may be affected by the size and representitiveness of the sample and the

nature of the population from which it is taken. In this study, the researcher was reliant on the clinical staff acting as 'gatekeepers' for the recruitment process as they undertook the initial identification of PsA patients. This process may have created an opportunity for selection bias to occur as staff may have identified patients who they had previously cared for or who they had some knowledge of, and as such, were patients who they believed would be willing participants, or on the contrary, would not feel empowered to refuse their request. It is also possible that the patients recruited generally had greater disease severity as they were accessing secondary care services. However, the sample obtained did reflect equal numbers of males and females and included a broad range of ages and the duration that patients had been diagnosed with the disease.

As is generally the case with qualitative research, only a small sample size was required meaning that not all patients attending the clinic were approached and included in the study. Although potentially this could have created bias and resulted in some experiences not being identified, interviews were conducted until saturation was achieved and the researcher considers that saturation of themes may be a valid indicator of the inclusion of all significant viewpoints.

Whilst acknowledging that the recruitment for this qualitative study was conducted at a single site, it should be noted that it is a regional centre of excellence, and draws patients from a wide geographical area so potentially increasing the representitiveness of the population.

Finally, the role of the researcher is recognised, as it is possible that the interviewer had an effect on the respondents. As may be the case with any interview situation, the participant may mistrust the interviewer and give misleading answers or provide answers that they think the interviewer wants to hear. However, in order to reduce such bias occurring, the researcher took time to explain the purpose of the study to participants, allowed sufficient time to conduct the interviews and to answer any questions raised and assured the participants that any data collected would remain confidential.

Determining the best methods to appraise the reliability and validity of qualitative data remains a topic of much debate, however the present study employs mixed methodology and advocates that qualitative and quantitative data collection can extend the range of information collected and can compensate for their relative weaknesses.

4.10   Conclusions

The aim of this initial qualitative study was to explore the lived experience of those people with PsA and psoriasis and to establish the nature of any psychosocial issues that they perceive as impacting on their quality of life.

People clearly indicated that living with psoriatic arthritis resulted in greater consequences than psoriasis. Whilst this may be due to the severe physical discomfort associated with PsA, it seems an additional explanation may be that participants can make some attempt to conceal their psoriasis, *"if my scalp's bad, the old hat goes on"* (Jack).

As expected, pain was a major factor, with all participants reporting their functional abilities frequently challenged by both the presence and intensity of pain, with the consequence being varying levels of disability. Although little exploration has been undertaken with PsA patients and the psychosocial impact of pain, it is of note that research with RA patients has reported a complex interrelationship between pain, depression and physical disability, with physical disability predicting levels of both (Covic, 2000). Furthermore, in studies of patients with RA, pain severity is thought to predict subsequent sleep disturbances (Drewes et al., 2000).

Of those people with psoriasis who responded to the 2005 National Psoriasis Foundation surveys, 49.5% reported that psoriasis interfered with sleep at least once per month, and 11.3% reported that psoriasis interfered with sleep more than fifteen days per month (Horn, 2007). This may be due to pruritus (a sometimes painful sensation in the skin that elicits the desire to itch) from psoriasis, as it is associated with poor sleep quality and frequent awakening from sleep (Yosipovitch et al., 200).

This finding could shed light on the sleep disturbance reported in the current study, particularly as patients with PsA may also have varying amounts of psoriasis and therefore pruritis, which may interfere with sleep.

Physical functionality was severely impaired for all participants, with most unable to work and with simple everyday tasks sometimes presenting enormous challenges. Functionality and emotions were entwined as feelings of frustration and uselessness were frequently expressed, whilst participants told of their sense of loss, as comparisons were made with the "old self". Reduced mobility appeared to be central to many of the emotions reported whilst several participants viewed it as the trigger for their depressive symptoms. This may add further support to a study by Husted et al (2005) that compared the health-related QOL (assessed using a generic health status measure) of patients with PsA and RA. The authors reported that those with PsA recorded higher levels of vitality yet they experienced higher levels of bodily pain and more role limitations due to emotional problems, leading them to conclude that there maybe unique disabilities associated with the psoriasis dimension of PsA.

In this study, fatigue emerged as a common component of pain - the impact of this warrants further investigation as research with rheumatoid arthritis patients has found that different aspects of fatigue selectively explained different dimensions of health related quality of life (Rupp, Boshuizen, Jacobi, Dinant, & van den Bos, 2004).

All participants reported consistent tiredness attributable to disturbed sleep. This finding is important given that sleep disturbance has deleterious effects on health, including daytime fatigue and an increased risk of depression (Malik & Kaplan, 2005).

Whilst all participants experienced various negative emotions that were all clearly associated with living with PsA, it was symptoms of depression that emerged as a key theme. Interestingly, the incidence of depression has been found to be higher among those with rheumatological disorders than in the general population, indeed the rate is similar to that found in individuals with other chronic conditions (DeVellis, 1993). Depression has been found to have an effect on disability, with one study reporting that RA patients were more

impaired than those who were not depressed (Katz & Yelin, 1993), whilst another found that psychological factors were a better predictor of disability than traditional measures of disease activity (McFarlane & Brooks, 1988).

The impact on social functioning was of interest as the majority of those interviewed reported a conscious effort to avoid social events, withdraw from friendship groups and would only seek practical or emotional support from immediate family members (*"I couldn't lower myself to ask anyone"* - Chris). Despite social invitations and offers of help from outside of their families, these same people report feelings of isolation and alienation. Such findings may have wider implications as social support is classically conceived as a protective factor for health, with a wide variety of studies documenting it's protective role with respect to both physical and psychological health (Cohen, 2000). Indeed, in one study of patients with RA, chronic obstructive pulmonary disease and psoriasis, coping by seeking social support was significantly related to better functioning (Scharloo et al., 1998).

There was evidence that various lifestyle changes were necessary for participants to cope with their arthritic condition, whether it be incorporating a seat in the shower or using a wheelchair when out shopping. However, coping strategies extended to dealing with pain, with various methods of distraction being employed by the participants.

4.11 Implications of Findings

This study has clearly indicated that, whilst the physical manifestations of psoriasis are unpleasant, it is PsA that has a major impact on patients' health-related quality of life, with symptoms resulting in impaired physical functioning and occupational capability and a severe negative affect on psychosocial domains.

An important finding to emerge from this study was that some problems, for example depression and lack of social support, are not routinely discussed in the outpatient clinic where the majority of those with PsA are seen. This warrants further exploration.

The findings of this study, with it's focus on PsA and the identification of potential domains requiring assessment, broadly supports that of the OMERACT group of experts (Outcome Measures in Rheumatology) who recently established, by means of a consensus exercise, that pain, physical function, QOL, and 'participation' were rated as the most pertinent factors (Gladman, 2005). However, the current study, somewhat uniquely, focused on patients perspectives and in addition to the aforementioned factors identified the following areas as important for assessment: emotions, treatment experience, fatigue and coping.

Whilst caution should be applied to the findings of a small study that drew participants from one source of referral, it would be prudent to determine the extent of such difficulties in the wider PsA population. Substantial implications may be revealed by confirmation of Study 1 results with a larger sample, for example, a potential gap in the care of such patients suggesting that health professionals may require additional training to engage patients in appropriate discussion and be able to offer advice or interventions as a way of reducing the psychological impact of PsA.

There are few studies exploring the psychosocial issues affecting individuals with psoriasis and psoriatic arthritis. The majority of research has been driven from a dermatology perspective and considers quality of life issues associated with psoriasis whilst the impact of PsA has been generally disregarded or overlooked. A review of the literature failed to identify studies exploring the impact of psychosocial factors from the patient's perspective and perhaps explains the current lack of consensus regarding which psychosocial domains should be included in a core set of outcome measures when assessing the impact of both psoriasis and PsA on an individual's quality of life.

This qualitative study has addressed the latter point and successfully identified, from the patient's perspective, which psychosocial factors are considered most pertinent. Study 2 will utilise instruments to measure the domains that patients indicated, in Study 1, were most pertinent to them. This will address some of the limitations of previous research and should also add to the work currently underway by OMERACT, as the study will consider the psychosocial variables in combination, not in isolation, as has previously been the case.

In order to develop a suitable test battery to measure the identified domains of pain, functionality, coping, fatigue and emotions, a review of existing outcome measures was undertaken and is described in the following chapter.

CHAPTER 5

REVIEW OF OUTCOME MEASURES

5.1   Why measure patient outcomes?

In 2008, the Office of Health Economics (OHE) Commission reported that, each year the NHS receives over £100 billion of taxpayers' money and that this figure increases by 10% per annum. Given the aim of the NHS is to improve the health of the UK population, relatively little is known about how the health of the nation is actually improving as a result of such massive expenditure.

In order to address this, the Commission stated that routine measurement and analysis of health care outcomes for patients is required. They also suggested that generic measures of patients' health related quality of life before, during and after treatment should be collected alongside disease-specific measures. It is their opinion that generic measures are essential to permit comparison between different types of treatment for different groups of patients, and to enable assessment of the overall productivity of the NHS (OHE, 2008).

Measuring the efficacy of a treatment or medical intervention traditionally involves the use of physician-based outcomes such as blood tests, x-rays and MRI scans, however, given that many of these clinical measures do not adequately capture the overall impact of the disease on individuals, there is increasing utilisation of patient-based outcomes in order to gain a patient's perspective of their health, illness and the efficacy of health-care interventions (Marra et al., 2005).

Across the broad spectrum of health and disease, accurate measurement of outcomes has become an important medical and social issue, as their use is not limited to the assessment of treatments, health promotions and disease prevention programmes. Indeed, outcome measures may be used to establish the cost-effectiveness of treatments and interventions, determine the

health needs of individuals or groups and monitor those needs, influence an individual's choice of a specific treatment plan and, ultimately, inform the development of health policy.

In most cases, the accepted "goal of healthcare is to protect, promote, and maintain the health status of people" (Steinwachs & Cagney, 1996, pp. 747), and whilst treatments and interventions aim to improve health, research suggests that physiological measures may change without individuals feeling better and conversely, individuals may report feeling better without their physiological function showing any measurable change. This being the case, there is a clear need to be able to include instruments that measure the health of patients from the patient's perspective, and which compliment conventional clinical measures and thus provide a more complete assessment of health.

There are two basic approaches to measurement that researchers utilise when assessing the impact of disease on areas such as health-related quality of life (HRQoL), pain or fatigue. The first involves the use of instruments that are specific to a disease (e.g. lung cancer, diabetes, PsA, etc.) a population (e.g. children) or a clinical problem such as pain, whilst the second approach uses generic instruments that measure broad aspects of, for example, HRQoL and provide a general sense of the effects of an illness, rather than assessing HRQoL relative to a particular medical condition.

5.2   Disease Specific Measures versus Generic Measures

5.2.1   Disease-Specific Measures

Disease-specific measures are likely to be more sensitive and clinically relevant as they are targeted to specific conditions, thus resulting in a measure that is more responsive to clinically important changes in health that result from interventions (Marra et al., 2005). Such measures do not contain any items or health dimensions that are not pertinent to the disease – this serves to increase their acceptability amongst patients as the instruments have clear relevance to patients with the presenting problem. However, the very nature of disease-specific measures

means they are usually only administered to those with the specific health problem, meaning that the resulting scores cannot be compared with those for the general population, which is a common approach for assessing the impact of a particular disease on health status. Marra et al. (2005) argue that this inability to draw comparisons across treatments for different diseases limits their application in economic evaluation, health policy and resource allocation.

5.2.2 Generic measures

Generic instruments are designed to measure very broad aspects of health across a variety of medical conditions and therefore may be administered to a wide range of patient and general population groups to examine the impact of disease and, where appropriate, the impact of various health care interventions. For example, The Sickness Impact Profile (SIP; Bergner et al., 1981) has been used across a large number of different populations including RA, angina, obesity, end stage renal disease, chronic obstructive pulmonary disease, as well as several healthy populations, and appears to discriminate among them and different degrees of disease severity (Deyo et al, 1982; VandenBurg, 1988; Sullivan, 1987; Hart & Evans, 1987; McSweeny et al., 1982; Bergner et al., 1988; 1985).

Generic measures may also be used with healthy populations to generate normative data that can then be used to compare different patient groups. Their broad scope means they have potential to capture the influence of co-morbidity on health, in addition to the positive or negative effects of an intervention. However, such wide applicability may limit the relevance of generic instruments when applied to a specific patient population, as they may not be sensitive enough to detect subtle treatment effects.

5.3 Psoriasis and PsA Outcome Measures

Researchers focussing on the impact of psoriasis are generally consistent in their use of measurement tools, many of which are disease specific, with those typically employed being the Dermatology Life Quality Index (DLQI; Finlay & Khan, 1994), Psoriasis Disability Index (PDI; Finlay & Kelly, 1987), Salford Psoriasis Index (SPI; Kirby et al., 2000), Psoriasis Area

and Severity Index (PASI; Fredricksson & Pettersson, 1978), Self- Administered Psoriasis Area and Severity Index (SAPASI; Fleisher et al., 1994), Beck Depression Inventory (BDI; Beck et al., 1961; 1974; 1984) and the Health Assessment Questionnaire (HAQ; Bruce & Fries, 2003).

However, limited research literature concerning the psychosocial impact of psoriatic arthritis presents a different picture, with studies such as that by Husted and colleagues (2001), reporting the use of generic instruments or those borrowed from rheumatoid arthritis or ankylosing spondylitis.

The introduction of new therapies, such as biologics, may be a cause for patient optimism as they have been shown to improve the debilitating physical symptoms associated with PsA. Such advancements highlight the need for a consensus regarding the domains to be measured, along with a core set of standardised and validated instruments, for, as Mease & Menter (2006) suggest, it is now vital that researchers be able to accurately assess these improvements.

5.4   Available Measures

In the current study, the analysis of the qualitative data revealed five key themes that were categorised as functionality, pain, emotions, coping and treatment experience and management. These categories incorporate various smaller themes, some of which warrant further exploration, in particular, fatigue and depression.

In order to achieve the aim of the second part of the current study, that is to quantitatively measure the impact of psychosocial factors that were identified by the participants, a brief review of available measures was undertaken. Given that fatigue and depression were clearly demonstrated as factors requiring further exploration, the identification of appropriate measures was required. Similarly, instruments for measuring pain and physical function needed to be identified, whilst a suitable measure to assess the impact of psoriasis was required.

Following the brief review, the measures that had been identified as suitable were included in the questionnaire booklet that was developed for use in the cross-sectional postal survey that comprises the second part of the current study.

For each of the searches undertaken for the review of measures, the key search terms are reported. In an attempt to keep findings current and relevant, a pragmatic decision was taken by the author, to limit the search to research published from the year 2000 onwards (until date of search - July 2006).

5.4.1   Function and Disability Measures

The databases, Blackwell Synergy (incorporating 849 journals), Psychinfo and Ovid and Cinahl were searched for papers between January 2000 and July 2006 using a combination of key terms - "psoriatic arthritis", "quality of life", "functional disability" and "functioning". A total of 14 matches were returned. The inclusion of the term "psoriasis" returned an additional 49 matches. The majority of these papers simply mentioned quality of life and did not necessarily measure the construct. Of those which did, the measures employed included The Arthritis Impact Measure Scales (Meenan, 1980), Short-Form Health Survey (SF-36; Ware & Sherbourne, 1992a), Hosptial Anxiety Questionnaire (HAQ; Bruce & Fries, 2003), European Quality of Life Scale (EQ-5D; EuroQol Group, 1990) and Dermatology Life Quality Index (DLQI; Finlay & Khan, 1994).

Functional disability and quality of life may be considered key outcome measures for individuals with psoriatic arthritis, for when considering the impact of any musculoskeletal disease on an individual, such measures may provide an additional method of assessing the damage caused by the disease (Kavanaugh & Cassell, 2005).

5.4.1.2   AIMS (Meenan et al., 1980)

The Arthritis Impact Measurement Scales (AIMS Meenan et al., 1980) is an arthritis–specific HRQoL instrument consisting of 45 items that are summed into 9 scales: mobility, physical

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activity (walking, bending, lifting), dexterity, household activity (managing money and medications, housekeeping), social activities, activities of daily living, pain, depression, and anxiety.

In addition to the original, there is an expanded version, AIMS2, incorporating a further three scales to evaluate arm function, work, and social support, a short-form of the AIMS2 (AIMS2-SF), a child version, and a version for the elderly (Geri-AIMS). AIMS have been translated into many languages including Portuguese, Canadian French, Italian, Spanish, French, Dutch, Swedish, Turkish, and Norwegian.

AIMS has been used in various other conditions including: psoriatic arthritis, ankylosing spondylitis, fibromyalgia, carpal tunnel syndrome, colles fracture, hemophilia and in patients undergoing joint replacement surgery.

Both AIMS & AIMS2 have been validated in patients with PsA and RA, although the expanded version in not widely used due to its relative length and complexity (Husted et al., 1996; Taal et al., 2004).

5.4.1.3 HAQ (Bruce & Fries, 2003)

Although sometimes viewed as a disease-specific measure because it emanated from the field of rheumatology, The Health Assessment Questionnaire (HAQ; Bruce & Fries, 2003) is in fact a generic instrument that is administered across diverse disciplines in many different cultures.

It was originally developed by Fries et al., (1980) to assess physical function in patients with RA, however, it has since been found to measure physical disability and pain in patients with PsA (Wanke et al., 2002).

The HAQ focuses on physical disability and pain, with a modified version available for spondylarthropathies (HAQ-S), which includes two spinal domains (Daltroy et al., 1990). In addition, the HAQ has been modified for psoriasis (HAQ-SK) and includes several items

relating to the effect of skin disease on health status, however when utilised in study of PsA patients the HAQ-SK scores did not differ from the original HAQ score suggesting that the inclusion of skin-related questions did not improve the assessment of health status provided by the original HAQ instrument (Husted et al., 1995).

The HAQ Disability Index (HAQ-DI) is the disability component of the HAQ that assesses functional ability. It comprises 20 questions in 8 categories of functioning which represent a comprehensive set of functional activities – dressing, rising, eating, walking, hygiene, reach, grip and usual activities.

There is consensus that the HAQ-DI possesses face and content validity, and correlations between questionnaire or interview scores and task performance have ranged from 0.71 to 0.95, indicating criterion validity. The construct/convergent validity, predictive validity, and sensitivity to change have also been established in numerous observational studies and clinical trials (Ramey et al, 1995).

According to Bruce & Fries (2003), the HAQ has been administered by the Stanford Arthritis Rheumatism and Aging Medical Information System (ARAMIS) in excess of 200,000 times to assess clinical status, evaluate effectiveness in clinical and observational trials, and to define health outcomes, and it is sanctioned by the American College of Rheumatology for assessing physical function in RA trials. Available in over 60 languages and supported by more than 500 references, the HAQ is one of the most comprehensive, validated, patient-orientated outcome assessment measures available.

5.4.1.4   SF-36 (Ware & Sherbourne, 1992a)

The Medical Outcomes Study Short–Form Health Survey (SF–36; Ware & Sherbourne, 1992a) is one of the most widely used generic HRQL instruments due to it's ability to estimate disease burden and compare disease-specific benchmarks with general population norms. With almost four thousand publications to date (Ware, 2006), describing in excess of two hundred

diseases and conditions, it is of note that arthritis, musculoskeletal conditions and rheumatoid arthritis have fifty or more SF-36 publications each (Turner-Bowker et al., 2002).

It is a 36-item instrument that measures health across eight dimensions of physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, vitality, pain, and general health perceptions. Responses to items within each dimension are summed to produce a health profile of eight scores, whilst the dimension scores also form physical component (PCS) and mental component (MCS) summary scores.

The SF-36 shows strong internal consistency, with reliability estimates for PCS and MCS usually exceeding 0.90 (Ware et al., 1990).

A major advantage of the SF-36 is its brevity - it can be incorporated into questionnaire packs whilst leaving space for other more precise general and specific measures to supplement it, a strategy that has been adopted in numerous studies, for example, Wagner et al., (1995).

The SF-36 has been employed in various PsA therapy trials (Schrader et al., 2002) and has been found to be a reliable measure, distinguishing PsA patients from the general population (Husted et al., 1997). Used in various studies, the SF-36 has shown that the impact of psoriasis is as great as that of other major medical disorders (Rapp et al., 1999)
A further study of PsA patients by Husted et al. (1998) reported that the SF-36 was equally, or more, responsive than both the AIMS and the HAQ to short-term changes in perceived health status and inflammatory disease activity.

5.4.1.5   Psoriatic Arthritis Quality of Life (PsAQoL; McKenna et al, 2004)

The PsAQoL measure, developed by McKenna, Doward, Whalley, Tennant, Emery & Veale (2004), is the first patient-derived instrument specific for PsA and was developed for use in clinical trials. It consists of twenty items, the content of which were derived from qualitative, unstructured interviews conducted with patients with PsA.

The researchers reported that the psychometric properties, test-retest reliability (0.89) and internal consistency (0.91) of the PsAQoL are excellent and that the measure is well accepted by patients as it takes less than five minutes to complete. McKenna et al. (2004) concluded that it is a valuable tool for assessing the impact of interventions for PsA in clinical studies and trials.

5.4.1.6   European Quality of Life Scale (EQ-5D; Euroqol group, 1990)

Established in 1987, the EuroQol Group initially comprised a network of international, multilingual and multidisciplinary researchers from seven centres in Finland, the Netherlands, Norway, Sweden and the UK. The process of shared development and local experimentation resulted in EQ-5D (www.euroqol.org, 1987)

The EQ-5D (EuroQol Group, 1990) provides a generic measure of health status that provides a simple descriptive profile and a single index value that can be used in the clinical and economic evaluation of health care and in population health surveys.

It consists of 5 items that measure 5 domains (Mobility, Self-care, Usual Activities, Pain/Discomfort and Anxiety/Depression) and one Visual Analogue Scale measuring Health State.

The first of 2 parts records a patient's health state along 5 dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression), each having a choice of three possible levels reflecting no problem, some problem, and extreme problem. This classifies respondents into 1 of 243 distinct health states.

The second part of the EQ-5D is a 20-cm VAS that has the end points: "best imaginable health state" (100) and "worst imaginable health state"(0). Respondents illustrate how they rate their own health status by drawing a line that best represents their own health state on that day.

It is applicable to a wide range of health conditions and treatments and was originally designed to complement other instruments but is now increasingly used as a 'stand alone' measure.

EQ-5D is designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics and face-to-face interviews. It is cognitively simple, taking only a few minutes to complete.

On one hand, the brevity of the EQ-5D has been considered a strength (Brooks, Robin & de Charro, 2003) as it has resulted in better completion rates, even in chronic debilitating diseases such as stroke (Dorman et al., 1997), but on the other hand, it appears to lack dimensions of HRQoL such as dexterity, social functioning and vitality that may be impacted by RA, and other chronic diseases (Johnson & Pickard, 2000). However, in two studies of RA patients, the EQ-5D was found to measure both current and changes in health status and demonstrated index scores that were significantly correlated with other condition-specific measures, including loss of function, joint pain, tenderness and mood. Such results suggest the EQ-5D has reliability and cross-sectional and longitudinal construct validity in RA (Hurst et al., 1994; 1997).

The measure has been used in numerous studies to assess quality of life in psoriasis patients (Weiss et al., 2002).

A summary of these measures is shown in Table 5.1.

Table 5.1: Summary of function and disability measures

NAME	Arthritis Impact Measurement Scales	Health Assessment Questionnaire Disability Index	Medical Outcomes Study Short –Form Health survey	Psoriatic Arthritis Quality of Life	European Quality of Life Scale
ABBREVIATION	AIMS & AIMS2	HAQ-DI	SF-36	PsAQoL	EQ-5D
OBJECTIVE	Measure changes in global health, pain, mobility & social function	To assess the difficulty in performing activities of daily living.	Generic health concepts	Assess impact of PsA and it's treatment	To characterize current health state
DISEASE	Rheumatoid & Osteoarthritis	Generic	Generic	Psoriatic arthritis	Generic
No. OF ITEMS	AIMS : 45 AIMS2-SF: 26	20	36	20	5 + 1 VAS
COMPLETON TIME	AIMS : 20 mins AIMS2-SF: 10 min	5 minutes	10 minutes	< 5 minutes	< 5 minutes
POPULATION	Adult	Adult	Adult/Adolescent	Adult	Adult
ADMINISTRATION	Self	Self/Interviewer or Telephone	Self/Interviewer/ Computer	Self	Self/interviewer/T elephone
TIME RECALL	Past month	Last week	Std vers: Last 4 wks Acute vers: Last wk	Present	Present
ORIGINAL LANGUAGE	English for the USA	English for the USA	English for the USA	English	English
AUTHOR/S	Robert F. Meenan	James F. fries	John E. Ware jr. & Cathy D. Sherbourne	McKenna, Doward et al.	EuroQol Group

5.4.2   Pain

The databases, Blackwell Synergy (incorporating 849 journals), Psychinfo and Ovid and Cinahl were searched for papers published between January 2000 and July 2006 using a combination of key terms - "psoriatic arthritis", and "pain". A total of 255 matches were returned. The inclusion of the term "psoriasis" returned an additional 964 matches. The majority of these papers mentioned pain but did not necessarily measure it. Of those which did, the measures employed included Visual Analogue Scales (VAS), Numerical rating Scales (NRS), AIMS/AIMS2 (Meenan et al., 1980), HAQ VAS Pain Scale (Bruce & Fries, 2003).

5.4.2.1   Pain Visual Analogue Scales (VAS; Bond & Pilowsky, 1966)

The Pain Visual Analogue Scale (VAS; Bond & Pilowsky, 1996)) is a self-report measure consisting of a ten centimetre (100 millimetres) continuous line, anchored at each end with a statement representing the extremes of the dimension being measured, usually pain intensity. The patient is asked to mark their perceived level of pain intensity (for a specified time frame) on the line. Scoring of the VAS is done by measuring the distance, in millimetres, from the zero to the patient's mark.

A VAS may be horizontal or vertical and, whilst it can be of any length deemed appropriate by the researcher, its most common form is a 10 centimetre (100 millimetres) horizontal line. Indeed, a horizontal VAS has been shown to produce a more uniform distribution of scores than a vertical VAS (Scott & Huskisson, 1976).

Visual Analogue Scales have been used in clinical and research settings since the 1920's. Freyd (1923) described the measurement of subjective phenomena using VAS, although at that time, they were generally referred to as 'graphic rating scales'. VAS were initially used for the measurement of pain in 1966 (Bond & Pilowsky) since which time, they have frequently be used to assess both acute and chronic pain (Wewers & Lowe, 1990).
The instrument is quick to complete, as patients are simply required to indicate their present pain level by marking the line. A widely used outcome measure, VAS are frequently employed by clinicians assessing the efficacy of drug regimes for psoriatic arthritis as changes in the VAS score represent a relative change in the magnitude of pain (for example, Cauza et al., 2006).

The test-retest reliability of the VAS has been evaluated in various studies and has demonstrated high correlation, for example Seymour (1982), requested participants to rate current intensity of dental pain and reported correlations ranging from .95 to .99, whilst its validity and reliability has been reported by Lara-Munoz and colleagues (2004).

5.4.2.2 Numerical Pain Rating Scales (NPRS; Downie et al., 1978)

Numerical Pain Rating Scales (Downie et al, 1978) are frequently used to assess a patient's level of pain and consist of a line with a numerical scale with the range 0 to 10. The words "no pain" anchor the "0", whilst "worst pain possible" is found by the "10". The patient is asked to choose a number from 0 to 10 that best reflects their level of pain and to indicate the point on the line.

The NPRS are easily administered and simple to score and have demonstrated moderate to high test-retest reliability, varying from 0.67 to 0.96 (Finch et al, 2002; Good et al., 2001)

5.4.2.3 Arthritis Impact Measurement Scales (AIMS; Meenan et al., 1980)

The AIMS and AIMS2 (Meenan et al, 1980) have been previously described, however they not only elicit information about physical functioning (six subscales), but also pain (five item scale).

The pain subscale consists of four items that measure the severity of the arthritis pain, the frequency of severe arthritis pain, the duration of morning stiffness and the frequency of pain in more than one joint.

Both measures have been validated for use with psoriatic arthritis patients (Husted et al, 1996; Husted et al., 1996), however, Gladman and colleagues (2004) note that clinicians at the University of Toronto PsA clinic have stopped using these instruments as patients reported they were tedious to complete.

5.4.2.4 Health Assessment Questionnaire Pain VAS (HAQ Pain VAS; Bruce & Fries, 2003)

As previously mentioned, the HAQ and HAQ-S (Bruce & Fries, 2003) have been validated for use with PsA patients (Wanke et al., 2002).

The HAQ contains the HAQ Visual Analogue pain Scale that, according to Bruce & Fries (2003) is designed to assess the presence (or absence) of arthritis-related pain and its severity. The objective is to obtain information from patients on how their pain has usually been over the past week, even though pain may be reported to vary over the course of a day or from day to day. The HAQ pain scale consists of a doubly anchored, horizontal VAS, that is scored from zero (no pain) to three (severe pain), or alternatively from 0 (no pain) to 100 (severe pain).

The VAS for pain has been used widely in experimental, observational, and clinical settings (Jansen et al., 2000; Kandziora et al, 1999; Ramey et al, 1995).

A summary of available pain measures is shown in Table 5.2

Table 5.2: Summary of pain measures

NAME	Pain Visual Analogue Scale	Numerical Rating Scale	Arthritis Impact Measurement Scales	Health Assessment Questionnaire VAS Pain Scale
ABBREVIATION	Pain VAS	NRS	AIMS & AIMS2	HAQ Pain VAS
OBJECTIVE	To measure severity or improvement of pain		Measure changes in global health, pain, mobility & social function	Assess severity of Arthritis-related pain
DISEASE	Generic	Generic	Rheumatoid & Osteoarthritis	Generic
No. OF ITEMS	1	1	AIMS2 : 45 AIMS2-SF: 26	20
COMPLETON TIME	< 1 minute	< 1 minute	AIMS : 20 mins AIMS2-SF: 10 mins	
POPULATION	Age 7 +		Adult	Adult
ADMINISTRATION	Self	Self/ Phone Interviewer	Self	Self/ Phone/ Interviewer
TIME RECALL	Variable	Variable	Past month	Last week
ORIGINAL LANGUAGE	English		English for the USA	English for the USA
AUTHOR/S	Bond & Pilowsky		Robert F. Meenan	James F. fries

5.4.3   Coping

The databases, Blackwell Synergy (incorporating 849 journals), Psychinfo and Ovid and Cinahl were searched for papers published between January 2000 and July 2006 using a combination of key terms - "psoriatic arthritis", "coping", "passive coping" and "emotional coping". A total of 44 matches were returned. The inclusion of the term "psoriasis" returned an additional 203 matches, most of which concerned coping with stigmatisation regarding the appearance of skin.

Although matches were returned by the search, none of the psoriatic arthritis studies specifically utilised instruments to measure coping. However, research with RA patients (Covic et al., 2002), suggests that useful measures include the Vanderbilt Pain Management Inventory (VPMI; Brown & Niccassio, 1987), the Arthritis Helplessness Index (AHI; Niccassio et al., 1985) and the Coping Strategies Questionnaire (CSQ; Rosentiel & Keefe, 1983)

5.4.3.1   Vanderbilt Pain Management Inventory (VPMI; Brown & Nicassio, 1987)

The Vanderbilt Pain Management Inventory (Brown & Nicassio, 1987) is an 18-item measure that assesses the frequency with which chronic pain patients use coping strategies when their pain reaches a moderate or greater level of intensity.

The VPMI consists of two internally reliable scales: Active Coping and Passive Coping. When developing the VPMI, Brown & Nicassio (1987) found that Active Coping was associated with reports of less pain, less depression, less functional impairment, and higher general self-efficacy, whilst Passive Coping was correlated with reports of greater depression, greater pain and flare-up activity, greater functional impairment, and lower general self-efficacy.

5.4.3.2 Arthritis Helplessness Index (AHI; Niccassio et al., 1985)

The AHI (Niccassio et al., 1985) measures self-perception of ability and inability to control arthritis. It consists of 15 items designed to assess patients' perceptions of loss of control in association with their RA. Nine of the items assess perception of ability and six assess inability. (Nicassio, Wallston, Callahan, Herbert & Pincus (1985).

5.4.3.2 Coping Strategies Questionnaire (CSQ; Rosentiel & Keefe, 1983)

The CSQ (Rosentiel 7 Keefe, 1983) is a 48-item checklist of coping strategies in which patients are asked to indicate the extent to which they use a given coping strategy on a scale of 1 ('not at all') to 6 ('always').

The measure assesses 6 cognitive coping techniques (Diverting Attention, Reinterpreting Pain Sensations, Coping Self-Statements, Ignoring Pain Sensations, Praying or Hoping, and Catastrophising), and 2 behavioural coping techniques (Increasing Activity Level and Increasing Pain Behaviours). Each domain is composed of 6 items, and participants rate the frequency of their use of specific coping strategies on a 7-point Likert scale from 0 ("Never do that") to 6 ("Always do that"). In addition, The CSQ also includes two 1-item scales that assess participants' subjective ability to control or decrease their pain - these two scales are not thought to measure coping strategies but rather their effectiveness (Rosentiel & Keefe, 1983)

The CSQ has demonstrated satisfactory internal consistency and test-retest reliability (Main & Waddell, 1991).

A summary of available measures for coping is shown in Table 5.3.

Table 5.3: Summary of coping measures

NAME	Vanderbilt Pain management Inventory	Pain Coping Strategies Questionnaire	Arthritis Helplessness Index
ABBREVIATION	VPMI	CSQ	AHI
OBJECTIVE	Assess 2 general coping strategies – Active and passive	Assess use of coping strategies when pain is experienced	Measures self-perception of ability and inability to control arthritis
DISEASE	Generic	Generic	Rheumatoid Arthritis
No. OF ITEMS	18	44	15
COMPLETON TIME	5 minutes	10 minutes	3 minutes
POPULATION		Adult	Adult
ADMINISTRATION	Self	Self	Self
ORIGINAL LANGUAGE			
AUTHOR/S	Brown & Nicassio	Rosenstiel & Keefe	Nicassio (1985)

5.4.4   Fatigue

The databases, Blackwell Synergy (incorporating 849 journals), Psychinfo and Ovid and Cinahl were searched using a combination of key terms - "psoriatic arthritis" and "fatigue". A total of 65 were returned. The inclusion of the term "psoriasis" returned an additional 211 matches. Generally, fatigue was not measured, but referred to as a symptom. However, of those that did measure fatigue, Visual Analogue Scales, the Fatigue Severity Scale (Krupp et al, 1989) and the Functional Assessment of Chronic Fatigue Therapy – Fatigue (Yellen et al., 1977) were used.

Within the realms of PsA research, fatigue is only just emerging as an important domain in its own right (Mease et al., 2005). Several multidimensional measures have been developed in order to capture the emotional and physical aspects of fatigue.

5.4.4.1 Fatigue Severity Scale (FSS; Krupp et al., 1989)

The FSS (Krupp et al, 1989) is a brief measure comprising nine statements that rate the severity of fatigue symptoms on a scale of 1 (Disagree) to 7 (Agree).

It has been widely used and validated in patients with systemic lupus erythematosus (SLE; Krupp et al., 1990) and has been used with PsA patients, successfully distinguishing them from controls and showing correlation with disease activity (Schentag, Cichon, MacKinnon, Gladman & Urowitz, 2000).

According to Krupp's et al (1989) the measure has demonstrated high reliability with SLE patients ($\alpha = 0.89$), those with Multiple Sclerosis ($\alpha = 0.81$) and normal healthy adults ($\alpha = 0.88$). In addition, it has good test-retest reliability (0.84).

5.4.4.2 Functional Assessment of Chronic Illness Therapy - Fatigue (FACIT-f; Yellen et al, 1997)

The FACIT-F (Yellen et al, 1997) is a measurement tool that gathers patient feedback about energy level, listlessness and the ability to start or finish activities, and can be used to assess various chronic disease states, so enabling comparisons across diseases.

The instrument was originally developed to measure fatigue in patients with cancer (Yellen et al., 1997) but has since been used in other patient groups and demonstrated good internal consistency (0.86 to 0.87) when used with RA patients (Cella, et al., 2005).

Although there is, as yet, a paucity of information concerning the use of this measure with PsA patients, it is currently being used in clinical trials with PsA patients. A press release by global health care company, Abbott, in which they report their preliminary findings of the Adalimumab Effectiveness in Psoriatic Arthritis Trial (ADEPT), states that patients' fatigue levels experienced a mean improvement seven points higher than patients taking the placebo, however, clinically meaningful improvements in the FACIT-F scale have not been specifically

defined for psoriatic arthritis, although in rheumatoid arthritis, meaningful improvement is defined as a four-point change (Abbott, 2005).

A summary of fatigue measures is shown in Table 5.4.

Table 5.4: Summary of fatigue measures

NAME	Krupps Fatigue Severity Scale	Functional assessment of Chronic Illness Therapy Fatigue Score
ABBREVIATION	FSS	FACIT-F
OBJECTIVE	To assess fatigue	To assess fatigue
DISEASE	Generic	Cancer
No. OF ITEMS	9	13
SCALE	7-point Lickert	5-point Lickert
COMPLETON TIME	Less than 5 minutes	Less than 5 minutes
POPULATION	Adult	Adult
ADMINISTRATION	Self-administered	Self
ORIGINAL LANGUAGE	English for the USA	English
AUTHOR/S	Lauren B. Krupps	Yellen et al.

5.4.5   Emotions

The databases, Blackwell Synergy (incorporating 849 journals), Psychinfo and Ovid and Cinahl were searched using a combination of key terms - "psoriatic arthritis", "depression", "depressive symptoms" and "psychological distress". A total of 106 matches were returned. The inclusion of the term "psoriasis" returned an additional 646 matches. The most frequently used measure was undoubtedly the Hospital Anxiety Depression Scale (Zigmond & Snaith, 1983), although the Beck Depression Inventory and CES-D (Center for Epidemiological Studies Depression Scale; Radloff, 1977) were also featured.

Within the context of the proposed study, the measurement of emotions is primarily concerned with depression.

5.4.5.1 Beck Depression Inventory (BDI; Beck, 1961)

The Beck Depression Inventory (Beck, 1961) is a 21-item instrument which aims to measure presence and degree of depression in adolescents and adults. Each of the twenty-one items attempts to assess a specific symptom or attitude and includes Mood, Pessimism, Sense of Failure, Lack of Satisfaction, Guilt Feelings, Sense of Punishment, Suicidal Wishes, Fatigability and weight Loss.

There are three versions of the BDI—the original BDI, first published in 1961 (Beck et al., 1961) and later revised in 1978 as the BDI-1A (Beck et al., 1979), and the BDI-II, published in 1996.

According to Beck and his colleagues (1988), the BDI has become one of the most widely used instruments not only for assessing the intensity of depression in psychiatrically diagnosed patients (Piotrowski, Sherry, & Keller, 1985), but also for detecting depression in normal populations (Steer, Beck, & Garrison, 1986). Numerous studies have addressed the internal consistency of the Beck Depression Inventory for psychiatric (0.76 to 0.95) and non-psychiatric populations (0.73 to 0.92).

The Beck Depression Inventory (BDI) has been used with PsA patients (Tyring, 2006).

5.4.5.2 The Hospital and Anxiety Scale (HADS; Zigmond & Snaith, 1983)

The HADS, developed by Zigmond and Snaith (1983), is a brief, self-administered rating scale of symptoms and functioning that is designed to detect anxiety and depression. It consists of 14 statements divided into two subscales, anxiety and depression, each with 7 items. The scores for the two components can also be added together to give a composite anxiety–depression score.

The measure has been used in routine care, multiple types of clinical investigations and is available in over 33 translations.

Both subscales demonstrate acceptable reliability (α = 0.80 to 0.93). (Herrmann, 1997). Indeed, in his review of validation data and clinical results, Herrmann (1997) maintains that the HADS gives clinically meaningful results as a psychological screening tool both in clinical group comparisons and in correlational studies with several aspects of disease and QoL.

Research with RA patients (Sharpe et al., 2001) suggests the Hospital Anxiety and Depression Scale (HADS) is worthy of inclusion as an outcome measure for depression.

5.4.5.3 Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977)

The CES-D is a 20-item, self-report scale designed to measure depressive symptomatology in the general population. It measures frequency of mood and behavioural symptoms that occurred during the previous week. Items are rated on a 4-point scale ranging from rarely/none of the time to most or all of the time.

The CES-D has been used extensively in community samples and demonstrates adequate reliability and validity in the general population (α = .85; Radloff, 1977), RA patients (average internal consistency = .92; Smith & Wallston, 1992), and a sample of older adults with either arthritis or no chronic disease (α = .87; Penninx et al., 1997).

A summary of depression measures is shown in Table 5.5.

Table 5.5: Summary of Emotions Measures

NAME	Beck Depression Inventory	Hospital Anxiety and Depression Scale	Center for Epidemiological Studies Depression Scale
ABBREVIATION	BDI	HADS	CES-D
OBJECTIVE	Assess intensity of depressive symptoms	Assess mood	Assess Depressive symptoms
DISEASE		Generic	Generic
No. OF ITEMS	21	14	20
COMPLETION TIME	10 minutes	< 5 minutes	< 5 minutes
POPULATION	Adult	Adult	Adult
ADMINISTRATION	Self	Self	Self
ORIGINAL LANGUAGE	English	English	English
AUTHOR/S	Beck, Ward, Mendelson, Mock & Erbaugh	Zigmond & Snaith	Radloff

5.5   Quality of Life Measures for Psoriasis

Assessing QoL in patients with psoriasis may be achieved using a variety of measures that are either psoriasis-specific, skin specific or generic QoL measures. Whilst the most sensitive measures are the psoriasis-specific ones, they do not enable comparisons to be made across diseases, often resulting in studies utilizing more than one measure.

5.5.1   The Psoriasis Index of Quality of Life (PSORIQoL; McKenna et al., 2003)

The PSORIQoL (McKenna et al., 2003) is a dichotomous, 25-item instrument used to measures the impact of the psoriasis on quality of life, rather than assessing impairment or disability.

With content derived from qualitative interviews with psoriasis patients, the items cover a number of areas including, fear of negative reactions from others, self-consciousness and poor self-confidence, problems with socialisation, physical contact and intimacy, limitations on personal freedom and impaired relaxation, sleep and emotional stability.

McKenna and his colleagues (2003) have demonstrated that the measure has high internal consistency ($\alpha = 0.94$) and good test – retest reliability (0.90).

5.5.1.2 Psoriasis Life Stress Inventory (PLSI; Gupta & Gupta, 1995)

The PLSI (Gupta & Gupta, 1995) is a 15-item instrument designed to measure psoriasis-related stress associated with cosmetic disfigurement and social stigma, symptoms of disease and treatment effects.

The PLSI (Gupta & Gupta, 1995) also permits patients to be classified as a function of their distribution of score: those patients who react significantly to the stress associated with having psoriasis (score > 10); and those patients who are not significantly affected by psoriasis-related stress (score < 10).

The psychometric properties of the PLSI were assessed by Fortune et al. (1997) and they reported good internal reliability ($\alpha = 0.88$).

5.5.1.3 Psoriasis Disability Index (PDI; Finlay & Kelly, 1987)

The PDI (Finlay & Kelly, 1987) is a 15-item scale that specifically addresses self-reported disability in areas of daily activities, employment, personal relationships, leisure, and treatment effects. The items are concerned with the practical effects of psoriasis in every day life.

The PDI has been shown to have good concurrent validity with the Sickness Impact Profile (SIP; Bergner et al., 1981) a widely used generic health status measure (Finlay et al., 1990).

Mease & Menter (2006) maintain that a major limitation of the PDI is its suboptimal sensitivity to changes in patients with mild to moderate disease.

5.5.1.4 Psoriasis Area and Severity Index (PASI; Fredriksson & Pettersson, 1978) and Simplified PASI (SAPASI)

The PASI (Fredriksson & Pettersson, 1978) and Simplified PASI (SAPASI) are measures used by clinicians to assess the severity of psoriasis.

Fredriksson and Pettersson created the PASI as a method to evaluate the clinical efficacy of a new treatment for psoriasis. It is widely used by clinicians whilst the SAPASI is a simplified self-report version (Louden et al., 2004), however, neither measure the impact of psoriasis on patients' QoL directly, making the use of other QoL scales necessary.

5.5.1.5 Salford Psoriasis Index (SPI; Kirby et al., 2000)

The SPI (Kirby et al., 2000) is derived from combining three figures - a score of current severity of psoriasis based on the PASI, a score indicating psychosocial disability, and a score based on historical information. The first figure reflects the extent of psoriasis, the second assesses the psychosocial impact of psoriasis on each patient using a 0-10 visual analogue scale and the third figure reflects historical severity of disease as judged by the need for systemic treatment, admission to hospital and number of episodes of erythroderma (Kirby et al., 2000).

Reliability and sensitivity of the SPI was assessed in two separate cohorts and demonstrated high reproducibility and was highly responsive to changes in health-related quality of life after treatment for psoriasis (Kirby et al, 2000).

5.5.2 Skin-specific measures

5.5.2.1 The Dermatology Life Quality Index (DLQI; Finlay & Khan, 1994)

Measuring HRQoL over the previous week in patients with skin diseases, the DLQI was

developed as a simple and practical instrument for use in dermatology clinical settings to assess limitations related to the impact of skin disease (Finlay & Khan, 1994).

It is a compact, self-reported questionnaire with ten items based upon the most commonly identified impacts upon dermatology-specific HRQoL, that were elicited from patients with skin disease. It contains six subscale scores: symptoms and feelings; daily activities; leisure; work/school; personal relationships; and treatment.

The DLQI is the most used and validated instrument in psoriasis, and has been used in several studies of PsA to consistently show discriminant ability (Mease et al., 2004). Reliability figures ranging between 0.62 – 0.92 have been demonstrated (Shikiar et al, 2003).

Table 5.6: Summary of measures for psoriasis

NAME	Psoriasis Index of Quality of life	Psoriasis Life Stress Inventory	Psoriasis Disability Index	Psoriasis Area and Severity Index	Salford Psoriasis Index
ABBREVIATION	PSORIQoL	PLSI	PDI	PASI	SPI
OBJECTIVE	Measure impact of psoriasis on QoL	Assess psoriasis-related stress	Assess functional disability	Measures severity of psoriasis	Assesses current & historical psoriasis severity & psychosocial disability
DISEASE	Psoriasis	Psoriasis	Psoriasis	Psoriasis	Psoriasis
No. OF ITEMS	25	15	15		3
COMPLETION TIME	< 5 mins	> 5 mins	5 minutes		5 mins
POPULATION	Adult	Adult	Adults	Adult	Adult
ADMINISTRATION	Self	Self	Self	Clinician	Clinician
TIME RECALL	Present	Last 4 weeks	Last 4 weeks	Present	
ORIGINAL LANGUAGE	English	English	English	english	English
AUTHOR/S	McKenna et al.	Gupta & Gupta	Finlay & Kelly	Fredricksson & Pettersson	Kirby et al.

5.6 Outcome Measures in Rheumatology (OMERACT) and the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA)

In 1992, an informal, international network of clinicians and investigators in the field of rheumatology established a group known as OMERACT (Outcome Measures in Rheumatology Clinical Trials). The group's objective was to achieve consensus on a core set of measures that should be included in clinical trials in rheumatoid arthritis, however, their remit has since widened and is now focussed on developing outcome measures for a variety of disease domains (the group, now called Outcome Measures in Rheumatology, still uses the acronym, OMERACT).

Since 2003 several consensus exercises have been completed. Taylor (2005) reports that a list of twenty-six domains was produced following an initial literature review and email discussions amongst members of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA). Four contexts of measurement were identified:

1) Disease controlling antirheumatic therapy (DC-ART)
2) Symptom modifying antirheumatic drugs (SMARDS)
3) Rehabilitation
4) Clinical record keeping with each context scored separately.

The participants, all rheumatologists and/or members of the Classification of Psoriatic Arthritis (CASPAR) study, completed a Delphi consensus exercise whereby they were each asked to determine the relative importance of each domain by distributing one hundred points amongst as many, or as few, of the twenty six domains as they wished.

For DC-ART the highest scoring domains were actively inflamed joint count, radiological damage score, patient global assessment, pain, physical function, acute phase response and QOL. For SMARD, the high scorers were pain, patient global assessment, physical function, QOL and active joint count scores, whilst for clinical record keeping participants rated pain, patient global assessment and active joint count as important. Finally, six domains were of

note for rehabilitation – physical function, QOL, pain, patient global assessment, work limitations and work incapacity.

Taylor (2005) acknowledged that as the participants comprised rheumatologists, not only was the perspective of the patient excluded, but so too was a domain for psoriasis or skin assessment. However, this exercise did reduce the number of potential domains from twenty-six to approximately twelve; although there was insufficient consensus regarding which of the lower scoring domains should be included in a core set.

Following on from this, GRAPPA undertook a further exercise in order to achieve greater consensus on the domains and attempt identification of instruments for each domain (Gladman, 2005). In his paper, Gladman notes the advantage of discussing "these domains in a face to face meeting of rheumatologists, dermatologists and patients" (pg.113), but it is unclear how many individuals with PsA, if any, were included in the exercise. However, the resulting consensus on the domains necessary to evaluate patients with PsA included assessment of joint inflammation, biomarkers, imaging, other areas of inflammation and patient derived indicies, including pain, quality of life related to joint and skin disease, itching and function. Several other domains, including fatigue, were noted as requiring further research and evaluation.

Although the list was incomplete, the recommended measurement tools included the patient global VAS for pain, the SF-36 (Ware & Sherbourne, 1992a) and Dermatology Life Quality Index (DLQI; Finlay & Khan, 1994) for quality of life measures and the HAQ (Bruce & Fries, 2003) for physical function.

At the seventh meeting of OMERACT in 2004, the focus was on outcome measures for PsA, with the workshop based on information obtained from the previous two consensus exercises carried out through GRAPPA (Gladman et al., 2005). This conference resulted in a list of proposed domains, that in addition to the requisite clinical response measures, included the assessment of pain, physical function, quality of life, fatigue and participation ("the capacity to engage meaningfully and capably in activities of life" (Mease et al., 2005, ii51).

The HAQ (Bruce & Fries, 2003) is the 'gold standard' accepted by the Outcome Measures in Rheumatoid Arthritis Clinical Trials (OMERACT) conference committees and the US Food and Drug administration.

The psychosocial domains highlighted by OMERACT are generally supported by the current qualitative study, although this has additionally identified emotions, treatment experience and coping as potential areas for assessment. In this study, fatigue was clearly identified by patients as a key factor so was included within the domain of functionality, so it is of note that OMERACT has also identified fatigue and has recommended that further research be undertaken to establish its impact and identify possible outcome measures.

Identifying appropriate and valid outcome measures for use in studies of PsA is particularly challenging given that it is a complex, multi-faceted condition that has both rheumatic and dermatological consequences for patients – indeed, this may account for the paucity of studies exploring the psychosocial impact of the disease.

5.7   Summary

Research within the field of rheumatology, particularly rheumatoid arthritis, has identified the important role that psychological and social factors may play in an individual's adaptation and response to rheumatic disease. It suggests that in future it may be necessary to broaden patient consultations to encompass more detailed psycho-social information as the use of appropriate measurement instruments can provide useful information regarding an individual's response to their illness and facilitate discussions on adaptation.

Estimated to occur in up to thirty percent of people with a diagnosis of psoriasis, psoriatic arthritis is a complex, multi-faceted condition meaning disease outcome in arthritis is multi-dimensional and requires assessment across a number of domains including quality of life, pain, fatigue, functionality and ability to work.

The introduction of new therapies, such as biologics, may be a cause for patient optimism as they have been shown to improve the debilitating physical symptoms associated with PsA. Such advancements highlight the need for a consensus regarding the domains to be measured, along with a core set of standardised and validated instruments, for, as Mease & Menter (2006) suggest, it is now vital that researchers be able to accurately assess these improvements.

In the current study, the qualitative results identified, from the patients' perspective, key constructs of pain, function, fatigue, depression and coping that warrant further exploration.

Following a brief review of the outcome measures that have previously been used with either psoriasis or PsA patients, it is apparent that a mixture of both generic and disease specific measures are required to establish the impact of these conditions on a patient's quality of life. Whilst the need to obtain meaningful information that is both valid and reliable remains fundamental to health research, this should not result in patients being burdened with numerous and lengthy questionnaires.

Guided by these requirements, it seems appropriate that the author's quantitative study exploring the role and impact of psychosocial issues in psoriasis and PsA, should utilise the SF-36 (Ware & Sherbourne, 1992a) as this will provide a broad picture of health-related QoL as this instrument measures not only functional status, but also well-being and general perceptions of health. Although the SF-36 (Ware & Sherbourne, 1992a) incorporates a subscale for bodily pain, two numeric rating scales (NRS) will be included to further assess the impact of pain. The DLQI (Finlay & Khan, 1994) will assess the impact of the skin element.

Given the strong credentials of the HAQ-DI (Bruce & Fries, 2003) its inclusion in the study is warranted, not least because it will allow for comparisons across other diseases. It is also of note that in their 2004 review of measures, Gladman et al. (2004) suggest that, as the HAQ (Bruce & Fries, 2003) measures physical function and pain, it should be included as an outcome measure in PsA clinical trials. This choice is particularly pertinent given that the

HAQ (Bruce & Fries, 2003) has recently become the 'gold standard' accepted by the OMERACT conference committees and the US Food and Drug administration.

The emergence of fatigue as an important factor for PsA patients necessitates that future studies consider the role it plays, indeed Mease et al., (2005) note that those patients prescribed the newer biological agents often report that fatigue is one area that shows significant improvement. Given that the Fatigue Severity Scale (FSS; Krupps et al, 1999) has previously been used with this patient group, it was proposed that this nine-item measure be included in the study.

Unfortunately, no studies exploring psychosocial issues in PsA were identified that had specified coping as an outcome measure. However, in RA studies research has found that passive coping is associated with greater pain, disability and depression, and active coping is associated with less pain, disability and depression (Brown et al., 1987). Furthermore, a study by Snow-Turek (1996) reported that active coping accounted for a smaller percentage of variance in relation to pain than passive coping and that passive coping was strongly related to general psychological distress and depression. Similarly, in a study of RA patients, the frequent use of passive pain coping strategies in the face of high pain contributed to the most severe level of depression over time (Brown et al., 1989).

Such findings may imply there is benefit to be gained by focusing attention on reducing passive coping rather than increasing active coping, but perhaps more importantly they provide evidence that coping impacts on disability and psychological health and may therefore warrant exploration and measurement in patients with PsA. However, given the lack of evidence for a suitable coping measure, the current study will utilise a self-efficacy measure – a factor that has been implicated in an individual's ability to cope.

As both PsA and psoriasis are considered chronic diseases, a brief 6-item scale, the Self-Efficacy for Managing Chronic Diseases Scale, will be employed (Lorig et al., 2001).

Following identification of suitable outcome measures, a questionnaire booklet was developed.

Chapter 6 outlines in detail, the design, methodology, analysis and results of the quantitative study.

CHAPTER 6

STUDY 2

6.1   Introduction

Study 1 employed qualitative methodology to gain an understanding of the lived experience of people with psoriasis and PsA and identified a number of psychosocial issues that they perceived impacted on their lives, specifically, pain, fatigue, depression and functionality. The generalisation of these findings is limited as they were drawn from interviews with a small sample of patients, meaning there is a need to quantitatively assess these issues in a larger sample and explore whether the results are consistent.

There are very few studies available which explore and compare health-related quality of life in patients with both psoriasis and PsA, and indeed none where the choice of quantitative measures has been initially patient-driven and based on qualitative data collected from patient interviews. Although none of the previous studies include all the variables that were identified by the patients in Study 1 as being important, several do include and measure one or more. For example, a Swedish study that used the DLQI and SF-36 to undertake a comparison between patients with psoriasis and those with psoriasis and PsA, concluded that individuals with a diagnosis of both conditions had significantly poorer HRQoL than those with just psoriasis (Lundberg et al., 2000), whilst a study by Husted et al., (2001) employed the SF-36 and the HAQ to compare HRQoL between patients with PsA and RA, and found that PsA patients reported greater role limitations, caused by emotional problems, as well as more bodily pain. In a subsequent study, Husted et al., (2009) determined that fatigue was associated with pain, physical functional disability and psychological distress, as measured by the modified Fatigue Severity Scale, SF-36 and the HAQ.

Given such results, and the findings of the current qualitative study, combined with research evidence that has emerged from other musculoskeletal diseases such as RA, which suggests, for example, that fatigue is not only significantly related to depression and anxiety (Lorish et

al., 1991), but to a large extent can be explained by pain, and self-efficacy (Riemsma et al., 1998) it is clear there is a need to assess the role of psychosocial issues and the burden they may have in patients with PsA and psoriasis.

Some of the symptoms associated with disease that reflect the impact it has on everyday life, are only known to the patient, and can therefore only be reported by the patient, consequently, patient-reported assessments of both the physical and mental burden of a disease are vital components in monitoring both the progression of disease and the effectiveness of treatments. With due acknowledgement of this, Study 2 sets out to address the gap in the current research, by utilising a broad selection of psychosocial measures with these two clinical populations, this is unlike previous studies which have tended to target a limited selection of variables or have been concerned only with clinical outcomes.

6.2   Clinical Populations

In order to obtain the clinical populations required for this study, participants were recruited from two different sources – a hospital rheumatology clinic, that was a recognised Centre of Excellence and The Psoriasis Association, a self-help group that operates predominantly online.

The Psoriasis Association was founded in 1968 by Dr Dick Cole, a Consultant Dermatologist in Northamptonshire, and is the leading national membership organisation for people affected by psoriasis – patients, families, carers and health professionals. The Association strives to support people who have psoriasis, raise awareness about the condition and also funds research into the causes, treatments and care of psoriasis. They achieve this through various means, including operating a helpline, maintaining social networking sites, providing information via their website, leaflets, CDs, quarterly journals, conferences and by providing grants for research (www.psoriasis-association.org.uk).

A consequence of recruiting from the Association is that the sample is drawn from an online support group. This may result in the participants having very different characteristics to the

group from secondary care, particularly as self-help groups are designed to develop and reinforce positive coping styles which are known to be associated with improvements in both medical and social outcomes (Idriss et al., 2009). Furthermore, there is an expanding body of research (for example, Shaw & Grant, 2002; van Uden-Kraan, 2008) that has found patients who have a deeper understanding of their diagnosis, treatment, and recovery, and who have support from others, are better equipped to cope with the illness, use the health system more effectively and change their health-related behaviours to influence their course of illness and reduce psychological distress.

Whilst there are very few studies available that have attempted to determine the demographics and experiences of online support users amongst dermatology patients, a recent study, exploring the role of online support to patients with psoriasis, reported that respondents to the study were primarily middle-aged, white, college educated (84%) with a mean age of 40.1 years (Idriss et al, 2009). Such information may offer a useful comparison when exploring the data for the psoriasis population in the current study.

The following study aimed to extend the findings of the qualitative study and quantitatively measure Pain, Fatigue, Self Efficacy, Physical and Social Function and the impact of skin disease and explore their impact on the participants, and thus explore the roles of the psychosocial variables that were initially identified through the comprehensive descriptions provided by the patients and their lived experience of PsA and psoriasis. In the light of participants being recruited from two different settings, and having a diagnosis of either psoriasis or psoriasis with PsA, differences in the self-reported levels of psychosocial variables were explored, as were the relationships that existed between them.

6.3 Design

This study employed a cross-sectional, postal survey and comprised an A4-size questionnaire booklet that was compiled using seven standard, self-report scales and a demographic data sheet, all of which are detailed in section 6.4.

6.4   Participants

The criteria for inclusion into the study was that participants be aged 18+ and have a new or existing diagnosis of psoriatic arthritis and/or psoriasis.

Participants were recruited from two establishments, The Psoriasis Association and the Rheumatology Clinic at Aintree Hospital, Liverpool. A total of 357 completed questionnaires were received.

As Table 6.1 shows, an overall response rate of 30% was obtained, although when analysed by the two different groups, the Psoriasis Association achieved a response rate of 31.6% compared to 22% recorded by the hospital group.

Table 6.1: Postal Questionnaire Response Rates

	Posted	Returned	Response Rate %	Useable Questionnaires
Psoriasis Association	1000	316	31.6%	313
Aintree Hospital	200	44	22.0%	44
TOTAL	**1200**	**360**	**30.0%**	**357**

Following data screening and tests for normality, 5 cases were deleted resulting in the two groups being represented as shown in Table 6.2:

Table 6.2: Useable Questionnaires following Normality Tests

	N	% of total
Psoriasis Association	310	88.1
Aintree Hospital	42	11.9
TOTAL	**352**	**100**

6.5 Variables and Measurement Tools

The questionnaire booklets comprised a demographics questionnaire, information sheet, consent form and standardised measurement instruments as detailed below (see Appendix 4):

6.5.1 Physical and Mental Health (The Medical Outcomes Study Short–Form Health Survey (SF–36®); Ware & Sherbourne, 1992a)

The SF-36® is a 36-item, self-administered questionnaire designed to assess generic HRQoL (Ware & Sherbourne, 1992a). It measures health across eight dimensions, including 4 domains of physical health (physical functioning, bodily pain, role limitations due to physical problems, and general health perceptions) and 4 domains of mental health (social functioning, role limitations due to emotional problems, mental health, and vitality-energy/fatigue). The scoring method for these domains is detailed in the SF-36® manual (Ware & Kosinski, 2002). Responses to items within each dimension are summed to produce a health profile of eight scores, these scores are then transformed into standard scores ranging from 0 (worst health status) to 100 (best health status). The standardised scores are then calculated to form physical component (SF-36® PCS) and mental component (SF-36® MCS) summary scores.

Table 6.3 details the SF-36 population norms for a large, community sample of participants with no long-standing illness. The norms were reported in a study by Jenkinson et al, (1993) who used postal survey data gained from the Oxford Healthy Life Survey. The data were also used to calculate MCS and PCS norms in a later study (Jenkinson et al., 1999).

The table also shows the Mean scores achieved on the SF-36 by PsA patients in a study that compared HRQoL between PsA and RA patients (Husted et al., 2001). Additionally, the Mean scores obtained by psoriasis patients in a HRQoL study (Lundberg, et al., 2000) are presented.

This measurement tool has strong internal consistency, with reliability estimates for PCS and MCS usually exceeding 0.90 (Ware et al., 1990). In the current study a reliability figure of 0.88 was obtained.

Table 6.3: **SF-36 Norms (and SD where available) for 3 different populations - healthy (Jenkinson, et al., 1993; 1999), PsA (Husted et al., 2001) & Psoriasis (Lundberg et al., 2000)**

Study Population	SF-36 Measure									
	MCS	**PCS**	**PF**	**SF**	**RP**	**V**	**MH**	**RE**	**BP**	**GHP**
Healthy	51.28 (9.01)	53.64 (5.88)	92.5 (13.4)	91.3 (15.8)	91.4 (23.2)	64.0 (18.2)	75.4 (16.3)	25.6 (29.3)	86.3 (17.9)	78.8 (15.7)
Psoriasis with PsA	50.0	42.1	67.0	80.7	62.6	56.2	72.7	68.5	60.5	58.8
Psoriasis	44.7 (11.9)	44.7 (12.2)	77.2 (25.3)	80.8 (25.1)	64.5 (41.3)	54.7 (24.1)	71.1 (19.8)	67.0 (42.6)	62.7 (29.8)	60.7 (23.9)

6.5.2 Fatigue (Fatigue Severity Scale (FSS); Krupps et al., 1989)

The FSS (Krupps et al., 1989) is a brief, 9-item, general fatigue scale measuring the characteristics and consequences of fatigue during the preceding week. Respondents rate how strongly they agree or disagree with 9 statements (e.g. 'Exercise brings on my fatigue') on a scale ranging from 1 ("completely disagree") to 7 ("completely agree"). The 9 scores are summed and a mean score calculated, with higher scores indicative of more severe fatigue. Krupp et al., (1989) have reported that the Norm for normal healthy adults is a Mean of 2.3 (SD ± 0.7). In the current study, the Mean was 3.83.

It has been shown to be valid in healthy controls and in those with PsA and other various chronic conditions, including systemic lupus erythematosus (SLE), fibromyalgia, cancer, and Parkinson's disease (Krupp et al., 1990; Giovannoni et al., 2001; Stone et al., 2000; Shulman et al., 2000).

The measure has good test-retest reliability and has demonstrated strong internal consistency across different patient groups, for example 0.89 (SLE patients), 0.81 (multiple sclerosis) and 0.88 in normal healthy adults (Krupp et al., 1989). In the current study, the FSS showed strong internal consistency ($\alpha = 0.95$).

6.5.3 Self-efficacy (Self-efficacy for Managing Chronic Diseases (SEMCD); Lorig et al., 2001)

The SEMCD is a 6-item scale that contains questions taken from several self-efficacy measures that were developed for use in the Chronic Disease Self-management Study (Lorig et al., 2001). The measure covers several domains that are common across many chronic diseases - symptom control, role function, emotional functioning and communicating with physicians.

In response to statements such as, "How confident are you that you can keep the fatigue caused by your disease from interfering with the things that you want to do?" respondents rate their current level of confidence on a scale consisting of a series of numbers ranging from 0 to 10. The ends of the scale were anchored with the words "not at all confident" (1) and "totally confident." (10). The score for the scale is the mean of the six items with a higher number indicating higher self-efficacy.

Lorig and her colleagues (2001) tested the measure on 605 patients with chronic disease and reported a mean score of 5.17 (SD = 2.22) and an internal consistency reliability figure of 0.91. In the current study the Mean score for the total sample was 7.04 and for the PsA-only group was 5.96, whilst the Chronbach's α of 0.88 demonstrated very good reliability.

6.5.4 Skin Disease and Health-Related QOL (Dermatology Life Quality Index (DLQI); Finlay & Khan, 1994)

The DLQI, developed by Finlay & Khan (1994), is designed to assess the impact of a wide rage of skin disease on patient health-related quality of life (HRQoL). It consists of ten items (e.g. item 1 reads 'over the last week how itchy, sore, painful or stinging has your skin been?') and covers six domains including symptoms and feelings, daily activities, leisure, work and school, personal relationships and treatment. The response categories are "not at all", "a little", "a lot" and "very much", with corresponding scores of 0, 1, 2 and 3 respectively; the response "not relevant" and any unanswered items are scored as "0". The total score is calculated by

summing the scores of all items. The DLQI score ranges from 0-30, (with 30 representing the worst quality of life and 0 the best). Scale scores may be calculated for each domain. Higher scores indicate poorer HRQoL and therefore more impairment (Finlay & Khan, 1994).

A study assessing the validity of the DLQI in 147 patients diagnosed with moderate to severe psoriasis reported a Mean score of 12.71 (SD = 7.18). (Shikiar et al, 2006), whilst in a study of 162 PsA patients evaluating the effects of a treatment (Adalimumab) on patient-reported outcomes of joint-related and skin-related functional impairment, health-related quality of life, fatigue and pain, a mean score of 10.3 (± 7.5) was reported.

Reliabilty figures ranging between 0.86- 0.92 have been demonstrated (Shikiar et al., 2003). In the current study the DLQI demonstrated very good reliability ($\alpha = 0.87$).

6.5.5 Functional Ability (The Health Assessment Questionnaire Disability Index (HAQ-DI); Bruce & Fries, 2003)

The disability assessment component of the HAQ, the HAQ-DI assesses a patient's level of functional ability. The HAQ-DI comprises 20 questions in eight categories of functioning, each of which has at least two component questions. The categories represent a comprehensive set of functional activities - dressing and grooming, arising, eating, walking, hygiene, reach, grip and common daily activities (Bruce & Fries, 2003).

The stem of each item asks over the past week, "Are you able to…" perform a particular task. For each item there is a four-level difficulty scale – without ANY difficulty (0), SOME difficulty (1), MUCH difficulty (2) and UNABLE to do (3). The highest component score in each category determines the score for the category, unless aids or devices are required. When aids or devices or help are indicated by the patient, the score for the category item is raised from a 0 or a 1, to a 2, but if the patient's highest score for that sub-category is a 3, it stays a 3. When there are no aids, devices or help indicated for a category, the category score is not modified. In order to compute the HAQ-DI score (one cannot be calculated unless at least 6 of the 8 categories have been completed), the categories are summed and divided by the number

of categories answered (which must be 6, 7 or 8). A complementary scoring method ignores scores for aids, devices or help when computing the category scores and represents residual disability after compensatory efforts. In either case, this yields a single disability index score from 0-3, with 0 indicating no functional disability and 3 indicating severe functional disability (Bruce & Fries, 2003).

In one study examining the safety, efficacy and effect of treatment in patients with PsA and psoriasis, the HAQ-DI was used and at baseline, a Mean score of 1.1 was obtained (Mease et al., 2004).

The HAQ-DI has been validated in numerous studies and disciplines and repeatedly shown face and content validity via comparison with other instruments in multiple disease conditions. Construct/convergent and predictive validity have also been established in a plethora of observational and clinical trials (Bruce & Fries, 2003). Furthermore, it has been validated in PsA by Husted and colleagues (1995; 1998) for face and content validity, and for responsiveness to disease state. In the current study the Chronbach's α obtained was 0.97.

6.5.6 Depression (The Hospital Anxiety and Depression Scales (HADS); Zigmond & Snaith, 1983)

The HADS, developed by Zigmond & Snaith (1983), is a 14-item scale designed to detect anxiety and depression, independent of somatic symptoms. The 14 items create two subscales, with 7 of the statements relevant to generalised anxiety, and 7 to depression, the latter being largely (but not entirely) composed of reflections of the state of anhedonia (inability to enjoy oneself or take pleasure in everyday things enjoyed normally).

The patient rates the statements, based on their experience over the past week, using a 4-point response scale (with 0 representing absence of symptoms, to 3 representing maximum symptomatology), with possible scores for each subscale ranging from 0-21. Scores of 0-7 on either subscale are considered 'normal', 8-10 represents 'borderline' or 'possible' case of depression/anxiety whilst 11 or more indicates probable case psychological morbidity.

Given the HADS uses cut-off points to establish the possible presence of mood disorders, population norms are not generally used, however, a Mean score of 9.3 (± 4.9) on the Anxiety subscale and 4.8 (± 3.7) on the Depression subscale was found in one study of psoriasis patients (N = 115) that assessed the significance of general and psoriasis-specific psychological variables in predicting psoriasis-related disability (Richards, Fortune, Griffiths & Main, 2001). Furthermore, a study exploring the long-term outcomes of an arthritis self-management programme (N = 112) reported Means of 9.37 (± 4.44) and 6.77 (±3.83) on the Anxiety and Depression subscales respectively (Barlow, Turner & Wright, 1998).

Zigmond & Snaith (1983) have demonstrated item correlation and comparison with psychiatric ratings and have shown both subscales to be discriminately valid. In the current study the measure demonstrated very good reliability ($\alpha = 0.88$).

6.5.7   Pain (Numerical Pain Rating Scales (NPRS); Downie et al., 1978)

The Numerical Pain Rating Scale is a single item scale that uses a 0 (no pain) to 10 (worst possible pain) rating scale (Hartrick et al., 2003). It is a short, valid, frequently used scale, which is easy to complete and interpret.

Two NPRS were used:
- 'Please rate the average level of pain you are experiencing TODAY'
- 'Please rate the average level of pain you have experienced during the LAST WEEK'.

Each consisted of a series of numbers ranging from 0 to 10. The ends of the scale were anchored with the words "no pain" and the "worst pain possible." The patient chooses the number that best corresponds to the level of pain he or she is experiencing.

In a study of 269 psoriasis patients that explored skin-pain and discomfort, a Mean pain symptom intensity score of 4.4 was reported (Ljosaa et al., 2010), whilst a score of 6.42 (± 2.60) was found in a population of arthritis patients (Barlow, et al., 1998).

The Pain NRS has shown good reliability (0.79 – 0.95) when correlated with the pain Visual Analogue Scale (VAS) and other pain measurement instruments, such as the McGill Pain Questionnaire. It has also demonstrated moderate to high (0.67 - 0.96) test-retest reliability (Kahl & Cleland, 2005).

6.5.8   Demographic Sheet

A demographic data sheet was used to collect information including age, gender, marital status, employment, education, ethnicity, duration of disease and treatment (see Appendix 4).

6.5.9   Consent Forms

Two copies of a consent form were included in the pack with instructions that the patient should sign both, retain one for their own records and return the other with the completed questionnaire, using the Freepost envelope that was also provided, to the researcher. (See Appendix 4).

6.5.10   Participant Information Sheet

The final inclusion was a Participant Information Sheet detailing the purpose of the study, the participant's right to withdraw at any time and also the contact details for the researcher. (See Appendix 5).

6.6   Pilot Study

In order to identify any potential difficulties with the questionnaire booklet, a pilot study was undertaken.

Opportunity sampling was used to recruit 8 participants from the hospital Rheumatology Clinic. Having explained the purpose of the study and obtained informed consent, the researcher requested that they complete the questionnaires. All the participants chose to read

and undertake the questionnaire whilst sitting in the clinic waiting room and when finished, returned them to the researcher.

No obvious problems were identified.

6.7   Procedure

A total of 1000 paper questionnaire packs were delivered to The Psoriasis Association office and a member of their staff labelled the envelopes and posted the questionnaires. In order to recruit participants from across the country, the staff member chose various counties and mailed out to members of the association within each chosen county.

Participants from Aintree Hospital were all registered as patients with a diagnosis of psoriatic arthritis (PsA) and were attending the Rheumatology Clinic. Questionnaire packs were posted to 200 patients.

Response rates are detailed in section 6.3.

6.8   Data Analysis

All data were entered into and managed via SPSS software for Windows version 13.0 (© SPSS Inc., Chicago, Illnois, 2005).

Whilst coding the data it became apparent that some participants responded to the question regarding treatment and medications by itemising numerous brands of topical creams, painkillers etc so a decision was taken to categorise the medications in a hierarchical fashion that reflected the strength or stages of medication used (moisturisers being the mildest and biologics being the strongest). A rheumatology clinical specialist assisted in categorising all the different treatments mentioned by respondents. The following categories and codes were utilised:

0 = No treatment	3 = Oral steroids	6 = Biologics
1 = Moisturisers	4 = Analgesics	
2 = Topical steroid creams	5 = DMARD's	

In cases where respondents listed multiple treatments that fell into different categories, the highest category was taken as their answer, for example, if a respondent used a topical steroid cream, oral steroids and DMARD's then a '5' (DMARD's) was used as their response.

6.8.1   Data screening and normality tests

Box plots for all the study variables were inspected and several outliers were identified, specifically with the HAQ-DI sub-scales of Arising, Eating, Grip, and Walking and also with the HAD sub-scales of Anxiety and Depression.

All the variable scores were transformed into Z-scores and any cases with scores >3.25 were identified and subsequently deleted. This resulted in the loss of 5 cases, reducing the total sample size to 352.

Prior to conducting descriptive analysis, the data were initially categorised into 2 separate groups of participants depending on the source of their recruitment, that is, one group of participants drawn from the hospital, and the other from the Psoriasis Association, in order to establish if any differences existed. Given that the demographic data suggested these two groups were similar, the total sample was then split into two 'disease groups' comprising participants who had psoriasis (Psoriasis Group) and those that had a dual diagnosis of psoriasis and PsA (Psoriasis with PsA Group), which enabled the impact of the psychosocial variables on each group to be established.

6.8.2 Descriptive Analysis

For each questionnaire, the Mean and Standard Deviation (SD) were computed, and where appropriate, independent t-tests were calculated to explore the differences in the means between the groups of participants.

One-sample t-tests were also conducted to compare the Means obtained in the current study with those from other known populations, to determine if any significant differences existed.

As previously stated, because the data were collected from participants drawn from two distinct sources – The Psoriasis Association and Aintree Hospital, Liverpool – it was initially examined by categorising participants into these two 'recruitment groups' to establish whether any differences existed between the two. Following this, descriptive, and subsequent analysis, were conducted once the participants were categorised into two groups that reflected whether participants had psoriasis or both psoriasis and PsA ('both conditions').

6.8.3 Correlations

Pearson's correlation matrix was used to establish the bivariate correlations between all the psychosocial and demographic variables.

The strength of the correlation coefficients were interpreted using Coolican's (2004) recommendations as a guide: 0 = no relationship, .2 = weak relationship, $\geq$ .4 to .7 = moderate relationship, $\geq$ .8 = strong relationship, 1 = perfect relationship.

Comparison of the correlation coefficients was undertaken to determine whether any of the differences were significantly different.

6.9 Results

6.9.1 Descriptives

The study population comprised adults with psoriasis, psoriatic arthritis (PsA) or both and were recruited from two organisations – The Psoriasis Association and Aintree Hospital, Liverpool. The ethnic origin of the sample was almost entirely white (98.9%) with only 4 participants declaring different ethnicity.

Of the 352 participants, 88.1% (310) were drawn from the Psoriasis Association, with the remaining 42 recruited from Aintree Hospital.

6.9.2 Descriptives by 'Recruitment Group'

As can be seen from Table 6.4 there is similarity between the two recruitment groups in terms of gender, age, and marital status. In fact, there was an almost even split in terms of gender with 178 females (50.6%) and 174 males (49.4%), whose ages ranged from 20 years to 87 years with a mean of 57.10 (SD = 14.30). It is worth noting that the broad range of ages was largely due to two participants reporting ages of 87 years (Psoriasis Association) and 79 years (Hospital Group), however, the mean ages in each group were similar at 57.56 (Psoriasis Association) and 53.67 (Hospital Group).

Table 6.4: Gender, Age and Marital Status displayed by Recruitment Group

	Total Sample N = 352	Psoriasis Association Group n = 310	Hospital Group n = 42
n (% of total n)	352 (100%)	310 (88.1%)	42 (11.9%)
Males (% of group)	174 (49.4%)	152 (49.0%)	22 (52.4%)
Females (% of group)	180 (50.6)	158 (51.0%)	20 (47.6%)
Age (years)			
Mean (SD)	57.10 (14.24)	57.56 (14.64)	53.67 (11.03)
Minimum	20	20	33
Maximum	87	87	79
Range	67	67	46
Marital Status (% of group)			
Married	222 (63.2%)	194 (62.8%)	28 (66.7%)
Single	59 (16.8%)	52 (16.8%)	7 (16.7%)
Divorced	33 (9.4%)	28 (9.1%)	5 (11.9%)
Cohabiting	24 (6.8%)	23 (7.4%)	1 (2.4%)
Widowed	13 (3.7%)	12 (3.9%)	1 (2.4%)
Missing data	1 (0.3%)	1 (0.3%)	0

The majority of the sample, 63%, was married, and this figure was fairly evenly replicated in the Psoriasis Association (63%) and Hospital group (67%).

Table 6.5 shows that the Mean disease duration for participants with psoriasis in the Psoriasis Association Group was 30.72 years (SD = 16.91), whilst for those in the Hospital Group it was 22.87 years (SD = 16.22). Of those in the Association Group, 91% report using some form of treatment, with the use of topical steroid creams reported by almost 57% of participants. Almost 55% of the Hospital Group reported using a treatment, of which 31% used moisturisers and 19% used topical steroid creams.

For participants with PsA, the Mean disease duration for those in the Association Group was 3.98 years (SD = 9.08), with almost 79% using no treatments. Conversely, for those in the Hospital Group the Mean disease duration was 11.89 years (SD = 10.97) with 96% reporting the use of some form of medication.

Table 6.5: Disease Duration and Treatment displayed by Recruitment Group

	Total Sample N = 352	Psoriasis Association Group n = 310	Hospital Group n = 42
PsA Disease Duration (years)			
Mean (SD)	4.88 (9.55)	3.98 (9.08)	11.89 (10.97)
Minimum	0	0	1
Maximum	50	50	50
Psoriasis Disease Duration (years)			
Mean (SD)	29.86 (16.99)	30.72 (16.91)	22.87 (16.22)
Minimum	0	0	0
Maximum	80	80	60
Current PsA Treatment			
No Treatment	246 (70.1%)	244 (78.7%)	2 (4.9%)
Topical steroid creams	3 (0.9%)	3 (1.0%)	0
Oral steroids	6 (1.7%)	4 (1.3%)	2 (4.9%)
Analgesics	30 (8.5%)	28 (9.0%)	2 (4.9%)
DMARD's	57 (16.2%)	26 (8.4%)	31 (75.6%)
Biologics	9 (2.6%)	5 (1.6%)	4 (9.8%)
Missing data	1 (0.3%)	0	1 (2.3%)
Current Psoriasis Treatment			
No treatment	46 (13.1%)	27 (8.7%)	19 (45.2%)
Moisturisers	85 (24.1%)	72 (23.2%)	13 (31%)
Topical steroid creams	184 (52.3%)	176 (56.8%)	8 (19%)
Oral steroids	1 (0.3%)	1 (0.3%)	0
Analgesics	5 (1.6%)	5 (1.6%)	0
DMARD's	25 (7.1%)	25 (8.1%)	0
Biologics	5 (1.4%)	4 (1.3%)	1 (2.4%)
Missing data	1 (0.3%)	0	1 (2.4%)

As displayed in Table 6.6, full-time employment was reported by almost 40% of the Association Group and 39% were retired, with 2 participants (0.6%) claiming they were unable to work due to psoriasis and a further 8 participants (2.6%) unable to work due to PsA. Within the Hospital Group, 45% were employed full-time whilst 21% were retired. Whilst no participants stated that they were unable to work due to psoriasis, 11.9% of participants (5) were unable to work due to PsA.

Of the total sample, 18.2% had no educational qualifications; In the Association Group this accounted for 17% of participants, whilst in the Hospital Group the figure was 26%. When combined, Graduate and Postgraduate qualifications were obtained by 15.5% of those in the Association Group, whilst for those in the Hospital Group the figure was 4.8%.

Table 6.6: Employment and Qualification details displayed by Recruitment Group

	Total Sample N = 352	Psoriasis Association Group n = 310	Hospital Group n = 42
Employment status			
Full time	141 (40.1%)	122 (39.4%)	19 (45.2%)
Part time	41 (11.6%)	36 (11.6%)	5 (11.9%)
Unemployed	5 (1.4%)	4 (1.3%)	1 (2.4%)
Homemaker	16 (4.5%)	13 (4.2%)	3 (7.1%)
Student	2 (0.6%)	2 (0.6%)	0
Semi-retired	1 (0.3%)	1 (0.3%)	0
Retired	131 (37.2%)	122 (39.4%)	9 (21.4%)
Unable to work due to PsA	13 (3.7%)	8 (2.6%)	5 (11.9%)
Unable to work due to Psoriasis	2 (0.6%)	2 (0.6%)	0
Qualifications			
None	64 (18.2%)	53 (17.1%)	11 (26.2%)
CSE/'O' Level/ GCSE	86 (24.1%)	70 (22.6%)	16 (38.1%)
'A Level/GNVQ/NVQ/City & Guilds	90 (25.6%)	79 (25.5%)	11 (26.2%)
Graduate	58 (16.5%)	58 (18.7%)	0
Postgraduate	50 (14.2%)	48 (15.5%)	2 (4.8%)
Missing data	4 (1.1%)	2 (0.6%)	2 (4.8%)

For the total sample, Mean and Standard Deviation statistics for all the measures are presented in the following table (Table 6.7) and include the 'Total' scores for Fatigue and Self-efficacy, although for these two measures it is the Mean scores (Mean total ÷ number of items on the measure) that are utilised for analysis purposes.

Table 6.7: Means and Standard Deviations (and minimum and maximum scores) for all measures for total sample

Measure (n = 352)	Mean	Standard Deviation	Minimum score	Maximum score
Fatigue (Mean of total score)	33.94	15.61	9	63
Fatigue (Mean of Item Scores)	3.77	1.73	9	63
Self Efficacy	42.50	12.49	6	60
Self Efficacy (Mean of Item Scores)	7.08	2.08	6	60
HADS - Anxiety	6.60	4.09	0	18
HADS - Depression	3.77	3.13	0	14
DLQI total	6.16	5.55	0	24
Current Pain NRS	2.97	2.37	1	10
Pain Last Week NRS	3.23	2.50	1	10
HAQ total score	.39	.60	0	2.50
SF- 36 PCS	44.31	13.46	7.33	71.30
SF 36 - MCS	46.47	13.77	6.35	71.30

In Table 6.8 the Mean scores for the measures are shown by Recruitment Group and indicate that the Hospital Group, all of whom had PsA, fare less well on every measure with the exception of the Dermatology Quality of Life Index (DLQI). Although the scores for all the SF36 components (shown in Table 6.9) are lower in the Hospital Group, this is due to the scoring method, whereby lower scores equate to greater impairment of quality of life.

Table 6.8: Means and Standard Deviations for measures displayed by Recruitment Groups

Measure	Psoriasis Association n = 310	Hospital Group n = 42
Fatigue (Mean of total score)	32.89 (15.18)	41.71(16.70)
Fatigue (Mean of Item scores)	3.65 (1.68)	4.63 (1.85)
Self Efficacy (Mean of total score)	43.49 (12.29)	35.16 (11.61)
Self Efficacy (Mean of item scores)	7.25 (2.04)	5.86 (1.94)
HADS - Anxiety	6.49 (4.07)	7.29 (4.23)
HADS - Depression	3.54 (3.03)	5.29 (3.43)
DLQI total	6.42 (5.57)	4.64 (5.30)
Current Pain NRS	2.67 (2.20)	5.19 (2.55)
Pain Last Week NRS	2.89 (2.33)	5.70 (2.37)
HAQ total score	.30 (.52)	.96 (.73)
SF- 36 PCS	46.05 (12.64)	33.57 (12.38)
SF 36 - MCS	46.81 (13.78)	42.99 (12.81)

Table 6.9: SF-36 Sub-scales Means and Standard Deviations displayed by Recruitment Groups

SF-36 Subscale (as %)	Psoriasis Association n = 310	Hospital Group n = 42	t-test result t (df = 350)	P value
GH	59.68 (23.76)	39.35 (25.64)	5.15	.000
BP	66.12 (22.41)	36.66 (19.71)	8.10	.000
PF	75.32 (28.29)	47.26 (29.34)	6.00	.000
RP	66.69 (41.53)	31.54 (42.07)	5.13	.000
V	55.66 (21.50)	41.42 (22.69)	3.99	.000
SF	73.40 (25.33)	56.08 (31.42)	3.42	.001
RE	75.91 (37.93)	57.93 (44.20)	2.51	.015
MH	70.06 (19.01)	65.04 (19.59)	1.59	.111

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6.9.2.1   T-tests for Recruitment Group

In order to test whether any of the Mean differences between the Psoriasis Association Group and the Hospital Group were significant, t-tests were conducted with the following results:

6.9.2.1.1   Fatigue

The fatigue Mean score for the Hospital Group was 4.63 (SD = 1.85) compared with a Mean of 3.65 (SD = 1.68) for those in the Psoriasis Association, representing a highly significant difference between the two groups, t (350) = -3.49, p = .001.

6.9.2.1.2   Self-efficacy

Self-efficacy was found to be significantly higher, t (350) = 4.14, p < .001, in the Association Group (M = 7.25, SD = 2.04) when compared with the Hospital Group (M = 5.86, SD = 1.94).

6.9.2.1.3   Anxiety and Depression

The mean scores for the Hospital Anxiety and Depression Scale (HADS) again demonstrate the Hospital Group reporting higher scores on both the anxiety and depression sub-scales.

The Hospital Group experienced higher levels of anxiety (M = 7.50, SD = 4.23) than those from the Association (M = 6.47, SD = 4.07, although the difference was not significant. However, the difference between the Hospital Group's Mean depression score (5.50, SD = 3.44) and the Association's Mean was highly significant (t (350) = - 3.87, p < .001).

6.9.2.1.4   DLQI

The Psoriasis Association Group achieved a higher Mean score (6.42, SD = 5.57) on the DLQI than the Hospital Group (4.64, SD = 5.30) which was a significant difference, t (350) = 2.59, p = .012.

6.9.2.1.5 Pain

The Hospital Group recorded higher Mean scores for pain. The results for 'Current Pain' show that the hospital patients' Mean of 5.19 (SD = 2.55) was higher than that of the Association Group (*M* = 2.67, SD = 2.20), which was a highly significant difference (t (350) = -6.92, *p* < .001.

Similarly, the Hospital Group mean for 'Average Pain Last Week' was 5.76 (SD = 2.29) compared to the Psoriasis Association mean of 2.89 (SD = 2.33), which was once again, a highly significant difference, t (350) = -7.49, *p* < .001.

6.9.2.1.6 HAQ

The Mean results for the total HAQ scores reflect the poorer function experienced by the Hospital Group (*M* = .96, SD = .73) compared to the Association Group (*M* =.30, SD = .52), which was a highly significant difference (t (350) = -6.16, *p* < .001).

Furthermore, the mean scores for all the sub-categories of the HAQ demonstrate that the Hospital Group reported greater difficulties with all types of function, with t-tests identifying all these differences as highly significant.

6.9.2.1.7 SF-36

In each of the eight sub-categories of the SF-36, the hospital participants are seen to report poorer quality of life than those participants drawn from the Psoriasis Association and once again, the t-tests identify all the differences as significant, with the exception of the Mental Health (MH) subscale.

When the sub-categories were combined to form the Physical Component Score (PCS) the difference between the Hospital Group (*M* = 31.88, SD = 12.76) and the Association Group

(M = 45.99, SD = 12.66, t (350) = 6.77, p < .001) was highly significant, suggesting that those in the Hospital Group experience decreased quality of life.

Although not a significant difference, the Mean scores on the MCS suggest that the Hospital Group endure increased mental health difficulties.

6.9.3 Descriptives by Disease Group (Psoriasis or Psoriasis with PsA)

Regardless of where the participants had been recruited from, the total sample of 352 participants were coded to form two groups – one consisting of participants with psoriasis (n = 225), and a second group consisting of those with both psoriasis and PsA (n = 127).

As can be seen from Table 6.10, the descriptive statistics for gender, age and marital status reflect those found when the data was explored by Recruitment Groups.

In the Disease Groups, both of which had a Mean age of 57 years, the percentage of males and females in each was very similar, with males accounting for 48.9% of the Psoriasis Group and 50.4% of the Psoriasis with PsA Group.

Table 6.10: Gender, Age and Marital Status displayed by Disease Group

	Total Sample N = 352	Psoriasis Group n = 225	Psoriasis with PsA Group n = 127
n (% of total n)	352 (100%)	225	127
Males (% of group)	174 (49.4%)	110 (48.9%)	64 (50.4%)
Females (% of group)	180 (50.6)	115 (51.1%)	63 (49.6%)
Age (years)			
Mean (SD)	57.10 (14.24)	57.07 (15.39)	57.15 (12.19)
Minimum	20	20	28
Maximum	87	87	86
Range	67	67	58
Marital Status (% of group)			
Married	222 (63.2%)	140 (62.2%)	82 (64.6%)
Single	59 (16.8%)	40 (17.8%)	19 (15.0%)
Divorced	33 (9.4%)	20 (8.9%)	13 (10.2%)
Cohabiting	24 (6.8%)	17 (7.6%)	7 (5.5%)
Widowed	13 (3.7%)	8 (3.6%)	5 (3.9%)
Missing data	1 (0.3%)	0	1 (0.8)

When examining the employment and qualification data by Disease Group, as shown in Table 6.11, the results are similar to that found in the Recruitment Groups, although it is of interest that 36% of the Psoriasis Group were either graduates or postgraduates, which is substantially higher than the 20% found in the group with psoriasis and PsA.

Table 6.11: Employment and Qualification details displayed by Disease Group

	Total Sample N = 352	Psoriasis Group n = 225	Psoriasis with PsA Group n = 127
Employment status			
Full time	141 (40.1%)	90 (40.0%)	51 (40.2%)
Part time	41 (11.6%)	26 (11.6%)	15 (11.8%)
Unemployed	5 (1.4%)	3 (1.3%)	2 (1.6%)
Homemaker	16 (4.5%)	12 (5.3%)	4 (3.1%)
Student	2 (0.6%)	2 (0.9%)	0
Semi-retired	1 (0.3%)	1 (0.4%)	0
Retired	131 (37.2%)	88 (39.1%)	43 (33.9%)
Unable to work due to PsA	13 (3.7%)	1 (0.4%)	12 (9.4%)
Unable to work due to Psoriasis	2 (0.6%)	2 (0.9%)	0
Qualifications			
None	64 (18.2%)	31 (13.8%)	33 (26.0%)
CSE/'O' Level/ GCSE	86 (24.1%)	51 (22.7%)	35 (27.6%)
'A Level/GNVQ/NVQ/City & Guilds	90 (25.6%)	61 (27.1%)	29 (22.8%)
Graduate	58 (16.5%)	43 (19.1%)	15 (11.8)
Postgraduate	50 (14.2%)	39 (17.3%)	11 (8.7%)
Missing data	4 (1.1%)	0	4 (3.1%)

For each of the disease groups, the disease duration and treatment types are presented in Table 6.12. The zeros recorded by the Psoriasis Group in the PsA Disease Duration and Treatment columns are to be expected as this group do not have a diagnosis of PsA. Of those in the Psoriasis and PsA Group, 16.5% reported having no current treatment, whilst 44.9% were taking DMARD's and a further 7.1% were receiving Biologic therapies. In this same group, 21.3% were having no treatment for psoriasis, whilst of those participants in the Psoriasis Group only 8.4% reported no current treatment for psoriasis, with almost 58% using topical steroid creams and 7.1% using DMARD's.

The Mean figures for psoriasis disease duration were similar for both the Psoriasis Group (30.69 years) and for the Psoriasis with PsA Group (28.31 years).

Table 6.12: Disease Duration and Treatment displayed by Disease Group

	Total Sample N = 352	Psoriasis Group n = 225	Psoriasis with PsA Group n = 127
PsA Disease Duration (years)			
Mean (SD)	4.88 (9.55)	0	13.52 (11.69)
Minimum	0	0	1
Maximum	50	0	50
Psoriasis Disease Duration (years)			
Mean (SD)	29.86 (16.99)	30.69 (16.86)	28.31 (17.21)
Minimum	0	1	0
Maximum	80	80	65
Current PsA Treatment			
No Treatment	246 (70.1%)	0 (100%)	21 (16.5%)
Topical steroid creams	3 (0.9%)	-	3 (2.4%)
Oral steroids	6 (1.7%)	-	6 (4.7%)
Analgesics	30 (8.5%)	-	30 (23.6%)
DMARD's	57 (16.2%)	-	57 (44.9%)
Biologics	9 (2.6%)	-	9 (7.1%)
Missing data	1 (0.3%)	-	1 (0.8%)
Current Psoriasis Treatment			
No treatment	46 (13.1%)	19 (8.4%)	27 (21.3%)
Moisturisers	85 (24.1%)	54 (24.0%)	31 (24.4%)
Topical steroid creams	184 (52.3%)	130 (57.8%)	54 (42.5%)
Oral steroids	1 (0.3%)	1 (0.4%)	0
Analgesics	5 (1.6%)	4 (1.8%)	1 (0.8)
DMARD's	25 (7.1%)	16 (7.1%)	9 (7.1)
Biologics	5 (1.4%)	1 (0.4%)	4 (3.1%)
Missing data	1 (0.3%)	0	1 (0.8%)

6.9.3.1 Means and t-tests for Disease Groups

The Means scores for all the measures are displayed by disease group in Table 6.13. Examination of the Means for these groups reveals that the psoriasis-only group report higher quality of life on all scores with the exception of one – the DLQI.

In order to test whether any of the Mean differences between the group of participants with psoriasis and the group with both psoriasis and PsA were significant, independent t-tests were conducted and are presented, with their *p* values, in Table 6.13 and Table 6.14.

Table 6.13: Means (SD) and t-test results with *p* values for all measures displayed by Disease Group

Measure	Psoriasis Group n = 225	Psoriasis with PsA Group n = 127	t-test result *t* *(df = 350)*	*p value*
Fatigue (Mean of total)	30.83 (14.81)	39.46 (15.51)	5.09	.000
Fatigue Mean Item Score	3.43 (1.65)	4.38 (1.72)	5.09	.000
Self Efficacy(Mean of total)	45.08 (11.84)	37.93 (12.35)	-5.28	.000
Self Efficacy Mean Item Score	7.51 (1.97)	6.32 (2.05)	-5.29	.000
HADS – Anxiety	6.50 (4.15)	6.75 (4.01)	0.55	.581
HADS – Depression	3.32 (2.95)	4.55 (3.30)	3.48	.001
DLQI total	6.41 (5.47)	5.72 (5.68)	-1.10	.270
Current Pain NRS	2.14 (1.89)	4.45 (2.43)	9.86	.000
Pain Last Week NRS	2.32 (2.03)	4.85 (2.45)	10.39	.000
HAQ total score	.19 (.42)	.73 (.70)	8.96	.000
SF- 36 PCS	49.03 (11.54)	35.95 (12.56)	9.65	.000
SF 36 – MCS	46.50 (14.01)	46.41 (13.38)	0.06	.949

The results of the independent t-tests between these two groups reflect similar differences as those reported for the Psoriasis Association Group and Hospital group. Indeed, with the exception of the DLQI, Anxiety and SF-36 MH and MCS scores, significant differences were found on all measures, with the Mean scores for the group with both conditions suggesting they experienced impaired quality of life.

Table 6.14: SF-36 Subscales Means and Standard Deviations displayed by Disease Group

SF-36 Subscale (As %)	Psoriasis Group n = 225	Psoriasis with PsA Group n = 127	t-test result t (df = 350)	p value
GH	62.61 (22.78)	47.76 (25.58)	-5.62	.000
BP	72.17 (20.15)	45.67 (20.92)	-11.56	.000
PF	80.48 (26.30)	56.89 (29.77)	-7.70	.000
RP	74.22 (38.62)	41.73 (42.85)	-7.28	.000
V	57.91 (20.78)	46.97 (22.72)	-4.47	.000
SF	74.86 (24.66)	65.09 (28.99)	-3.35	.001
RE	74.62 (36.57)	66.93 (42.52)	-2.48	.013
MH	69.67 (19.45)	69.10 (18.60)	-2.71	.787

6.9.3.2   One Sample t-tests

In order to establish if the Mean scores that were obtained for each group in the current study differed from norms obtained from known populations (as previously described in sections 6.4.1 through to 6.4.7), one-sample t-tests were conducted, the results of which are presented in Table 6.15 (Psoriasis with PsA Group) and Table 6.16 (Psoriasis Group).

Table 6.15   One-Sample t-tests between Psoriasis with PsA Group and a known population

Measure	Norms (SD) from PsA with Psoriasis population (unless otherwise stated)	Psoriasis and PsA Group Mean n = 127	t-test *df = 126*
Fatigue	2.3 (0.7) †	4.38 (1.72)	13.62***
Self Efficacy	5.17 (2.22) ††	6.32 (2.05)	6.32***
HADS - Anxiety	9.37 (4.44) †††	6.75 (4.01)	7.36***
HADS - Depression	6.77 (3.83) †††	4.55 (3.30)	7.58**
DLQI	10.3 (7.5)	5.72 (5.68)	9.08***
Current Pain NRS	4.4 (2.4) †††	4.45 (2.43)	0.23 n/s
HAQ	1.1	0.73 (.70)	5.95***
SF-36 PCS	42.1	35.95 (12.56)	5.51** *
SF-36 MCS	50.0	46.41 (13.38)	3.02*
GH	58.8	47.76 (25.58)	4.86***
BP	60.5	45.67 (20.92)	7.98***
PF	67.0	56.89 (29.77)	3.82*
RP	62.6	41.73 (42.85)	5.48***
V	56.2	46.97 (22.72)	4.57***
SF	80.7	65.09 (28.99)	6.06***
RE	68.5	74.62 (36.57)	1.88 n/s
MH	72.7	69.10 (18.60)	2.18*

*   t-test significant at the 0.05 level (2-tailed)
**   t-test significant at the 0.001level (2-tailed)
*** t-test significant at the 0.0001 level (2-tailed)

†   Mean established in a healthy population
††   Mean established in a chronic disease population
††† Mean established in an arthritis population

The results of the one-sample t-tests concluded that a significant difference existed between the means of the known population and the Psoriasis with PsA Group, with only two exceptions – the Current Pain NRS and the SF-36 subscale of RE (Role Limitations – Emotional). However, the Pain NRS Mean in the current study was marginally higher than the Mean of the comparison group, suggesting that patients in the current study experienced marginally worse pain than those in the arthritis group with which it was compared.

Although a non-significant result, the RE Mean score found in the current group with both conditions indicated that their role limitations caused by emotional factors were less (M = 74.62) than those reported by a similar group (M = 68.5).

The Mean score for Fatigue (M = 4.38) was higher than that found in a healthy population (M = 2.3), suggesting the current participants experienced greater levels of fatigue, however, this group also reported greater levels of Self Efficacy than that found in the arthritis comparison group, with Means of 6.32 and 5.17 respectively.

The current group fared less well on the DLQI & HAQ measures when compared with a similar population; however they experienced less Anxiety and Depression when compared with the levels reported by an arthritis group.

It is of particular interest, given that the comparison was done with a similar group, that the one sample t-tests and Mean scores for the SF-36 (except RE) suggest that the current group experienced significant reductions in their quality of life.

Overall, the results for the HAQ, SF-36 and Fatigue indicate that individuals with a dual diagnosis (psoriasis with psoriatic arthritis), may experience reductions in their physical and social functionality, mental health and endure greater levels of fatigue.

Table 6.16 details the results of the one-sample t-tests that were conducted between the Psoriasis Group and known populations.

The SF-36 produced 5 non-significant results (MCS; GH; PF; RE & MH), of these, according to the Mean scores, the current Psoriasis Group fared less well, than the similar group they were compared with, on the GH, RE & MH.

All the other results suggested they fared better than the comparison group, with the exception of Fatigue and Social Functioning.

Table 6.16   One-Sample t-tests between Psoriasis Group and known population

Measure	Norms (SD) from psoriasis population (unless otherwise stated)	Psoriasis Group Mean n = 225	t-test df = 224
Fatigue	2.3 (0.7) †	3.43 (1.65)	10.18**
Self Efficacy	5.17 (2.22) ††	7.51 (1.97)	17.81**
HADS - Anxiety	9.3 (4.9)	6.50 (4.15)	10.12**
HADS - Depression	4.8 (3.7)	3.32 (2.95)	7.52**
DLQI	12.71 (7.18)	6.41 (5.47)	17.27**
Current Pain NRS	4.4	2.14	17.93**
HAQ	1.1 †††	0.19 (.42)	32.50**
SF-36 PCS	44.7 (12.2)	49.03 (11.54)	5.62***
SF-36 MCS	44.7 (11.9)	46.50 (14.01)	1.92 n/s
GH	60.7 (23.9)	62.61 (22.78)	1.25 n/s
BP	62.7 (29.8)	72.17 (20.15)	7.04***
PF	77.2 (25.3)	80.48 (26.30)	1.87 n/s
RP	64.5 (41.3)	74.22 (38.62)	3.77**
V	54.7 (24.1)	57.91 (20.78)	2.31*
SF	80.8 (25.1)	74.86 (24.66)	3.61**
RE	67.0 (42.6)	66.93 (42.52)	0.02 n/s
MH	71.1 (19.8)	69.67 (19.45)	1.10 n/s

*   t-test significant at the 0.05 level (2-tailed)
**   t-test significant at the 0.001level (2-tailed)
*** t-test significant at the 0.0001 level (2-tailed)

†   Mean established in a healthy population
††   Mean established in a chronic disease population
†††   Mean established in a population with psoriasis & PsA

6.10   Correlations

Pearson's Correlations were used in order to establish the degree of relationship between the study variables. These were conducted on the three groups, that is, the total sample (see Table 6.16), the group with both psoriasis and PsA (Table 6.17) and the group with psoriasis (Table 6.18).

The chance of a Type I error increased due to the number of correlation tests calculated, however in order to reduce the likelihood of this occurring, a more conservative significance level was adopted. For each group, this level was calculated by dividing the conventional probability level of 0.05 by the number of correlation tests performed. Given that 20 variables were used for the correlations the probability level was calculated as follows: $0.05 \div 20 = 0.0025$, thus a conservative significance level was set at 0.001.

Examination of the three tables shows that the vast majority of the tests produced significant correlation coefficients that were significant at the .001 level. Although, it is of interest that 'Time with PsA', that is to say, the length of time an individual had been diagnosed with PsA' produced only one significant result, (found in the Group with Psoriasis and PsA) which was a moderately strong relationship (r = .51) with 'Time with Psoriasis'.

6.10.1 Correlations for Group with Psoriasis with PsA

Closer inspection of the correlation matrix for the group with both conditions (Table 6.17) shows a moderately strong, significant relationship between Fatigue and all the included variables, with the exception of the DLQI, which shows a weak, albeit significant relationship (r =.316). Of particular note is the relationship between Fatigue and 'Current Pain' (r = .547), 'Pain Last Week' (r = .519) and Anxiety (r = .423) and Depression (r = .670) and the SF-36 subscale of Vitality (r = -.738).

In the same group, 'Current Pain' was significantly related to all the other measures, with the strongest relationship found with the HAQ (r = .704) and the SF-36 subscales of Bodily Pain (r = -.773) and Physical Functioning (r = -.678). The relationship with Depression (r = .607) was stronger than that found with either Anxiety (r = .304) or the SF-36 MCS (r = -.394). Although a weak correlation was found with the DLQI (r = .228), it was significant at the .01 alpha level which was outside the .001 level deemed acceptable by the researcher.

Significant relationships were found between Self Efficacy and all the measures, however, the strongest relationships were observed with Depression (r = -.650), the HAQ (r = -.618) and the

SF-36 subscales of Bodily Pain (r = .647), Physical Functioning (r = .668) and Social Functioning (r = .637), whilst the weakest correlation was with the DLQI (r -.330).

All, but one variable (SF-36 MH) was significantly correlated with the HAQ, with moderate relationships found with SF-36 Bodily Pain (r = -.705) and SF-36 PCS (r = -.761). The association with Depression was moderate (r = .603) and almost twice the strength of the relationship found with Anxiety (r = .307).

6.10.2 Correlations for Group with Psoriasis

The correlation matrix for the Psoriasis Group is presented in Table 6.18 and whilst some of the results are similar to those found in the Group with Psoriasis and PsA, there are some differences worth noting.

As reported for the Group with Psoriasis and PsA, Fatigue showed significant, moderate correlations with all the variables, and, whilst the association with the DLQI was only fairly weak (r = .345) it was slightly stronger than that found in the Psoriasis with PsA group, as was the relationship with the SF-36 MH (r = -.480). A marginally stronger correlation was also found with SF-36 Bodily Pain (r = -.532), whilst with the HAQ it was much lower (r =.463). Interestingly, the association between Fatigue and Depression (r = .645) was weaker than that found in the Psoriasis with PsA group, whilst with Anxiety it was marginally stronger.

The negative relationship between Current Pain and SF-36 PF was slightly weaker than that found in the Psoriasis with PsA group (r = -.585).

It is noteworthy that the Psoriasis Group recorded a stronger inverse correlation between the DLQI and SF-36 Social Functioning subscale (r = -.546), whilst the positive relationship between Social Functioning and Self Efficacy (r = .636) was almost identical to that found in the group with Psoriasis and PsA (r = .637).

6.10.3 Comparison of correlation coefficients

To examine whether the correlations obtained by the Psoriasis Group differed significantly to those of the Group with Psoriasis and PsA, the correlations coefficients were compared, the results of which are displayed in Table 6.20.

The results concluded that there was a significant difference ($p \leq 0.05$) between 18 of the correlations, including those found between Self Efficacy and 5 other variables - the DLQI, HAQ and SF-36 PCS, PF and MH. Confirmation that the correlations were significantly different between Social Functioning (SF) and Vitality (V) was also of note, as were the findings regarding MCS, MH, RE and their correlation with Anxiety.

Of the correlation coefficents that were significantly different, the original Pearson's r correlations were found to indicate that a stronger relationship existed in the Psoriasis with PsA Group in 10 of the 18:

Self Efficacy – HAQ	Fatigue – HAQ	PF – Vitality	SF - MCS
Self Efficacy – PF	Fatigue – PF	PF - MCS	
Self Efficacy – PCS	Current Pain – Vitality	PF – Depression	

For the remaining 8 significant comparisons, the Pearson's r correlations were stronger in the Psoriasis Group:

Self Efficacy – DLQI	Anxiety – MCS	SF - DLQI
Self Efficacy – MH	Anxiety – RE	SF - MH
MH - RE	Anxiety - MH	

These results clearly suggest that significant differences exist between the group with psoriasis and the group with a dual diagnosis of psoriasis and Psa.

Table 6.17 Correlations between study variables for total group (N = 352)

	Time with PsA	Time with psoriasis	Self-efficacy (Mean)	Fatigue (Mean)	Current Pain	Pain Last Week	DLQI (Total)	HAQ (Total)	GHP %	BP %	PF %	RP %	V %	SF %	RE %	MH %	PCS	MCS	Anxiety
Time with PsA																			
Time with psoriasis	.175**																		
Self-efficacy (Mean)	-.190**	.039																	
Fatigue (Mean)	.235**	-.065	-.593**																
Current Pain	.319**	-.025	-.583**	.555**															
Pain Last Week	.314**	-.040	-.565**	.575**	.916**														
DLQI (Total)	-.025	-.044	-.453**	.305**	.204**	.225**													
HAQ (Total)	.356**	.018	-.576**	.582**	.726**	.704**	-.127*												
GHP %	-.228**	.078	.658**	-.684**	-.606**	-.610**	-.294**	-.580**											
BP %	-.343**	.012	.635**	-.564**	-.816**	-.849**	-.220**	-.730**	.657**										
PF %	-.311**	-.045	.578**	-.614**	-.690**	-.684**	-.102	-.857**	.653**	.746**									
RP %	-.212**	.088	.498**	-.565**	-.571**	-.608**	-.163*	-.629**	.533**	.643**	.695**								
V %	-.199**	.036	.660**	-.707**	-.571**	-.559**	-.328**	-.521**	.664**	.575**	.549**	.450**							
SF %	-.182**	.001	.650**	-.586**	-.527**	-.544**	-.439**	-.571**	.607**	.601**	.559**	.537**	.672**						
RE %	-.121*	.018	.475**	-.436**	-.359**	-.370**	-.257**	-.387**	.434**	.346**	.393**	.455**	.523**	.561**					
MH %	-.049	.013	.538**	-.454**	-.291**	-.299**	-.399**	-.215**	.452**	.312**	.242**	.225**	.743**	.596**	.504**				
PCS	-.311**	.039	.538**	-.595**	-.716**	-.738**	-.101	-.782**	.686**	.825**	.880**	.829**	.453**	.492**	.198**	.078			
MCS	-.052	.020	.512**	-.424**	-.256**	-.250**	-.392**	-.197**	.403**	.231**	.165**	.205**	.690**	.651**	.811**	.836**	-.046		
Anxiety	.001	-.092	-.502**	.426**	.249**	.274**	.443**	.218**	-.396**	-.314**	-.217**	-.220**	-.557**	-.510**	-.453**	-.723**	-.111*	-.656**	
Depression	.130*	-.116*	-.658**	.669**	.546**	.537**	.395**	.549**	-.666**	-.546**	-.569**	-.511**	-.711**	-.668**	-.522**	-.614**	-.493**	-.584**	.611**

** Correlation is significant at the 0.001 level (2-tailed).

Table 6.18 Correlations between study variable for group with both conditions (n = 127)

	Time With PsA	Time with psoriasis	Self-efficacy (Mean)	Fatigue Mean	Current Pain	Pain Last Week	DLQI (Total)	HAQ (Total)	GHP %	BP %	PF %	RP %	V %	SF %	RE %	MH %	PCS	MCS	Anxiety
Time with psoriasis	.511**																		
Self-efficacy (Mean)	-.006	-.055																	
Fatigue (Mean)	.124	.107	-.564**																
Current Pain	.003	.058	-.598**	.547**															
Pain Last Week	-.038	.074	-.554**	.519**	.881**														
DLQI (Total)	.034	-.019	-.330**	.316**	.228*	.254*													
HAQ (Total)	.121	.043	-.618**	.642**	.704**	.666**	.181*												
GHP %	-.071	-.009	.628**	-.688**	-.612**	-.584**	-.275*	-.570**											
BP %	.045	-.012	.647**	-.495**	-.773**	-.822**	-.244*	-.705**	.604**										
PF %	-.118	-.083	.668**	-.692**	-.678**	-.678**	-.186*	-.867**	.665**	.712**									
RP %	.079	.075	.484**	-.490***	-.491**	-.523**	-.142	-.557**	.463**	.591**	.649**								
V %	-.082	-.041	.582**	-.738**	-.628**	-.581**	-.271*	-.519**	.688**	.554**	.599**	.388**							
SF %	-.131	-.090	.637**	-.603**	-.563**	-.574**	-.329**	-.602**	.644**	.668**	.642**	.529**	.678**						
RE %	-.065	-.085	.514**	-.439**	-.420**	-.431**	-.199*	-.431**	.450**	.397**	.459**	.462**	.480**	.558**					
MH %	-.093	-.068	.439**	-.445**	-.356**	-.357**	-.289**	-.220*	.462**	.331**	.305**	.156	.725**	.522**	.362**				
PCS	.016	.035	.580**	-.600**	-.657**	-.672**	-.158	-.761**	.667**	.776**	.863**	.825**	.467**	.570**	.247**	.109			
MCS	-.116	-.105	.506**	-.485**	-.394**	-.387**	-.294**	-.291**	.498**	.344**	.323**	.229*	.722**	.675**	.816**	.773**	.066		
Anxiety	-.045	-.136	-.456**	.423**	.314*	.351**	.452**	.307**	-.404**	-.378**	-.332**	-.205*	-.503**	-.457**	-.345**	-.610**	-.211*	-.537**	
Depression	.005	-.071	-.650**	.670**	.607**	.558**	.325**	.603**	-.708**	-.580**	-.662**	-.449**	-.729**	-.676**	-.481**	-.568**	-.555**	-.583**	.607**

* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.001 level (2-tailed).

Table 6.19 Correlations between study variables for group with psoriasis (n = 225)

	Time with psoriasis	Self-efficacy (Mean)	Fatigue (Mean)	Current Pain	Pain Last Week	DLQI (Total)	HAQ (Total)	GHP %	BP %	PF %	RP %	V %	SF %	RE %	MH %	PCS	MCS	Anxiety
Self-efficacy (Mean)	.066																	
Fatigue (Mean)	-.140*	-.559**																
Current Pain	-.029	-.491**	.479**															
Pain Last Week	-.063	-.487**	.539**	.901**														
DLQI (Total)	-.064	-.586**	.345**	.290**	.318**													
HAQ (Total)	.060	-.466**	.463**	.614**	.597**	.168*												
GHP %	.106	.631**	-.639**	-.515**	-.546**	-.359**	-.503**											
BP %	-.035	.571**	-.532**	-.753**	-.786**	-.330**	-.641**	.633**										
PF %	-.069	.443**	-.499**	-.585**	-.572**	-.100	-.823**	.576**	.682**									
RP %	.066	.418**	-.543**	-.487**	-.535**	-.234**	-.590**	.492**	.557**	.645**								
V %	.059	.673**	-.656**	-.465**	-.480**	-.406*	-.456**	.608**	.539**	.449**	.411**							
SF %	.041	.636**	-.547**	-.468**	-.499**	-.546**	-.525**	.550**	.570**	.464**	.507**	.647**						
RE %	.070	.425**	-.408**	-.273**	-.291**	-.315**	-.315**	.393**	.282**	.312**	.425**	.532**	.545**					
MH %	.054	.621**	-.480**	-.303**	-.322**	-.463**	-.259**	.474**	.374**	.228**	.284**	.786**	.659**	.600**				
PCS	-.005	.419**	-.523**	-.626**	-.655**	-.138*	-.725**	.642**	.766**	.857**	.783**	.351**	.399**	.090	.063			
MCS	.084	.547**	-.414**	-.219**	-.221**	-.449**	-.166*	.374**	.229**	.089	.213**	.704**	.657**	.825**	.868**	-.124		
Anxiety	-.065	-.547**	.441**	.237**	.265**	.444**	.173*	-.408**	-.337**	-.157*	-.238**	-.606**	-.553**	-.524**	-.782**	-.051	-.717**	
Depression	-.127	-.637**	.645**	.466**	.491**	.474**	.472**	-.610**	-.507**	-.465**	-.508**	-.677**	-.643**	-.532**	-.658**	-.405**	-.603**	.625**

* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.001 level (2-tailed).

Table 6.20: Comparison between the correlation coefficients and *p* values (*p*) on all measures for Disease Groups

	SE	Fatigue	Current Pain	Pain Last Wk	DLQI	HAQ	GHP	BP	PF	RP	V	SF	RE	MH	PCS	MCS	Anxiety
Fatigue	0.065 / 0.95																
Current Pain	1.36 / 0.17	-0.82 / 0.41															
Pain Last Week	0.82 / 0.41	0.25 / 0.80	0.87 / 0.39														
DLQI	-2.93 / 0.003	0.29 / 0.77	0.59 / 0.53	0.62 / 0.53													
HAQ	1.93 / 0.053	-2.32 / 0.020	-1.43 / 0.15	-1.03 / 0.30	0.84 / 0.40												
GHP	0.04 / 0.96	0.78 / 0.43	1.27 / 0.20	0.49 / 0.62	-0.83 / 0.40	0.84 / 0.40											
BP	1.08 / 0.28	-0.45 / 0.65	0.43 / 0.67	0.91 / 0.36	-0.84 / 0.40	1.05 / 0.30	0.42 / 0.68										
PF	-2.95 / 0.003	2.70 / 0.006	1.39 / 0.17	1.56 / 0.12	0.78 / 0.43	1.38 / 0.17	-1.29 / 0.19	-0.52 / 0.60									
RP	-0.74 / 0.46	-0.65 / 0.52	0.05 / 0.96	0.15 / 0.88	-0.85 / 0.39	-0.44 / 0.66	0.34 / 0.74	-0.45 / 0.65	-0.86 / 0.95								
V	1.34 / 0.18	1.43 / 0.15	2.09 / 0.036	1.26 / 0.21	-1.36 / 0.17	0.74 / 0.46	-1.23 / 0.22	-0.19 / 0.84	-1.85 / 0.06	0.24 / 0.80							
SF	-0.01 / 0.99	0.75 / 0.46	1.16 / 0.25	0.94 / 0.35	-2.42 / 0.015	0.75 / 0.46	-1.31 / 0.19	-1.42 / 0.15	-2.31 / 0.02	-0.26 / 0.78	-0.49 / 0.62						
RE	-1.02 / 0.31	0.34 / 0.74	1.49 / 0.13	1.44 / 0.15	-1.10 / 0.27	1.20 / 0.23	0.62 / 0.54	-1.16 / 0.24	-1.54 / 0.12	-0.41 / 0.68	0.62 / 0.53	-0.16 / 0.86					
MH	2.28 / 0.02	-0.39 / 0.69	0.53 / 0.59	0.35 / 0.72	-1.82 / 0.07	-0.37 / 0.71	0.14 / 0.89	0.43 / 0.66	-0.73 / 0.50	1.20 / 0.22	1.27 / 0.20	1.89 / 0.058	2.80 / 0.005				
PCS	-1.93 / 0.054	1.01 / 0.31	0.47 / 0.64	0.27 / 0.79	0.18 / 0.85	0.72 / 0.47	-0.39 / 0.69	-0.21 / 0.82	-0.20 / 0.83	-1.06 / 0.28	-1.24 / 0.21	-2.00 / 0.044	-1.44 / 0.15	-0.41 / 0.68			
MCS	0.51 / 0.61	0.79 / 0.43	1.73 / 0.08	1.64 / 0.10	-1.61 / 0.11	1.18 / 0.24	-1.36 / 0.17	-1.11 / 0.26	-2.19 / 0.02	-0.15 / 0.88	-0.32 / 0.74	-0.28 / 0.77	0.24 / 0.80	1.60 / 0.10	-1.70 / 0.09		
Anxiety	-1.08 / 0.23	0.19 / 0.84	-0.74 / 0.46	-0.85 / 0.39	-0.09 / 0.91	-1.27 / 0.20	-0.04 / 0.96	0.41 / 0.67	1.66 / 0.09	-0.31 / 0.76	-1.33 / 0.18	-1.15 / 0.24	-1.98 / 0.047	-3.04 / 0.002	1.46 / 0.14	-2.68 / 0.007	
Depression	0.19 / 0.84	-0.39 / 0.69	-1.78 / 0.08	-0.83 / 0.41	1.59 / 0.11	-1.65 / 0.09	1.55 / 0.12	0.92 / 0.35	2.61 / 0.009	-0.68 / 0.49	0.91 / 0.35	0.52 / 0.60	-0.61 / 0.54	-1.29 / 0.19	1.74 / 0.08	-0.27 / 0.78	0.25 / 0.79

P = < 0.05

6.11   Summary of Quantitative Results

The descriptive statistics confirmed that of the total sample, 225 participants had a diagnosis of psoriasis, whilst 127 participants had psoriasis with an additional diagnosis of PsA.

Given that participants were originally recruited from two distinct sources, (a hospital and the Psoriasis Association) the data was initially categorised into these two Recruitment Groups and explored to establish whether any differences existed between the two.

The demographic data for the two Recruitment Groups indicated that both were fairly similar in terms of their Mean age, gender split and marital status. It was however interesting to note that 34% of the Association Group had obtained graduate or post-graduate qualifications compared to only 5% of those in the Hospital Group. Whilst this may, in part, be a reflection of the differences in the sample size, it may also reflect characteristics of individuals who join support groups, perhaps indicating, for example, an association between higher educational attainment and the ability or preference to seek out help and information about their disease and therefore actively cope with it.

Examination of the Mean scores for the all the measures, with the exception of the DLQI, suggest that the participants in the Hospital Group experienced greater difficulties with their functionality, higher levels of fatigue, pain, anxiety and depression and lower levels of self efficacy and reduced quality of life, with t-tests confirming that the differences between the Means were significant, (except for the SF-36 MCS and HADS Anxiety subscale).

The finding that the DLQI Mean score was higher for participants in the Psoriasis Association Group was not unexpected, as this measure is used to assess the impact of skin disease on patient health-related quality of life. Furthermore, a t-test confirmed that this difference was significant.

Given that PsA affected all of the participants in the Hospital Group, yet only a proportion of those in the Psoriasis Association Group, it is possible that PsA may provide an added burden which contributes to reductions in quality of life. In order to explore this further,

the data was categorised into two groups – one comprising participants with psoriasis (Psoriasis Group, n = 225), and the other, participants with both psoriasis and PsA (Psoriasis Group with PsA, n = 127). The data was then analysed according to these two groups.

Inspection of the Mean scores showed the Group with Psoriasis and PsA fared less well on all measures with the exception of the DLQI, although an independent t-test revealed that the difference was not significant.

Further Independent t-tests reflected significant differences on all but the HADS-Anxiety, SF-36 MCS and MH scores, suggesting that it was the individuals who have both conditions, that is, a dual diagnosis of psoriasis and PsA who experienced impaired quality of life.

Furthermore, correlations for this group identified highly significant relationships (p < 0.001) between the majority of the variables. The relationship between Self Efficacy and the HAQ (an inverse correlation), and SF-36 subscales of Bodily Pain, Physical and Social Functioning were all fairly strong, whilst it is of note that a stronger (inverse) association existed with Depression than with Anxiety. Interestingly, these variables displayed similar, negative associations with Fatigue, whilst Current Pain was, as might be expected, most strongly related, inversely to SF-36 Bodily Pain and PCS, and positively to the HAQ - all measures that assess physical functioning, although there was a fairly strong, positive association with Depression. Interestingly, although the DLQI correlated significantly with most of the variables, the associations were generally the weakest seen in the matrix, indeed the strongest was with Anxiety, followed by Depression, both of which were positive relationships.

The Psoriasis Group also displayed significant relationships between most of the variables, although generally, the strength of the relationships were lower than those found in the Psoriasis with PsA Group. Noteworthy exceptions were the DLQI which significantly correlated with all the other measures, bar the SF-36 Physical Functioning (PF) subscale. It's positive association with Fatigue was slightly higher and the negative correlations with the SF-36 were all stronger than those found in the group with 'both conditions', except for Physical Functioning and PCS, suggesting that psoriasis may be associated with poorer

psychological health in this group of participants. Although it is of interest that the association between Self Efficacy and Anxiety was slightly stronger (r = -.547 compared with -.456), whilst conversely, the correlation with Depression, was weaker.

Comparisons between the correlation coefficients, the results of which are displayed in Table 6.20, confirmed that significant differences ($p = \leq 0.05$) existed between 18 of the correlations.

The correlation coefficients for the groups differed significantly when Self Efficacy was correlated with the DLQI, HAQ, PCS, MH and PF, as did Fatigue with the HAQ and PF. The correlations also differed between the SF-36 subscale of PF and Vitality, MCS and Depression. The difference in the correlations obtained between the DLQI and SF for each group, were significantly different, as were those for SF with MH and PCS. Other differences included Anxiety with RE, MH and MCS, RE with MH, whilst finally, the correlation between Current Pain and Vitality was also significantly different.

The coefficients between both Fatigue and the HAQ, and Fatigue and Physical Functioning (PF) were significantly different, and for each, the strength of the association was greatest in the Group with Psoriasis and PsA. These results suggest that fatigue and functional ability are related, given that the HAQ measures physical disability and pain and the PF subscale measures limitations in physical activities because of health problems. Interestingly, the group with both conditions also had the strongest relationship between the variables of Physical Functioning and Depression, implying that in this group, reductions in physical ability may be associated with increased levels of depressive symptoms, a result which this same group also reflects in their association between Physical Functioning and the Mental Component Score (MCS).

The Pearson's r results showed that the Psoriasis with PsA Group recorded stronger correlations, which were significantly different to the Psoriasis Group, when Self Efficacy was correlated with three other variables – HAQ, Physical Functioning and the Physical Component Score – implying that there is a greater association between levels of self efficacy and physical and functional ability in the group with both conditions.

Whilst the results indicate that reductions in both physical and psychological health are greater in the group with PsA, the psoriasis group appear to experience reductions in psychological health rather than limitations that impact on their physical functioning.

It is of interest that comparison of the correlation coefficients highlighted a significant difference between the SF-36 Social Functioning (SF) and the DLQI. When examined, the Pearson's r coefficient reveals a stronger relationship between these two variables (r = -.546) than the Group with both conditions (r = -.329), suggesting those with psoriasis experience greater limitations in social activities due to physical or emotional problems, than the group with PsA. Similarly, the correlation coefficients for Social Functioning and Mental Health are significantly different, and again, the strongest relationship between these two variables is found in the Psoriasis Group, implying that poorer mental health is associated with decrements in social functioning.

Significantly different from those found in the group with both conditions, the Psoriasis Group reported stronger associations between Self Efficacy and both the DLQI and MH, suggesting that levels of self efficacy are associated with limitations related to the impact of psoriasis and also to levels of psychological distress. It is also noteworthy that it was the Psoriasis Group that recorded the strongest associations when Anxiety was correlated with MCS, RE and MH, giving an indication that psoriasis may be associated with psychological health.

When considering the differences between the correlation coefficients in combination with the Mean scores and Pearson's r correlations, it appears that in the Psoriasis with PsA Group, decrements in physical functioning, as measured by the HAQ and SF-36, were associated with greater fatigue and pain, less vitality, poorer psychological health and increased depression, whilst physical functioning was also shown to be related to Social Functioning. However, for the Psoriasis Group, decrements in their health-related quality of life appear to be less associated with physical functioning and physical disability, and more with reductions in their psychological health and social functioning.

In the following chapter, these results are discussed in the light of previous research and their implications for practice considered.

CHAPTER 7

DISCUSSION

7.1   Introduction

This thesis has attempted to identify, from the patients' perspective, psychosocial issues that were perceived to be detrimental to their quality of life. Furthermore, through the use of standardised psychometric instruments, the impact of these factors has been investigated and their role assessed.

This chapter contains a discussion of the results from both the qualitative and quantitative aspects of this study. The principal findings will be presented and discussed with due consideration also given to the merits of the author having utilised not only mixed methodology, but also postal surveys that were largely dependent on a membership organisation. Then follows the implications of this research for practice, the limitations of this study, possible directions for future research, followed by the author's concluding comments.

7.2   Discussion of Qualitative Results

The qualitative study in the first part of this thesis clearly illustrates the complexities and multi-faceted nature of living with PsA, for whilst five major themes were identified and described as conceptually distinct, it was almost impossible to separate them from one and other (Aitken et al., 2006).

Although many smaller themes supported the development of five superordinate themes – Pain, Functionality, Emotions, Coping and Treatment Experience/ Management - the lived reality, as conveyed by the patients, suggests that these are not necessarily contained within one major category, but overlap and are entwined.

The first major theme to emerge, Pain, clearly permeated every aspect of the participants' lives and had a major impact on daily activities, mood, social functioning, employment, relationships, fatigue and mobility.

The participants identified pain as a symptom that was ever-present in varying degrees and considered it an integral part of living with an arthritic condition. It was clear that pain impacted on their ability to engage in physical activities, a finding which may be expected, however, it was also clear that pain greatly affected their ability and intention to attempt even the most minor of normal activities of daily living, such as opening a box of cornflakes. This finding reflects the results of a study by Husted at al. (2001), who found that PsA patients reported greater role limitations as a result of both bodily pain and emotional problems, whilst those with PsA have also been found to report significantly worse pain and physical mobility levels, as indicated by the Nottingham Health Profile, when compared with a healthy population (Borman et al., 2007).

Although participants in the qualitative study generally acknowledged that the presence of psoriasis was a minor issue compared to PsA, it was of interest that they all discussed pain and discomfort as symptoms associated with their psoriatic arthritis, not their psoriasis. This is noteworthy in the light of a survey of skin disease in general practice which found that 25% of patients with psoriasis reported pain (Verhoeven et al., 2007). Furthermore, previous studies have found that patients with psoriasis frequently experience pain and skin discomfort (Sampogna et al., 2004; Unaeze et al., 2006). It is possible that in this study, the level of pain that occurs as a result of PsA outweighs the impact of any pain or discomfort that is generally associated with psoriasis.

Pain not only had consequences for everyday capacities, but also resulted in participants evaluating themselves in relation to former capabilities and achievements, and comparing this with their present expectations. This in turn fuelled the sense of loss and grieving experienced by sufferers, as pain was viewed as an obstacle to activities that formerly had been a source of pleasure, such as working, playing football, going to the gym or simply being able to get down on the floor and play with young children.

Similar feelings of grief and loss were reported in Dildy's (1996) qualitative study, which used Grounded Theory to identify the nature of suffering in fourteen people with

rheumatoid arthritis. The participants acknowledged what would have been different in their lives, especially in relation to careers, hobbies, leisure activities, and plans for retirement, had they not been diagnosed with RA, whilst managing to identify that it was the loss of personal dreams and the need to restructure a future orientation that was implicit in their experiences of suffering and grief. Explaining these findings, Dildy (1996) suggests that many aspects of suffering may relate to the issue of control, and that loss, particularly of independence and personal control, has been found to have serious implications to the overall health of individuals as it may impede an individual's ability to exert control and successfully manage their disease.

In the current study there was consensus that living with PsA imposed a series of losses, which, in turn contributed to the sense of ongoing grief experienced by the participants, themes which have been identified in studies of people with RA (Stephens & Yoshida, 1999).

Interestingly, fatigue has been implicated in feelings of loss, grief and sorrow following research with Multiple Sclerosis (MS) patients. The researchers found that when MS patients became fatigued and were unable to manage what they intended (shopping trips, housework etc.) they experienced a sense of grief and sorrow for what they had lost. Each time they failed to manage their tasks, the same feelings were aroused, leading the researchers to suggest that when the grief feelings are recurrently experienced, fatigue may act as the triggering event as it reminds the individuals' of the loss of energy or ability (Flensner et al., 2003). In order to protect oneself from such feelings, Lazare (1992) suggested that a strategy of 'hiding' may be adopted, so that instead of showing their loss of ability in the presence of others, people may choose isolation. Although this research related to MS patients it is possible that it has application for those with PsA and may offer a starting point from which patients can re- frame their lives, alter their goals and accept their limitations, so reducing their experiences of loss and grief. Altering one's goals in life, in order to feel well, may be seen as being in harmony with Nordenfelt's theory of the nature of health (1995) and could be used as a framework for exploring and enlarging our understanding of loss and grief, and determining whether fatigue is a causal factor.

The feelings of loss expressed by the participants were generally linked to the functional disability caused by PsA and also their deliberate decisions to withdraw from social events,

however, it was unclear whether, in this study, the presence of psoriasis was implicated in any of their feelings of loss or isolation. This warrants consideration, given that previous research has found that psoriasis patients experience increased levels of isolation and rejection. Indeed, Ginsburg and Link (1993) reported that in their study of 100 psoriasis patients, 19% reported 50 episodes of gross rejection, most often from a gym, swimming pool, hairdresser or job, as a direct result of their skin condition. The authors posit that those patients, who experience such feelings of rejection and isolation, may feel stigmatized and suffer further adverse effects on their emotional and occupational life. In view of this, it is interesting that a later study found that, in individuals with psoriasis, perceptions of stigmatisation were significantly related to both psychological distress and degree of disability (Richards et al., 2000).

A variety of studies exploring the incidence of psychological distress consistently report that patients with psoriasis are at an increased risk of experiencing depression. Most recently, a large, population-based cohort study using data collected as part of patient's electronic medical record from 1987 to 2002, was conducted in order to determine the incidence of depression, anxiety, and suicidality in patients with psoriasis compared with the general population. The data included 146,042 patients with mild psoriasis, 3,956 patients with severe psoriasis, and 766 950 patients without psoriasis. The researchers concluded that patients with psoriasis had an increased risk of depression, anxiety, and suicidality and they estimated that in the United Kingdom, in excess of 10,400 diagnoses of depression, 7,100 diagnoses of anxiety, and 350 diagnoses of suicidality are attributable to psoriasis annually (Kurd et al., 2010).

The negative emotions experienced by individuals with PsA extended beyond feelings of loss and grief. Indeed, all of the participants referred to feelings of depression, anger, frustration and fear at various times. The unpredictable and flaring nature of PsA may contribute to the emergence of such feelings, and would support previous findings from studies with RA patients, such as those of Ryan (1996) who found participants associated their frustration with increased physical disability.

Although there are few studies exploring the impact of depression in PsA patients, the current qualitative study confirmed that episodes of low mood and depressive symptoms were an issue for all ten participants. Evidence from the RA literature has found that

depressive symptoms and depression are more common in individuals with RA (Dickens et al., 2002), and indeed other chronic illnesses (Chapman, 2005) when compared with healthy controls. Whilst depression in RA is frequently considered to be a consequence of chronic pain, the causal nature of the association often remains unclear given the multitude of other variables that could be implicated. Although several cross-sectional studies of patients with RA, such as Hurwicz & Berkanovic (1993), have examined the degree of association and concluded that depression varies in proportion to the level of pain being experienced, others have found that once the effects of other variables, such as demographics and disability, are controlled for, the magnitude of the association weakens and can become non-significant (Newman et al., 1989).

For the participants in the current study, symptoms of depression were detrimental to their confidence and assertiveness, and seemed to contribute to problems in accessing help and support, from both social networks and their GP's and other healthcare providers. Indeed, from some participants there was a sense that their condition did not entitle them to GP time and resources and so deterred them from raising concerns about their emotional distress and depressive symptoms. Similar findings have been reported by others (Rogers et al, 2001; Lester et al., 2005), yet results from a study by Pollock (2007) simply found that patients actually suppressed the expression of emotional distress during medical consultations because they were trying to 'maintain face' and conform to "the socially sanctioned role of the stoic, good and uncomplaining patient in order to retain the social esteem and good will of others" (page 175).

Within the RA literature, the relationship between symptoms and depression has been explored from a variety of perspectives, including whether pain is a predictor of depression (for example, Nicassio & Wallston, 1992) or whether depression influences pain (for example, Parker et al., 1992) whilst other studies have sought to identify factors that may mediate the pain-depression relationship (for example, Schiaffino et al., 1991). However, a somewhat unique study conducted by Fifield and her colleagues (1998) departed from the predominately exclusive focus on the connection between current emotional distress and current illness, to consider whether a patient's affective history may influence their future illness experience. The researchers endeavoured to determine whether a previous episode of major depression leaves a 'scar' that places previously depressed patients with RA at risk for experiencing high levels of pain, fatigue and disability. They concluded that an

episode of major depression, even if it occurs prior to the onset of RA, leaves patients at risk for higher levels of pain when depressive symptoms persist, even years after the depressive episode.

Although Fifield et al (1998) could only speculate as to the possible mechanisms that operate with respect to major depression and future symptom reports, their study and the 'scar' hypothesis does offer some evidence of the long-term risk associated with a past episode of major depression and suggests that a patient's affective history warrants consideration in future studies.

In the current study, there was a sense that a broad array of negative feelings prevailed at various times. Whether in the guise of depression, frustration, fear or anger, often these feelings seemed linked to flare-up's of the disease and were a response to forced limitations and role changes caused by reduced physical abilities and severe episodes of pain.

Similar emotional responses have been reported in qualitative studies about RA, such as that by Barlow et al. (1999) who used focus groups to explore the realities of parenting from the perspectives of mothers, fathers and grandparents with arthritis. The researchers found that there was consensus among the participants that pain, fatigue and restricted physical functioning combined to interfere with the parenting role, with the key themes concerning physical limitations, practical and caring issues, social factors, emotional response, hereditary risks and safety issues. The perceived inability to fulfil parenting roles resulted in feelings of anger, depression, frustration and guilt, leading Barlow et al (1999) to conclude that the presence of a painful, disabling, chronic disease, such as arthritis, may have implications for perceived ability to fulfil a parenting role.

In the current study, reduced physical abilities not only compromised domestic tasks, but also impacted on participant's employment capabilities. Half of the group were unable to work due to their disease, whilst two had changed their work roles in an attempt to stay working and earning a wage.

For most adults, participation in paid employment is a major life role and is central to many peoples' life goals however, for those of working age, having arthritis can affect the

ability to remain employed. In their recent report, 'Differences in the Workforce Experiences of Women and Men with Arthritis Disability', Kaptein et al. (2009) have suggested that, when compared with individuals with other types of chronic disease or disabilities, arthritis appears to have a more profound impact on the ability to work and participate in other life activities - a view supported by various studies that have found approximately 50% of people with arthritis or arthritis-related disability were out of the workforce (Badley & Wang, 2001; Backman, 2004). Given that individuals with severe psoriasis report missing work frequently, and experience increased levels of unemployment as a result of their psoriasis (Linden & Weinstein, 1999), it is possible that a dual diagnosis of psoriasis and psoriatic arthritis has a greater impact on occupational employment than if an individual just has one of the conditions.

According to Ryan (1996), the enforced physical disability and role changes that occur as a result of RA lead to negative self-esteem, whilst the significant association between loss of valued activities and poor health outcomes, such as depression, has been observed as a consequence of RA (Neugebauer, Katz & Pasch, 2003). Indeed, in the current qualitative study, decreased functional ability pervaded every aspect of the participants' lives resulting in the need to be adaptive and develop various coping strategies in order to manage their condition.

The participants used numerous strategies in an attempt to remain independent and be able to carry out everyday activities. These included using a wheelchair when out shopping, sitting down to prepare food and installing a seat in the shower – all positive adaptations designed to help the individual cope with the disease.

Conversely, in an attempt to deal with their pain and fatigue, several participants described the excess use of alcohol as a way of helping them induce sleep – clearly a negative coping strategy that may have deleterious implications for their health.

The finding that self-medication with alcohol is a coping strategy in this patient group aligns itself with other research such as that of Riley & King (2009) who examined the use of alcohol to manage pain, including arthritis pain, in a sample of community-dwelling adults and concluded that self-medication of pain with alcohol was associated with pain frequency, depression and use of pain medications, whilst interestingly, among patients

with chronic back and neck pain there is some evidence to suggest that weekly alcohol consumption predicts the development of widespread chronic pain (Sjolander & Johansson, 2004).

Such findings suggest there may be a need to address adverse self-medication behaviours as they may be implicated in longer-term health problems that not only add to the burden of living with a chronic pain condition, but also contribute to the development of maladaptive coping strategies.

Alcohol use may be considered a transparent strategy, however, what was less clear, were the strategies employed when social interaction was pending, for an element of contradiction existed. On the one hand, most participants reported feeling lonely and isolated, yet on the other, they reported frequently rejecting offers of help from friends and family, deliberately shunning social contact, reducing communication with friends and avoiding social events – the common reasons being that they felt a burden, or, perceived that other people didn't understand the disease, or people would try and help.

This was an interesting finding, particularly in the light of much research that suggests social support, whether negative or positive, is an important coping resource in managing illness and is thought to act as a buffer between the individual and the source of stress or demands of a chronic illness, as well as providing tangible assistance in meeting needs (Miller, 2000). Indeed, according to Silver, Wortman and Crofton (1990), one of the most challenging aspects in managing illness, is to maintain social support and preserve interpersonal relationships as valued coping resources.

Within the RA literature, there is increasing evidence that social support is predictive of long-term functional disability and pain, with both the qualitative aspects of perceived social support and the quantitative aspects of the size of the social network believed to play a role. In their study, Smith & Wallston, (1992), found that lower levels of perceived support were prospectively related to more interference in the daily activities of RA patients after one year, whilst another study reported increased pain after one year (Waltz et al., 1998). Similarly, Evers et al. (1998) found that smaller social networks predicted functional disability after one year.

Furthermore, a study conducted in Ireland tasked with identifying the prevalence of depression and anxiety in RA patients attending hospitals, which also explored the role played by psychosocial, illness and disability variables, reported 65% of patients had evidence of depression (37.5% moderate or severe) whilst 44% had evidence of anxiety (17.8% moderate or severe). After controlling for age, gender, marital status and duration of disease, perceived social support was a highly significant, independent predictor of both depression and anxiety, suggesting that that increasing social support may be particularly important in the management of depression and anxiety in RA. (Zyrianova et al., 2006).

Social support has also been shown to play a role in the levels of psychological distress experienced by individuals with psoriasis. For example, Evers et al. (2005) explored contributors to psychological distress in 248 adults with either psoriasis or atopic dermatitis, and found that less social support was one of the best predictors of psychological distress in both groups of patients. Given that participants in the current study admitted they had times when they specifically avoided engaging social support, this finding suggests that the issue of actual or perceived social support may be a complex one.

In the current study, participants were reluctant to mobilise social support ("if family don't help, that's it, you either do without or do it yourself"), partly because it required them to engage and interact with other people, an act they claimed, that was often exhausting and contributed to feelings of fatigue. It was clear that the participants experienced varying intensities of fatigue on most days and perceived it as having a significant impact on their lives, affecting their mental health and physical functioning and causing them to limit or give up activities - "I used to walk miles, I was outgoing…now I spend most of my time sitting".

All those interviewed seemed to experience problems resulting from the incapacity that was induced by the extreme tiredness and fatigue. The fatigue was generally viewed as two types – one being the sheer and complete exhaustion that arose after activities of some sort, such as shopping, whilst the other was a physical and mental lethargy that left participants feeling fragile, without energy and often needing to lie down.

Emerging from the qualitative data is the shared experience of fatigue as a distressing, disruptive, unpredictable, extreme, frequent and multidimensional symptom that impacts

on every aspect of life. The participants clearly perceived fatigue as a threat to their traditional roles as they struggled to complete housework, care for children, attend and enjoy social engagements and maintain both social and close relationships.

Although little has been written about the impact of fatigue on patients with psoriasis, the results of the 1998 National Psoriasis Foundation Patient–Membership Survey found that among the 17,425 who responded to the question regarding symptoms, 19% reported that fatigue was a frequent symptom (Krueger et al., 2001), which serves to highlight the far-reaching impact that psoriasis can have.

Examination of the available literature revealed a paucity of qualitative studies that explored the impact of fatigue on those people with conditions that fall under the umbrella of Rheumatology, let alone PsA. However, of the handful of studies identified, all reported similar experiences and offer some evidence for the nature, consequences and management of fatigue (Hewlett et al., 2005; Power et al., 2008; Repping-Wuts et al., 2008).

The descriptions given to fatigue in this study are similar to those used by participants in other studies - its unresolving and unpredictable nature being key themes. Hewlett and her colleagues explored the concept of fatigue as experienced by RA patients and found it to be a severe and dramatic symptom that was intrusive and overwhelming (2005), whilst comparable descriptions were noted by Power et al. (2008) in their study of fatigue in Osteoarthritis patients.

The commonality of themes that emerge from these studies extends to the consequences of fatigue, as participants comment on the far-reaching effects on their traditional roles, physical function, employment, everyday tasks, relationships and social functioning, in addition to their mental and emotional health.

Repping-Wuts and his colleagues (2008) undertook a qualitative study with the aim of exploring fatigue as experienced by patients with RA and clearly demonstrated that RA-related fatigue was viewed as being different from "normal" fatigue. It was seen as an unpredictable, almost daily experience that had a great impact on quality of life. Half the respondents described fatigue as more bothersome than pain and felt it required everyday adaptation and although it had consequences for roles, relationships and leisure time,

respondents rarely mentioned it to their health professionals assuming it was an untreatable symptom that they must manage alone. Despite the disease focus being RA, the findings of this study certainly align themselves with those of the current qualitative study exploring PsA.

The lack of research examining fatigue communication in rheumatology out-patient clinics certainly results in a gap in the current knowledge that needs addressing, however, it is also of note, particularly in the light of the finding that fatigue is a key theme, that to date, no studies were found exploring health professionals knowledge, attitude, and current care for fatigue in PsA patients. Even a search of the RA literature produced only a couple of studies exploring these areas – both published in 2008 by Repping-Wuts, van Riel and Achterberg.

Describing rheumatologists' knowledge and management of fatigue, Repping-Wuts et al (2008) found that these health professionals underestimated the prevalence of RA-related fatigue, although they were willing to assess and manage it. Although there was acknowledgement of poor communication about fatigue, there was awareness that if a patient is asked about fatigue, they rarely denied the symptom.

Fatigue communication at the outpatient clinic of rheumatology was the focus of a further study by Repping-Wuts et al (2008). They concluded that fatigue, although a common and severe symptom for RA patients, was only communicated in 6% of the total encounter time, and that, mostly, it was the patients who initiated the communication on fatigue in the consultations. Interestingly, the researchers noted that patients used implicit cues more than explicit concerns in their communication on fatigue, and whilst there were no suggestions as to why this occurs, this finding supports other health literature that reports patients more often use cues to express their worries instead of communicating their concerns (1996).

Whilst the qualitative data is limited, quantitative studies have sought to explore the role and impact of fatigue in various rheumatological diseases. For example, Pollard et al. (2006) sought to determine the relative contribution of RA disease activity to fatigue, in comparison with factors such as pain and depression in established RA. They found that fatigue was the dominant symptom and, that the patients' scores on the Health Assessment

Questionnaire (Zigmond & Snaith, 1983) were positively associated with high levels of fatigue, indicating they experienced greater disability, whilst the association with disease activity was secondary. In this case, disease activity was established using both clinical (Erythrocyte Sedimentation Rate - ESR, tender and swollen joint counts) and patient measures (Patient Global Assessment), however many musculoskeletal conditions may utilise different routine measures of disease activity and severity, therefore it is not always possible to generalise results across conditions.

The interviews clearly demonstrated the detrimental effect that PsA has on many aspects of life, much of it resulting from having to cope with intense pain and fatigue. Pain has long been recognised as a major symptom of many musculoskeletal conditions whereas fatigue has only recently begun to emerge as a core symptom – possibly because it has previously been viewed as a subjective functional sign of other factors, such as co-morbid diseases, medication side-effects or depression.

Fatigue, it seems, warrants further investigation. Indeed, writing an Editorial in Rheumatology (2009), Repping-Wuts and his colleagues note their disappointment that, despite fatigue being a common symptom in RA patients, few studies have focussed on the treatment of fatigue and undertaken trials to establish the efficacy of interventions. Unfortunately, the same is true of fatigue in patients with PsA.

The interviews in the first study gave the participants a voice and facilitated the identification of common themes. In order to explore these themes further, the findings were used to drive the choice of measures adopted in the quantitative study – as described in Chapter 5 of this thesis.

7.3   Discussion of Quantitative Results

The qualitative results suggested that, in those with PsA, pain, fatigue and depression were perceived as key issues that impacted on quality of life. Pain was viewed as always being present in some form and in varying degrees, whilst fatigue was difficult to manage because of its unpredictable nature, both of which impacted on the participants physical functioning. Meanwhile depressive symptoms and low mood were universal features

discussed by all the participants, as were reductions in social functioning, all of which combine and seemingly contribute to decrements in health-related quality of life.

The lack of existing published studies that have explored the health-related quality of life in PsA patients means a comparison of this sample to others is exceptionally difficult, however a Canadian study by Husted et al., (2003) did examine and compare health-related quality of life in patients with RA and PsA, using a study sample comprising of 107 PsA patients (and 43 RA patients). Of the 107 participants, 38% were female (62% male) which compares favourably with the 48% (52% male) of females found in the hospital group of patients. Similarly, in Husted et al.'s study the mean age for those with PsA was 50.2 (± 12.6), whilst in the current study it was 53.67 (± 11.03). The average duration of disease was slightly higher in the Canadian study (14.2 years, ± 8.18) when compared with the current one (11.89, ± 10.97).

It is of note, that Husted and her colleagues found that both the RA and PsA patients in the study experienced lower physical health compared with that of a general population sample, but when compared to the RA group, the PsA patients reported more role limitations due to emotional problems and more bodily pain.

The very nature of PsA is such that it is very rare for those affected by the disease not to have had, or continue to have, psoriasis. Indeed, of the respondents in the present sample only eleven participants had PsA without simultaneously experiencing psoriasis. The quantitative data in the current study was therefore split into two groups and explored by 'participants with psoriasis' and 'participants with psoriasis and PsA'

Examination of the quantitative results for the group of participants with both psoriasis and PsA revealed significant correlations between the study variables, although of particular note were the moderately strong correlations between fatigue, pain, depression and vitality – all of which were positive relationships, except for vitality which was negative due to the scoring method. Further exploration of the correlation coefficients determined that strong associations, which were significantly different to those found in the Psoriasis Group, existed between physical functioning and several other variables – fatigue, self efficacy and mental health, whilst social functioning was related to mental health. Furthermore, an

interesting finding in this group was that the mean scores on all the measures signified poorer physical and mental health when compared to the norms of known populations.

Conversely, in the Psoriasis Group, key associations were identified between psychological health, anxiety and social functioning, whilst the DLQI was related to social functioning. It is also interesting to note, that this group, as indicated by the mean scores, reported more anxiety, depression, current pain, and reductions in physical function (as measured by the HAQ) and greater role limitations due to emotional health problems, when compared with the norms of a known population.

Levels of fatigue were higher in the group with PsA, with a mean score that was significantly different to that found in a healthy population.

In the current study, the relationships between fatigue and the other variables supports various studies of RA patients that have stressed the importance of psychosocial factors in relation to fatigue. For example, Lorish et al (1991) found that fatigue was significantly related to depression, anxiety and helplessness, whilst Wolfe et al (1996) concluded that depression, together with pain and sleep disturbance, are the strongest independent predictors of fatigue.

The association between depression and fatigue would appear to be a complex one as fatigue has been found to be higher among RA patients who have a lifetime history of current or previous clinical depression or generalised anxiety. Consequently their fatigue trajectories are usually stable, but elevated over time when compared to those RA patients without mood disorders, whose fatigue trajectories commence at a lower level, but increase over time (Fifield et al., 2001). Although it was not known whether respondents in the current survey had a previous history of depressive episodes, given the incidence in the general population and other pain populations, it is possible, and may therefore be implicated in the levels of fatigue they experience.

A study by Pollard et al. (2006) explored the association between RA fatigue and pain and concluded that high fatigue levels are common in RA and are mainly linked to pain and depression. The researchers assessed fatigue by means of a 100mm VAS and the vitality subscale of the SF-36 questionnaire (the lower the score the more severe the fatigue, with a

range of 0 – 100). In their cohort, the VAS scores indicated 80% of patients had clinically relevant fatigue and over 50% had high fatigue scores, whilst the mean SF-36 Vitality score was 51 – a figure that is substantially less than the 61 – 65 usually reported in the normal UK population. Interestingly, in the current study, the mean SF-36 Vitality score for the group of participants with both psoriasis and PsA was 47, whilst for those with psoriasis alone it was 58. As was the case in the study by Pollard et al (2006), the SF-36 Vitality scores moderately correlated with the HAQ scores suggesting that those individuals with lower energy levels, which may reflect fatigue, experience greater physical disability.

Although the Psoriasis Group reported lower levels of fatigue and had weaker correlations with the other variables, than the group with both conditions, a significant difference was found when the mean was compared to that of a healthy population. In the current study it appears that fatigue was experienced by individuals with psoriasis, but not to the same extent as the group with PsA, although previous research suggests that fatigue is of concern to those with psoriasis. For example, the results from a study of 492 patients with skin disease found that 50% of the respondents reported fatigue as a frequent symptom (Verhoeven et al., 2007), whilst Evers et al. (2005) concluded that higher levels of fatigue, perceived helplessness and less social support best predicted psychological distress in patients with psoriasis.

According to Swain (2000), fatigue is being recognised as the least well-managed symptom in many chronic illnesses and is largely responsible for a loss of health-related quality of life. Various studies have demonstrated the wide-ranging impact, such as social isolation and unemployment that fatigue can have on the lives of those individuals suffering with a chronic illness (Schreurs et al, 2002; Dittner et al, 2004).

A recent study by Salaffi et al. (2009) lends further weight to these findings as the researchers utilised, amongst other measures, the SF-36 as they sought to compare the health-related quality of life in RA, AS and PsA with a selected sample of healthy people. Their findings indicate that adults with inflammatory rheumatic disease have poorer self-reported health status than those without arthritis in all domains of living, but notably with respect to those scales measuring physical functioning, mobility, role limitation due to physical health and bodily pain. Although RA emerged as the disease with the worst

health-related quality of life for physical dimensions of the SF-36, their mean PCS score was 32.5 which is comparable to 35.95 found in the current study in the group of participants with PsA and psoriasis – as Pollard et al note, based on the PCS scores alone, the physical functioning of these patients is comparable to patients with congestive heart failure (Ware, 2000). The impact of PsA on physical functioning is further emphasised when the mean scores are compared with the 49.03 recorded by the psoriasis-only group – a substantial difference that serves to highlight the decreased physical functioning associated with PsA.

Furthermore, Pollard et al. (2009) also found that patients with PsA reported more psychosocial problems than patients with RA and AS, and that the SF-36 MCS dimensions typically affected by PsA were mental health, limitations due to emotional health, and social functioning. In the current study those participants with both PsA and psoriasis seemingly endured poorer mental health than those with just psoriasis, as was confirmed by a t-test which found a highly significant difference between the groups on the depression scale of the HADS. It is also of note that although the Mean score for the Mental Component Score was marginally higher in the Psoriasis Group, the difference was non-significant.

Given that PsA usually only presents in people who have, or previously had, psoriasis, it is possible that this finding reflects the additional burden of the joint disease, although it must be acknowledged that generally there is widespread ambiguity regarding the relative contributions of skin and joint disease to overall health-related quality of life among patients with psoriasis. Assessing quality of life in this patient group is challenging and often confounded by the simultaneous presence of joint and skin disease.

Lesion severity was not assessed in the present study so it is not possible to ascertain the additional impact that this may have had on psychological distress and functionality. However, the burden of living with psoriasis has already been established in various studies, such as that by Schmitt & Ford (2007) who found that of their sample of 285 psoriasis patients, 32% screened positive for depression. Furthermore, they concluded that specific disease-related problems in everyday life seemed to cause depression in a significant proportion of patients.

A finding to emerge from the current data for the Psoriasis Group was that social functioning was related to psychological health. This result certainly supports previous research with psoriasis patients that consistently report that that individuals with psoriasis experience reductions in their social functioning. For example, one study that explored the psychological effects of psoriasis amongst 104 Irish patients found that a large percentage of patients avoided common social activities, for example swimming and sports; 50% felt that psoriasis had inhibited their sexual relationships and 11% of patients said they would avoid having children in case their offspring should develop the condition (Ramsay & O'Reagan, 1988). Further support for the impact that psoriasis can have on social functioning is provided by Weiss et al. (2002) who evaluated the health effects of skin disease by comparing psoriasis to other primary medical disorders. Using 3 different scales of health-related quality of life, the researchers concluded that individuals with psoriasis are significantly affected in their social functioning when compared with individuals without chronic disease and those with certain primary medical conditions.

In the group with both conditions, social functioning was also found to be associated with psychological health, as measured by the SF-36 Mental Component Score. Given that the initial qualitative study revealed that participants would regularly avoid social events, this finding was perhaps to be expected. However, in the light of a similar finding in the Psoriasis Group, further research may be useful to disentangle whether the impact on social functioning in PsA patients is due to psoriasis or the presence of the arthritic condition.

Unfortunately, few studies are available that compare the health-related quality of life of patients with psoriasis with those patients who have both psoriasis and PsA. One such study undertook a comparison among three groups of Swedish patients – one group had psoriasis, another had atopic dermatitis whilst the third had psoriasis and PsA. Using the DLQI and the SF-36 the researchers concluded that those people with the dual conditions of psoriasis and PsA had significantly poorer health-related quality of life than those patients with psoriasis only. However, as no objective measures of severity or skin disease area were used, there is a possibility that this result could have been related to greater psoriasis severity among those with PsA (Lundberg et al., 2000).

Furthermore, a study conducted by Zachariae and his colleagues (2002) employed the Psoriasis Disability Index (PDI) and the Psoriasis Life Stress Inventory (PLSI) in order to

compare health-related quality of life between patients with PsA and patients with psoriasis only. Their findings supported those of Lundberg et al. (2000) as the patients with both PsA and psoriasis exhibited significantly decreased health-related quality of life. Interestingly, this group also reported more cutaneous lesion severity than the group with just psoriasis, which raises the possibility that their diminished heath-related quality of life could still have been associated with a greater burden of skin disease.

In the current study, the impact of skin disease on HRQoL, as measured by the DLQI, was found to be greater in the Psoriasis Group, furthermore, examination of the correlation coefficients indicated that there was a moderately strong, inverse association with social functioning. However, similar to the study by Lundberg et al.(2000), no objective measure of skin disease was used.

The findings of the current study clearly demonstrate that poor mental health, low mood and depressive symptoms impact on those individuals with PsA, yet within the literature the research once again is focussed on the experiences of RA patients. Nevertheless, examination of this literature is useful as it underlines that depression is RA'S most common co-morbidity and that it is a complex multitude of interactions between clinical, psychological and demographic factors (Covic et al., 2006).

Indeed, a meta-analysis of twelve studies found that depression was significantly more common among RA patients than healthy individuals and was influenced by levels of pain but not demographic factors (Dickens et al., 2003). Although pain is largely viewed as a sensory experience, there is increasing evidence that it is strongly linked to depression, with various studies reporting that pain leads to depression (for example, Sharpe et al., 2001) whilst others suggest it is depression that leads to pain (for example, Zautra & Smith, 2001). However, Covic et al. (2003), in a series of cross-sectional and longitudinal studies, found depression to be mostly independent of pain and predicted by physical disability – a relationship which it has been suggested, is further influenced by the level of importance attached to leisure and social activities at risk or lost due to RA (Katz & Yelin, 2001). Furthermore, Smith & Zautra (2008), in a study that explored the effects of anxiety and depression on weekly pain in women with OA and RA, suggested that the absence of pleasure (activities, etc) may have played a role in the greater vulnerability experienced by

depressed persons in time of stress. They also found that in the RA group, those low in depression reported less pain in times of stress.

It is interesting that in the present qualitative study, one of the findings concerned people's reluctance to discuss pain levels and the management of their pain with health professionals, yet the quantitative study clearly identifies pain as a key issue that is associated with reduced quality of life and appeared to seriously interfere with the continued involvement with valued activities and interests.

In the present study pain was shown, in the group of respondents with both PsA and psoriasis, to have a positive, moderately strong, significant relationship with fatigue, depression, HAQ and self-efficacy. The same association existed with all sub-scales of the SF36 and the two component scores (PCS and MCS), although due to the scoring method the correlation was negative.

The correlation between HAQ and Fatigue was stronger in the group with both conditions and was also significantly different from that found in the Psoriasis Group. This result not only suggests that greater reductions in functional ability are found in the group with PsA, but also that it is associated with levels of fatigue.

The HAQ has been found to have good predictive value in various studies of RA patients, for example, Cohen et al. (2006) examined the utility of HAQ as the best predictor of 5-year quality of life in early rheumatoid arthritis. Using the Arthritis Impact Measurement Scales 2 (AIMS2) as the outcome measure for quality of life, the researchers found that the baseline HAQ score was the best predictive factor for the physical, symptom, psychological, social interaction, and work scores of the AIMS2.

The relationship between pain and physical disability is far-reaching and has been shown to lead to diminished health-related quality of life and life satisfaction amongst RA patients (Borman, 2007), whilst Katz (1998) found that patients with RA report pain, fatigue, functional impairment and unpredictability of symptoms as having a significant impact on their lives (Katz, 1998). Furthermore, Covic et al. (2000) studied 111 RA patients and examined the association between pain and coping and the impacts of psychological variables on the relationship. In order of strongest correlations with pain, the strongest link

was passive coping, followed by physical disability, depression and helplessness, whilst the only significant predictors of pain were physical disability and passive coping.

Such studies suggest that physical disability is an outcome of the underlying disease and is closely linked to pain. However, differences in the disease itself may play a role given the unpredictable and chronic nature of RA, meaning the importance of key factors may change. For example, physical disability may dominate during a disease 'flare-up', whilst psychological factors may have a greater impact over time due to the perceived and real loss of quality of life caused by the disease.

Despite the variety of studies investigating the relationship between pain and depression, causal effect remains difficult to determine. However, what such studies do indicate is that a multimodal assessment of a broad set of physical, psychological, and social stressors and resources are needed for the understanding and prognosis of psychological distress.

When considering the current study, in which levels of depression and anxiety were assessed using the Hospital Anxiety and Depression Scale (HADS), it is important to acknowledge that many of the participants had the additional burden of skin disease to contend with, which could potentially be a causal factor for any symptoms of depression or psychological distress. The results identified 13 people (3.7%) with probable depression and a further 39 (11%) as being border-line for depression. These figures not only support those reported in the RA literature that used research interviews – the gold standard of psychiatric assessment – to conservatively estimate the prevalence of depression to be in the region of 13 -20% (Creed, 1990) but also clearly demonstrate the heightened levels of psychological distress experienced by those with PsA and psoriasis.

Whilst the focus of this study is PsA, it is impossible to ignore the role of psoriasis, and the profound impact it can have on some patients. Psoriasis-related decrements in health-related quality of life have been shown to result in significant stress for the patient, as they have to manage and cope with, what can be a disfiguring disease. Significantly higher degrees of depression have been noted in psoriasis patients when compared with controls, with Beck Depression Inventory (BDI) scores shown to be strongly correlated with the severity of the psoriasis symptoms (Devrimci-Ozguven et al., 2000). In their study of 127 psoriasis patients, Gupta et al (1993) found a 9.7% prevalence of a death wish and a 5.5%

prevalence of acute suicidal ideation at the time of the study, furthermore at least 20% had contemplated suicide.

Studies of psoriasis patients consistently report elevated levels of depression and depressive symptoms. Indeed in a large questionnaire-based study of Italian psoriasis patients (n = 2391), 62% returned scores indicating the presence of depressive symptomatology, as determined by the Centres for Epidemiologic Studies Depression Scale (Esposito et al., 2006), whilst another study used the General Health Questionnaire to assess the psychiatric morbidity of patients with psoriasis and vitiligo and concluded that 53% of psoriasis patients versus 17% of vitiligo patients had scores suggesting the presence of psychiatric illnesses, such as depression, anxiety, and sleep disturbance (Sharma et al., 2001).

In the current study, the Psoriasis Group reported lower levels of depression and anxiety that a similar reference group, and it is particularly interesting that in the current study, although the difference between the groups was not significant, the Psoriasis Group experienced greater levels of anxiety, than depression, as measured by the HADS, than those with PsA. However, when the three variables of MCS, RE and MH were correlated with Anxiety, the resulting coefficients were not only stronger than the group with PsA, but they were also significantly different. Whilst acknowledging that the MCS takes into account the correlations among the RE and MH subscales, it may be argued that the result for the MCS may be expected in this case, but it is possible, according to Ware et al. (1994) to just use the component scores to clearly reflect the impact of the disease without substantial loss of information. The source of the anxiety in this group is unknown and warrants further investigation, particularly in the light of the various psychosocial issues perceived to have an impact on quality of life, and cited by respondents in the 1998 National Psoriasis Foundation Patient-Membership Survey, as being workplace difficulties, socialisation with family members and friends, exclusion from public facilities and contemplation of suicide (Krueger et al., 2001).

These studies not only illustrate the severe and deleterious effect that psoriasis can have on an individual's well-being but serve to show that clinical measures of disease status alone are insufficient to describe the burden of illness.

Mease & Menter (2006) have suggested that health-related quality of life is a relatively new area of research focus in psoriasis as there is a growing awareness among health professionals that the physical manifestations of psoriasis such as redness, scaling and pruritus represent only part of the burden of the disease, as these physical problems inevitably impact on psychosocial domains.

The results of the present study clearly show that the group of participants with both psoriasis and PsA experience decreased quality of life, measured using the SF36, when compared with the group who have psoriasis only, and that living with PsA and psoriasis is clearly a challenge as patients contend with the varying influences of pain, fatigue and depression and their inevitable impact on daily activities.

An individual's ability to manage such symptoms varies, but one concept that may help in understanding the variation in adjustment and the perceived ability to self-manage is that of self-efficacy. Developed within the framework of social-cognitive theory by Bandura (1977), self-efficacy refers to the belief that one is capable of performing in a certain manner to attain certain goals, and once formed, self-efficacy beliefs influence not only the course of action pursued, but also the effort expended, level of perseverance and the amount of stress experienced in demanding situations. It is not concerned with the skills one has, but with the judgement of what one can do with whatever skills one possesses.

Researchers have suggested that self-efficacy is one of the key cognitive factors that influence pain tolerance, negative affect (e.g. stress and anxiety) and choice of coping strategies (Arntz & Schmidt, 1989; Haerkaepaeae et al., 1996; Schermelleh-Engel et al., 1997) and that it is possibly the most important factor in predicating long-term change for those dealing with pain disorders (Schermelleh-Engel et al., 1997).

To date, there has been little exploration of the role of self-efficacy in individuals with PsA, although various studies of patients with rheumatoid arthritis, osteoarthritis and ankylosing spondylitis have included various self-efficacy measures.

Measurement of self-efficacy in the current study was undertaken using the Self-efficacy for Managing Chronic Disease measure (Lorig et al., 2001). The mean score recorded for the group with psoriasis (M = 7.51) was higher than the mean of 6.32 for the other group –

a figure similar to the mean of 5.17 reported in the validation study by Lorig et al. (2001). It is possible that self-efficacy measurement needs to be more in context - that is, specific to either psoriasis or psoriatic arthritis or possibly arthritis- related pain. It may be the case that the instrument needs to incorporate not just the expectation that a person could perform a particular behaviour or task, but also their confidence in being able to do it despite their pain.

Nonetheless, the results confirm the existence of associations between self-efficacy and physical and psychological health, as low self-efficacy was associated with more pain, more fatigue, greater depression and anxiety and greater physical impairment.

The group with both conditions recorded lower levels of self efficacy than the psoriasis group. However, of particular interest were the correlations found between self efficacy and the HAQ, PF and PCS, as all three were significantly different to those found in the psoriasis group. They are results which clearly suggest an important association between physical and functional ability and self efficacy.

These findings are similar to those of Barlow et al. (2002) who examined the psychosocial well-being, self-efficacy and preferences for psycho-educational interventions among a group of fifteen RA patients. The researchers concluded that low self-efficacy was related to greater physical impairment, more fatigue, more depressed and anxious mood and less acceptance of their condition. Furthermore, Higher self-efficacy scores have been associated with lower pain intensity (Brekke et al., 2001; Cross et al., 2005), less functional impairment (Turner et al 2005; James et al, 2005) and better adherence to non-analgesic medication (Brus et al., 1999).

Cross-sectional studies have generally been used by the handful of researchers who have studied the effect of self-efficacy on certain aspects of RA. For example, Taal et al. (1993) found that the higher the level of self-efficacy, the better the patients judged their health status, independently of disease activity. Self-efficacy has also been found to correlate with the level of fatigue (Riemsma et al., 1998) and with daily pain and mood (Lefebvre et al., 1999).

In the psoriasis group, stronger correlations, that were significantly different to those in the other group, were found between self efficacy and the both the DLQI and SF-36 subscale of MH, implying that for those individuals with psoriasis self efficacy is more clearly associated with psychological health rather than physical health. It is of interest that this finding is somewhat opposite to that found in the group with both psoriasis and PsA and may reflect a subtle difference in the burden of the different conditions. It certainly warrants further investigation as it may just reflect the need to measure self efficacy with a disease specific measure rather than a generic one.

The concept of self-efficacy is widely accepted and acknowledged to be important in the study of pain and there is evidence to suggest that patients with higher perceived self-efficacy report less pain (Keefe et al., 2005) Cross-sectional measurements of self-efficacy are believed to be a meaningful indicator of daily pain and coping, with greater self-efficacy often leading to more effective pain coping mechanisms (Gustafsson, 1999). Indeed, people with high levels of self-efficacy (for pain) have reported less pain then those with low self-efficacy when subjected to painful stimuli in a laboratory (Keefe, 2005).

Given the evidence that higher self-efficacy is associated with better health behaviours, researchers have explored ways of enhancing self-efficacy. Interventions such as exercise and stress management programmes have been utilised with patients and their impact assessed. For example, in one UK study, Buszewicz and her colleagues (2006) randomised 812 patients with osteoarthritis to six sessions of self-management of arthritis and an education booklet (intervention group) or the education booklet alone (control group) and found that the two groups showed significant differences at twelve months on the Anxiety sub-score of the HADS, Arthritis Self-efficacy Scale for Pain and self-efficacy for other aspects of management. They concluded that the self-management of arthritis programme reduced anxiety and improved participants' perceived self-efficacy to manage symptoms. These results provide further evidence that self-efficacy is a modifiable factor that is associated with current and future health behaviours.

7.4   Summary of Results

The results of both the qualitative and quantitative studies have clearly shown that reductions in health-related quality of life occurred, and were perceived, by the participants, to be as a result of having either psoriasis or psoriasis with PsA.

The Group with Psoriasis and PsA experienced greater reductions across all the psychosocial variables that were measured, with the exception of the DLQI, than the Psoriasis Group. However, those individuals in the Psoriasis Group undoubtedly experienced decrements to their quality of life and what is more, the decrements appear to be different in nature to those experienced by the group with both conditions.

Fatigue emerged as a key issue for those with PsA, impacting on physical functioning and pain, whilst levels of self efficacy and depression were also associated with the ability to function well.

By comparison, in the Psoriasis Group, anxiety levels were highlighted as an issue and were associated with other measures of psychological functioning, as was social functioning and self efficacy.

When encompassing all the findings of the current study in which higher levels of fatigue, depression and pain, and decreased self-efficacy have been found to be detrimental to health-related quality of life, impacting on both physical and social functioning, the implication is that the traditional medical model of care needs expanding to incorporate psychological and social support into the assessment and management of patients with PsA and psoriasis. The use of a multi-disciplinary team could support and facilitate coping strategies for pain management and fatigue, assess and monitor actual and potential psychological distress whilst physiotherapy and occupational therapy could be used to maintain and enhance physical functioning to improve activities of daily living.

7.5   Discussion of Mixed Methodology

Mixed methods investigations involve integrating more than one type of research method and may be a mix of both qualitative and quantitative methods, or a mix of just qualitative methods or just quantitative methods in a single study.

The use of mixed methodology remains the focus of much debate amongst researchers, with the advocates of quantitative and qualitative research paradigms seemingly engaged in ardent dispute for more than a century, with purists emerging on both sides claiming that their paradigm is the superior (Johnson & Onwuegbuzie, 2004) thereby positing that qualitative and quantitative research paradigms cannot and should not be mixed.

Clarke and Yaros (1988) have argued that combining research methods is useful in some areas of research, such as nursing, because the complexity of phenomena requires data from a large number of perspectives, whilst Haase & Myers (1988) have strongly advocated that the two approaches can be combined because they share the goal of understanding the world in which we live. Moreover, Reichardt & Rallis (1994) maintain that the use of mixed methods is acceptable because they are united by a shared commitment to understanding and improving the human condition, a common goal of disseminating knowledge for practical use, and a shared commitment for rigor, conscientiousness, and critique in the research process.

Whilst it is outside the scope of this thesis to engage at length about the intrinsic worth of each type of research, the author fully appreciates the differences in the paradigms, and suggests that by utilising quantitative and qualitative techniques within the same framework, mixed method research can incorporate the strengths of both methodologies. Indeed almost fifteen years ago, Sechrest & Sidana (1995) argued that a growth in the mixed methods movement would have the potential to reduce some of the problems associated with singular methods. In the context of the current study this is certainly the case, for it is the author's position that neither qualitative nor quantitative methodology alone would have answered the research question, whereas a combination of the two would be more productive. The approach was viewed as being complimentary as it offered the potential to provide insights that may not be achievable through the use of a singular method.

Within this research, the justification for employing both a qualitative and a quantitative study was driven by the distinct lack of published literature. This highlighted the need for an initial exploration of the phenomena as a first step to understanding the key issues that impacted on patients with PsA. A qualitative study would achieve this objective whilst at the same time it would allow the research to be patient-driven and patient-centred and would ground the research in the lived experiences and real world of the sufferers, so infact, the qualitative study became an essential preliminary to the quantitative research.

A phenomenological approach was chosen as it aims to describe or elucidate such experiences of a phenomenon as the individual lives it. It was deemed appropriate because complex phenomena such as feelings and experiences of illness and disease cannot always be explained and accounted for in terms of things or objects as in the natural sciences (Karlsson, 1995).

As PsA research has rarely explored, either qualitatively or quantitatively, the psycho-social consequences of the disease, the author believed that the findings of the initial qualitative study could be used to inform the selection of measures which could then be employed in a quantitative study. Therefore, the merits of combining both quantitative and qualitative methodology to adequately elucidate patients' perspectives were advocated.

7.5.1 Integration of Results

There is certainly no guarantee when a mixed method approach is adopted, that the final results will support each other, however in this study the quantitative study certainly supported the findings of the qualitative study, and vice versa.

It is of note that the health-related quality of life of participants in the small qualitative group was just as affected as that of the much larger sample used in the quantitative study. This not only adds to the reliability of this research, but also provides general further support for the argument that mixed methodology has a role to play in health research.

In this instance, the rich, descriptive data of the qualitative study enabled an appropriate selection of measures to be identified in order to quantify the issues that had been

highlighted by the participants. Regardless of the methodology used, the key issues found were the same.

7.6 The Use of Postal Surveys and Self-Report Measures

Postal surveys are widely used to collect data in health research and are a useful tool for examining the attitudes and behaviours of both patients and health professionals. Indeed, often they are the only financially viable option when collecting information from large, geographically dispersed populations.

In the current study, the postal survey achieved an overall response rate of 30%, although it is of note that of the questionnaires sent out to members of the Psoriasis Association, 31.6% were returned, whilst of those mailed to hospital patients only obtained a 22% return.

When considering why a higher response rate was not obtained, it is important to acknowledge the impact of several factors. Firstly, the questionnaires were mailed during the summer period so there was a possibility that people may have been away on holiday so when returning to their mail they may have simply viewed the survey as low priority and categorised it as 'junk' mail. Secondly, given that staff at the Psoriasis Association and not the researcher, mailed out 1000 of the 1200 surveys, it is not known how many were undeliverable because of incorrect addresses and lastly, due to financial and time constraints, the study design did not include any type of follow-up procedure, such as sending a written reminder or using a telephone call, to contact non-responders.

According to Asch et al. (1997) postal surveys need high response rates to be successful. They suggested that a high response rate typically lowers the cost per response and the cost necessary to achieve a sufficient sample, and that it reduces the extent or possibility of non-responder bias.

Furthermore, Cook et al. (2009) maintain that low response rates increase the potential for bias and threaten study validity. However, in their study of response rates in postal surveys of healthcare professionals between 1996 and 2005, the researchers found that only 17% of 350 studies attempted assessment of possible non-response bias, leading them to suggest

that researchers should at least recognise the influence of non-responders and consider whether they undermine the generalisability of findings to a wider population.

Whilst the author acknowledges there is an ever-growing body of research examining possible methods for increasing response rates and reducing non-response bias in postal surveys, such as using multiple mailings to make frequent contact and the use of financial incentives (Van Geest et al., 2007), as previously noted, these were not feasible within the current study.

Similarly, it has not been possible to perform any non-responder analysis given the anonymity of the sample. However, there is some evidence suggesting that demographic characteristics of responders and non-responders to health surveys may be similar. In an American study, Filip et al. (2004) conducted a postal survey of a dermatology patient population, all of whom had a diagnosis either of non-melanoma skin cancer, acne rosacea, dermatophytosis, eborrheic keratosis or warts, and a response rate of 69.8% (3203 patients) was achieved. The researchers analysed the non-responders and found that their characteristics did not generally differ from those of the responders, indicating that non-response bias may be of less concern than in some studies, and that their respondents were probably representative of their target population.

Given that the design of the current study excluded the use of follow-up or reminder mailings, it could be argued that a good response rate of 30% was achieved, however in order to improve the informativeness of postal survey findings in future studies, researchers should routinely consider the use of follow-up reminders and assess the potential for non-response bias, as this would undoubtedly increase response rates. This is supported by research that found the use of reminders, either telephone or written, increased response rates by approximately 13% (Asch et al., 1997).

Postal surveys may be a less accurate method of collecting data due to the self-report style of the questionnaires, which highlights not only the issue of using postal surveys, but also the issue of using of self-report measures.

Firstly, it is important to recognise that information such as functional disability, depression and pain describe the progressive disability and suffering endured by these patients and as such, is information that cannot be easily obtained except through patient

self-report instruments and interviews, however, the latter undoubtedly require greater resources in terms of time and expertise. Secondly, such data is perhaps best viewed as adding value to the usual clinical data. It is not that one type of data is superior, but simply that the combination of both sets can be used to better inform clinicians' judgements regarding potential treatments, and also assists in the early identification of comorbid conditions such as depression. Indeed, Wolfe & Pincus (1999) in their commentary paper entitled 'Listening to the Patient', argue that self-report questionnaires are probably more informative than clinical measures such as tender joint counts. They do however, recognise that self-report data are not perfect as it is impossible to determine whether the patient responses are truthful and they suggest that, whilst there is general agreement that the patient is the best source of data regarding pain, function and global severity, it is the combination of clinical and patient data that facilitates the best estimate of disease status.

7.7   Membership Groups

The majority of the returned questionnaires were from members of the Psoriasis association – therefore it could be argued that the responses are representative of a group of individuals who are willing to take the time to participate in the survey and may be more involved and knowledgeable about their condition.

It was interesting to note that a higher proportion of the participants from the Psoriasis Association had attained either graduate or post graduate qualifications – the implications of this are unclear and the author can only speculate that members of the Association may be more likely to engage in seeking out information about their health condition or be more comfortable engaging in a self-help group.

Previous research with AS patients, that focussed on the possible differences between members and non-members of self-help groups for people with this form of chronic disease, analysed health locus of control beliefs along 3 dimensions: internality, powerful others and chance. The results showed that members of National Ankylosing Spondylitis Society self-help groups placed significantly less reliance on "powerful others" for control of health, than did non-members. The researchers posited that such patterns of beliefs may be related to the nature of AS, which is incurable, progressive, unpredictable and difficult

to diagnose – infact, very similar to PsA. It may be from the patient perspective that health care professionals have little to offer them and that people who join a self-help group feel less reliant on medical professionals to control their health. The group members not only displayed a tendency to seek out information about their disease, but also differed from non-members in terms of belief in the value and frequency of exercise for AS and interestingly, received a valuable source of social support from fellow members (Barlow et al., 1992).

These findings mirrored those of an earlier study by Volle et al., (1990) who had investigated psychological correlates of membership in self-help groups for rheumatic diseases among 138 patients with either RA, AS or arthrosis. Volle et al. found that self-help group members display specific control beliefs that differ from the non-self-help group members, with group members viewing the disease as more controllable by themselves and as less dependent on health personnel. They too searched out more information and demonstrated better disease and treatment knowledge.

This evidence suggests that members of self-help groups may speak more frequently about their disease and the available treatments and 'tap in' to the knowledge shared by other sufferers, which in turn empowers them to take greater control over their symptoms. Such empowerment could be argued to have a beneficial effect on an individual's level of self-efficacy, which as a consequence facilitates their management of symptoms such as fatigue and pain.

Self-help groups may be considered as a therapeutic extension to health services as they appear to offer important benefits to their members. They provide a structure for mutual aid and support, and offer a forum for knowledge exchange and social action, which then has the potential to empower people to deal with a chronic disease.

Again, the author can only speculate as to the degree these results were affected by the majority of the respondents being members of the Psoriasis Association. However as evidence of group membership is associated with improved locus of control when dealing with a chronic disease, it is likely that health-related quality of life would have shown even greater decrements, had the sample consisted of non-members.

7.8   Limitations/Future studies

The current study did not address the presence of comorbidity and therefore did not account for any additional impact they may have on quality of life. Research into PsA could certainly be enhanced by incorporating an assessment of comorbidity into future studies of PsA involving health-related quality of life outcomes, as coexisting conditions may impact on outcomes of interest such as depression, physical functioning and global health status. Measures of comorbidity are often sourced from health records that may be difficult to obtain, however research suggests patients can accurately assess current and past medical conditions including comorbidities by means of a questionnaire (Katz et al., 1996). This suggests future studies may overcome this limitation by including a patient self-report, such as the Self-Administered Comorbidity Questionnaire that has been found to be an efficient method to assess comorbid conditions in clinical and health services research (Sangha, Stucki et al, 2003).

Health-related quality of life is a relatively new area of research focus in patients with PsA and, to a lesser extent psoriasis, although there is a growing awareness amongst health professionals that the physical manifestations of PsA and psoriasis represent only a part of the total impairment and disability that may result from living with these diseases.

There are a limited number of validated, disease-specific tools that are currently available to measure health-related quality of life in this patient group. The findings of this study underline the need to strive towards the development of suitable measuring instruments that are patient driven. The incorporation of patients' perspectives into outcome measures is essential as it respects the uniqueness and individuality of patients' experiences and ultimately reflects a more accurate assessment of the health and psychosocial concerns associated with the disease.

In this study, fatigue, depression and pain were found to overlap and entwine and may produce additive impairments in many areas of an individual's life, including daily functioning, social functioning and, unemployment. Although significant rates of work disability in PsA patients have been reported (Mau et al., 2005), most researchers largely ignore employment and work disability. Employment was one of the issues identified in the qualitative study, but was not the focus in the quantitative study, thus leaving a gap that

future research should aim to bridge, particularly as work disability associated with inflammatory arthritis accounts for the majority of the costs associated with diseases such as RA and ankylosing spondylitis. (Shanahan & Ahern, 2008). Furthermore, Shanahan & Ahern (2008) suggest that it may be feasible for simple workplace changes to reduce work disability from arthritis, and posit adjustments such as start time, shift work and ergonomic adjustments to work stations as possible solutions.

Future research should investigate the possibility of self-efficacy as a mechanism or an intervention to effect positive change in fatigue and health-related quality of life. Measurement of self-efficacy is useful for planning patient education programmes because the identification of areas with low self-efficacy helps in the targetting of self-management to individual patients. For example, Barlow et al (2002) established that RA patients preferred education about the disease, it's treatment and emotional issues to be dealt with on a one-to-one basis by health professionals, a group intervention format for self-management and exercise and relationship issues, but preferred videos for the demonstration of aids and coping. Such information would enhance the design and development of appropriate interventions and ensure their delivery was accurately targeted to achieve maximum impact.

The effect of belonging to a self-help group for both psoriatic arthritis and psoriasis needs further investigation as this may have implications for the self-management of disease. Through such groups it may be possible to facilitate empowerment and knowledge about PsA and treatment and enable patients to take greater control over their condition, thereby making more efficient use of the primary and secondary care services that are available to support them.

It must be acknowledged that small study numbers can limit the generalisation and significance of findings, particularly those from the qualitative study. Nonetheless, this methodology has highlighted fatigue, depression and pain as the predominant health status impairment and provides a good springboard from which to launch further research.

7.9   Practical Implications for Treatment

The results of the two studies presented in this thesis have implications for the treatment of patients with psoriasis and PsA, or indeed, psoriasis.

Key issues identified in the current research concerned pain, fatigue, self efficacy, physical and social functioning, all of which may benefit from a range of interventions.

Although the development of new 'biologic' treatments for both PsA and psoriasis continues, their use is in their infancy, they remain expensive and are currently not available to a large percentage of patients. Whilst health professionals continue to rely heavily on treatments primarily based on the traditional medical model, there are a variety of psychosocial interventions that have been shown to improve the quality of life of patients with established disease, are generally inexpensive to administer, and which may be used alongside traditional medical treatments.

For many people with PsA and psoriasis, managing their chronic disease is an ongoing process, where the day-to-day care responsibilities fall most heavily on patients and their families, and where medical interventions are focussed on minimising symptoms, such as pain, rather than being curative.

Interactions with close family members have consequences for the emotional and physical well-being of individuals who are dealing with chronic physical illness, which may suggest that a logical treatment approach would be to consider the inclusion of a close family member in psychosocial interventions that have the potential to boost the effects of intervention on the patient, and also benefit the family member.

In the current study, patients with PsA experienced levels of pain that were detrimental to their physical functioning and restricted their participation in other roles, including those integral to family life, such as being a parent, managing a household, and maintaining relationships. Although many were prescribed regular pain medication, the participants referred to a constant awareness of a background level of pain.

This finding suggests there is a need for other interventions that may alleviate the experience of pain. Indeed, evidence from the results of an education and support intervention for osteoarthritis patients and their spouse, found that patients in the family intervention experienced a greater gain in their efficacy for managing arthritis than patients who received information and support with other patients, although there is contradictory evidence from a study that utilised a family intervention where the partners (88% spouses) attended arthritis self-management sessions with patients. Unexpectedly, the educational program attended by patients was found to enhance self-efficacy and reduce fatigue significantly better than the program attended by patients and partners. In fact, patients receiving the family intervention experienced decreased self-efficacy and increased fatigue. (Martire et al., 2003).

Whilst such studies may produce mixed results, a meta-analytic review that focused on multiple chronic illnesses, showed that psychosocial interventions incorporating a family member had small effects on patient depression and mortality and small to medium effects on burden, depression, and anxiety in the family member (Martire, et al., 2004), suggesting that family interventions have a valuable role to play.

There is undoubtedly a need to keep evaluating the efficacy of family caregiver interventions as this will illuminate specific programmes that support and benefit the patients and, in turn, may inform conceptual models of the impact of family interactions on health.

As previously stated, patients living with PsA and psoriasis make day-to-day decisions about the self management of their illness, which suggests there is a need for self-management education which goes beyond the traditional patient-education offerings of information leaflets. Self-management education teaches problem-solving skills and complements traditional patient education in supporting patients to live the best possible quality of life with their chronic condition.

A central concept in self-management is self-efficacy which is defined as having the confidence to carry out behaviour necessary to reach a desired goal. In the current study self efficacy was found to be associated with physical functioning in PsA patients, whilst in those with psoriasis it was associated with psychological functioning

Research suggests that self efficacy is enhanced when patients succeed in solving patient-identified problems and that this can be achieved through the use of self management education. Moreover, there is evidence from controlled clinical trials that found programmes teaching self-management skills are more effective than information-only patient education in improving clinical outcomes and, that in some circumstances self-management education improves outcomes and can reduce costs for arthritis patients (Bodenheimer et al., 2002).

The routine measurement of self-efficacy in rheumatology and dermatology clinics may be beneficial as it may be used to detect individual differences between patients and identify those with low levels of self efficacy. This information may be used as an indicator to predict important health outcomes such as health-related quality of life and even hospital admissions, so highlighting those patients most at need of an intervention to improve their levels of self efficacy. Changes in self-efficacy over time can be easily measured and this facilitates the evaluation of the impact of patient education programmes.

An association was found in the current study between self efficacy and psychological health, although anxiety and depression were also associated with decrements in both physical and social functioning in the participants. It is possible that early screening for such conditions may result in prescribing therapies and drugs to improve emotional functioning and potentially impact on the levels of pain and fatigue.

It would be beneficial to highlight the importance of identifying anxiety and depression in this clinical group with health professionals, in order that timely, appropriate treatment be given. This is one area, where the use of an education programme with practice nurses and 'nurse prescribers' in Primary Care may be useful, as they are well placed to provide interventions to patients with chronic conditions.

For many healthcare providers, pharmaceutical treatments may be the first choice to manage depression and anxiety however, there is much evidence to support the use of psychosocial interventions as an effective treatment. A systematic review of psychological interventions was completed by Astin et al. (2002) and included a review of studies that examined the efficacy of interventions such as relaxation, biofeedback, cognitive-behavioral therapy and stress management. Their conclusions were based on data from 25

randomised controlled trials that compared these interventions to non-intervention control groups (usual medical care or waiting list). Overall, the researchers reported small, but statistically significant, average effect sizes for pain, functional disability, depression, coping, and self efficacy post-treatment. Additionally, after follow-up (an average interval of 8.5 months) the effect sizes for coping, psychological status, and tender joints were significant, whereas those for pain, disability, and self efficacy became non-significant.

It is clear that such interventions are a useful treatment and as such, their use in psoriasis and PsA patients warrants exploration as they may provide an effective adjunct to conventional medical management.

Similarly, cognitive-behavioural therapy (CBT) may have a role to play in improving the psychological health of PsA and psoriasis patients. CBT addresses the links between thoughts or beliefs, feelings and behaviours, and uses individualised goal-setting and cognitive restructuring to help patients make desired changes in behaviour. In RA patients, such changes have been shown to have a positive impact on psychological health, which in turn, resulted in significant improvement in fatigue post-intervention, and at follow-up six months later (Evers et al., 2002).

An understanding of the different contributions of depression, fatigue, and pain to health-related quality of life may inform future interventions and advice provided to those with PsA with a possible beneficial effect.

Social functioning emerged in the current study as an issue for the participants, and was shown in the quantitative study to be associated with self efficacy and psychological health. Furthermore, the participants would actively avoid social events, yet they didn't enjoy being isolated. This finding requires further exploration as several participants mentioned that they would feel more comfortable in a group of similar patients as they would be sympathetic and understanding. This suggests that interventions that employ a group format may be an appropriate strategy for this clinical group.

Psychosocial and psychological interventions have been delivered in individual as well as group formats, with each offering the potential of providing different benefits. A group format may provide a context to normalise patient experiences and to benefit not only from

interaction with a designated group leader, but also from the experience of other patients, whilst also gaining the social support provided by the group members. This contrasts with the benefits associated with individual interventions which offer the opportunity to specifically tailor interventions to the needs of the individual patient and to intervene intensively with that patient (Bracke & Thoresen 1996).

It is clear from this research that negative emotions and loss impact greatly on the patients and their families, yet it seems that during clinic visits, there is little offered in the way of support, particularly emotional support. The specialist rheumatology nurses that are usually present in clinic are ideally placed to provide support through empathic listening, yet the results of this study suggest that patients are reluctant to discuss issues, firstly because they feel it is not appropriate to seek support, and secondly because they fear they are wasting the nurses' time. In order to overcome these barriers nurses need to develop a trusting relationship with the patient and to this end may benefit from the acquisition of counselling skills. Once the dialogue is open, nurses should be able to assist in identifying suitable pain management strategies, the development of healthy coping skills and the management of negative outcomes of the disease process, such as increasing disability and deformity.

The participants in the current study have emphasised the need in Secondary Care for more clinical time to be made available for multidisciplinary care that optimises patient outcomes. What is more, undergraduate and postgraduate medical education needs to reflect the prevalence and importance of psoriasis and PsA in the population so that, in future, they can identify and manage these conditions, whilst consultants and specialists need to embrace the new concepts and array of possible interventions that may be used in effectively managing these diseases.

In a world that is constrained by health economics, easy access to a multi-disciplinary team of health professionals may be a distant vision, yet may prove to be the best answer to improving the health-related quality of life for people with PsA and psoriasis; consultants, nurses, physiotherapists, occupational therapists and counsellors all have a role to play.

PsA and psoriasis are complex, multi-faceted diseases which require multi-faceted answers and therapeutic decisions should be based on thorough assessments that include health-related quality of life.

7.10   Concluding Comments

Whilst recognising that there is no one best method of research, the inference from this study is that it is the combined data from rheumatologists, dermatologists, clinical measures, health-care professionals and patients that should be utilised to impact positively on health status and prognosis in patients with PsA and psoriasis.

Through the use of mixed methodology this PhD research has firstly, by means of a qualitative study, identified, from the perspective of those patients with PsA and psoriasis, psychosocial issues that were perceived to be detrimental to their quality of life. A quantitative study then proceeded to employ standardised psychometric instruments in order to investigate the impact of these variables and assess their role.

While acknowledging that qualitative research findings should not be generalised, the areas of concern highlighted are noteworthy. In addition to fatigue, pain and depression and self efficacy, concerns emerged that related to the uncertainty imposed by the disease due to limitations in both the treatment and understanding of disease aetiology. Also, disease unpredictability was viewed as impacting on fatigue and pain levels that in turn were reported to affect numerous daily activities, role competencies, dependency levels and relationships.

The impact of living with psoriasis and PsA has been highlighted in the current study and furthermore, the burden of disease has been shown to be different, depending on whether patients have psoriasis and PsA or just psoriasis.

The results of this study contribute to the current understanding that pain is a complex phenomenon that is capable of pervading every aspect of a person's life. Whilst it was not unexpected that pain emerged as a major symptom in patients with PsA and psoriasis, the qualitative study certainly revealed the far-reaching impact that pain can have. There is little doubt that in this patient group, it cannot be viewed as a stand-alone symptom as it is implicated in, and affected by, a variety of other factors such as mood and fatigue.

Fatigue continues to defy efforts to conceptualise or define it and typically remains ignored or excluded from the assessment of symptom severity or outcome in many disease

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processes including PsA and, given that it is consistently neglected as a target for treatment, it is not surprising that little is known about the phenomenology of fatigue.

This study has found that patients with PsA perceive fatigue to be an untreatable symptom, and that they generally fail to express their concerns about it to their health carers. It is a subjective symptom, meaning the only way that health professionals can understand the patient's experience of fatigue, is by listening to their patient and exploring their concerns. It is therefore of paramount importance that health professionals are aware of fatigue and the impact and consequences it can have on the daily lives of those it affects.

These findings have highlighted the need to elucidate the symptom of fatigue in PsA and position it as an appropriate target not only for clinical management, but also psychological management. By advocating fatigue as a legitimate concern this may offer patients the chance to discuss fatigue explicitly and obtain appropriate health advice.

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Appendix 1

Audio & questionnaire consent Forms

SUPPLEMENTARY CONSENT FORM FOR AUDIO TAPING

Title of project: Quality of life in people with psoriasis and psoriatic arthritis

Name of researcher: Cathy Aitken

Please initial box

1. I confirm that I have completed the consent form to participate in the above   study and had the opportunity to ask questions

2. I understand that interviews and focus groups will be audio taped and that   as soon as the tapes have been transcribed they will be destroyed.

3. I agree to the audio taping of my focus group.

4. 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.

5. I agree to take part in the above study

Name of Patient   Date   Signature

Name of person taking consent   Date   Signature
(if different from researcher)

Researcher   Date   Signature

1 copy for patient, 1 copy for researcher, 1 copy to consultant

Audio tape consent form, Version 1 (06/06/05)

Appendix 2

Participant invitation letter & questionnaire consent form

Dear Psoriasis Association Member,

The Psoriasis Association has sent the enclosed questionnaire to you, as they are assisting me, Mrs Cathy Aitken, with PhD research entitled 'Psoriasis and Psoriatic Arthritis: The role and impact of psychosocial factors'.

It is anticipated that this research will enhance our understanding of the ways in which these conditions may impact on quality of life.

I have enclosed a full participant information sheet for you to read, however, if you have any questions please do not hesitate to contact me.

May I take this opportunity to thank you in advance for assisting with this valuable research.

Yours faithfully,

Mrs Cathy Aitken
PhD Student
Liverpool John Moores University
Room 303b Henry Cotton Bldg
15-21 Webster Street
Liverpool
L3 2ET

liverpool
JMU

CONSENT FORM

Title of Project: Quality of life in people with psoriasis and psoriatic arthritis

Name of Researcher: Cathy Aitken, Liverpool John Moores University.

Please tick box

1. I confirm that I have read and understand the information sheet dated 08/12/06 (Version 1) for the above study and that full details of the project/procedure have been described in writing.

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 any information I may provide to the researcher will be kept confidential and secure in accordance with ethical guidelines of the British Psychological Society, and furthermore that my name will not be linked to any data used in publications or research reports arising from this study.

4. I agree to take part in the above study.

Name of Participant

Date

Signature

Witness (an independent third party)

Date

Signature

1 copy for participant, 1 to be returned to researcher with questionnaire pack

Appendix 3

Participant information Sheet

Participant Information Sheet

Quality of Life in people with psoriasis and psoriatic arthritis

You are being invited to take part in a research study looking at quality of life in people with psoriasis and psoriatic arthritis. 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 friends, relatives and your doctor if you wish. Ask us if there is anything that is not clear of if you would like more information. Take time to decide whether or not you wish to take part.

Why have I been chosen? This study is intended for people who have been diagnosed with psoriasis or psoriatic arthritis (or both).

Who is doing this research? The study is being carried out by researchers from Liverpool John Moores University and Aintree Hospital. If after reading this information you have any questions at all about the study, please contact Cathy Aitken (0151 231 4110) who will be pleased to discuss any aspect of the study with you.

What is it about? As health professionals we understand that psoriasis and psoriatic arthritis can sometimes affect the quality of many aspects of your daily life (such as work life, social life, leisure activities etc). As we routinely measure the impact of these conditions it is important that we continue to measure the aspects that affect you most. In order to do this we are looking for patients to complete a questionnaire booklet.

What will I have to do if I take part? If you decide that you would like to take part in this research all that you will have to do is complete the enclosed questionnaire that will take approximately twenty minutes.

Who will see the information I give? The research team will use any information you give for the purposes of the project only; it will not be passed on to any other agencies. All information given will remain **strictly confidential**. All data will be destroyed once the research is complete.

Will my decision affect the treatment I am getting already? <u>No.</u> Participation in this research is entirely **voluntary** and you are free to withdraw at any time. Your decision to take

part or not will have no effect whatsoever on the care you receive from your consultant or the NHS.

What do I have to do next? If you have decided that you would like to take part, all that you have to do is sign the two consent forms (retain one copy for you own records), complete the questionnaire booklet and return them to the research team at the university in the FREEPOST envelope enclosed (No stamp needed).

How can I get further information? If you have any questions or would like to discuss any aspect of this research, please contact Cathy Aitken on **0151 231 4110**   or by email at cathyaitken@hotmail.com or at the following address: Room 303b, Henry Cotton Building, 15-21 Webster Street, Liverpool, L3 2ET.

Indemnity: If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain 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 may be available to you.

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 you may want to ask. A copy can be viewed online at www.ceres.org.uk.

Thank you for taking the time to read this information.

Appendix 4

Questionnaire Booklet

Aintree University Hospitals **NHS**
NHS Foundation Trust

Please complete the following questions in order to provide us with some background information:

Study No:_____

Age: _____

Gender: Male ☐   Female ☐

Marital Status: Married ☐   cohabiting ☐   Divorced ☐   Single ☐

Employment Status (please tick appropriate box):

Full Time ☐   Part Time ☐   Unemployed ☐   Homemaker ☐   Student ☐

Retired ☐   Unable to work due to either psoriatic arthritis ☐   and/or psoriasis ☐

If employed, what is your job? _____

If previously employed, what was your job? _____

What educational/professional qualifications do you have? (Tick all boxes that apply to you)

None ☐   CSE/ 'O' Level/ GCSE ☐

'A' Level/ GNVQ/ NVQ/City & Guilds ☐   Graduate ☐   Postgraduate ☐

How would you best describe your ethnic origin? (Tick box)

White ☐   **Black**   **Asian**
African ☐   Indian ☐
Caribbean ☐   Pakistani ☐
Black Other   Bangladeshi ☐
(Please state) _____   Chinese ☐
Asian Other
(Please state) _____

If none of the above accurately describe your ethnic origin please provide your own description: _____

9.   Please state how many years/months you have had a diagnosis of:
     (*If you can't remember exactly, state approximately how many years/months*)

     Psoriatic Arthritis: _____   Psoriasis: _____

10. Please state below all the treatment you currently use for
     your psoriatic arthritis e.g. medicines prescribed by your
     consultant or doctor (include doses if possible), over the
     counter medicines, TENS machine, acupuncture,
     physiotherapy etc...

     _____

     _____

     _____

     _____

11. Please state below all the treatment you currently use for your
     psoriasis e.g. medicines prescribed by your consultant or doctor
     (include doses if possible), over the counter medicines etc.

     _____

     _____

     _____

     _____

12. Have you ever visited any other type of therapist for your pain?
     e.g. physiotherapist, osteopath, acupuncturist, masseur ?

     Yes   ☐   No ☐
     If yes, please give brief details (e.g. type of therapist, number of visits,
     did the therapy help reduce your pain etc..)

     _____

     _____

     _____

     _____

We would like to know how confident you are in doing certain activities. For each of the following questions, please <u>circle</u> the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?

not at all | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

not at all | | | | | | | | | | | totally
confident 1 2 3 4 5 6 7 8 9 10 confident

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions please give the best answer you can and make any of your own comments if you like. Do not spend too much time in answering, as your immediate response is likely to be the most accurate.

1. In general, would you say your health is:

Excellent   **Very Good**   **Good**   **Fair**   **Poor**

2. Compared to one year ago, how would you rate your health in general now?
   (mark one box)
   Much better now than 1 year ago
   Somewhat better now than 1 year ago
   About the same
   Somewhat worse now than 1 year ago
   Much worse now than 1 year ago

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 one 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	☐	☐	☐
b) **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	☐	☐	☐
c) Lifting or carrying groceries	☐	☐	☐
d) Climbing several flights of stairs	☐	☐	☐
e) Climbing one flight of stairs	☐	☐	☐
f) Bending, kneeling, or stooping	☐	☐	☐
g) Walking **more than a mile**	☐	☐	☐
h) Walking **half a mile**	☐	☐	☐
i) Walking **100 yards**	☐	☐	☐
j) Bathing and dressing yourself	☐	☐	☐

4. During the **past 4 weeks**, have you had any of the following problems with your work other regular daily activities **as a result of your physical health?** (Mark one box on each line.)

	Yes	No
a) Cut down the **amount of time** you spent on work or other activities	☐	☐
b) **Accomplished less** than you would like	☐	☐
c) Were limited in the **kind** of work or other activities	☐	☐
d) Had **difficulty** performing the work or other activities (for example, it took extra effort)	☐	☐

5. During **the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (Mark one box on each line)

	Yes	No
a) Cut down the **amount of time** you spent on work or other activities	☐	☐
b) **Accomplished less** than you would like	☐	☐
c) Didn't do work or other activities as **carefully** as usual	☐	☐

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? (Mark one box)

Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely ☐

7. How much **bodily pain** have you had during the **past 4 weeks**? (Mark one box.)

None ☐ Very Mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very Severe ☐

8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? (Mark one box.)

Not at all ☐ **Slightly** ☐ **Moderately** ☐ **Quite a bit** ☐ **Extremely** ☐

9. These questions are about how you feel and how things have been with you **during the past month**. (For each question, please give the one answer that comes closest to the way you have been feeling)

(Please mark one box on each line)

How much time during the last month:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life?	☐	☐	☐	☐	☐	☐
b) Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c) Did you feel so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d) Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e) Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f) Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐
g) Did you feel worn out?	☐	☐	☐	☐	☐	☐
h) Have you been a happy person?	☐	☐	☐	☐	☐	☐
i) Did you feel tired?	☐	☐	☐	☐	☐	☐

10. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time ☐
Most of the time ☐
Some of the time ☐
A little of the time ☐
None of the time ☐

11. How **TRUE or FALSE** is each 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 know	☐	☐	☐	☐	☐
b) I am as healthy as anybody I know	☐	☐	☐	☐	☐
c) I expect my health to get worse	☐	☐	☐	☐	☐
d) My health is excellent	☐	☐	☐	☐	☐

The aim of these questions is to measure how much your skin problem (psoriasis) has affected your life OVER THE LAST WEEK. Please tick one box for each question.

1. Over the last week how itchy, sore, painful, or stinging has your skin been?

Very much ☐
A lot ☐
A little ☐
Not at all ☐

2. Over the last week, how embarrassed or self-conscious have you been because of your skin?

Very much ☐
A lot ☐
A little ☐
Not at all ☐

3. Over the last week how much has your skin interfered with you going shopping or looking after your home or garden?

Very much ☐
A lot ☐
A little ☐
Not at all ☐   **Not relevant** ☐

4. **Over the last week how much has your skin influenced the clothes that you wear?**

Very much ☐
A lot ☐
A little ☐
Not at all ☐   **Not relevant** ☐

5. **Over the last week how much has your skin affected any social or leisure activities?**

Very much ☐
A lot ☐
A little ☐
Not at all ☐   **Not relevant** ☐

6. Over the last week, how much has your skin made it difficult for you to do any sport?

Very much ☐
A lot ☐
A little ☐
Not at all ☐   **Not relevant** ☐

7. Over the last week has your skin prevented you from working or studying?

Yes ☐
No ☐   **Not relevant** ☐

If "NO" – over the past week how much has your skin been a problem at work or studying?

A lot ☐
A little ☐
Not at all ☐

8. Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?

Very much ☐
A lot ☐
A little ☐
Not at all ☐   **Not relevant** ☐

9. Over the last week, how much has your skin caused any **sexual difficulties**?

Very much ☐
A lot ☐
A little ☐
Not at all ☐   **Not relevant** ☐

10. Over the last week, how much of a problem has the **treatment** for your skin been, for example, by making your home messy, or by taking up time?

Very much ☐
A lot ☐
A little ☐
Not at all ☐   **Not relevant** ☐

The Fatigue Severity Scale (FSS) is a method of evaluating the impact of fatigue on you. The FSS is a short questionnaire that requires you to rate your level of fatigue.
The questionnaire contains nine statements that rate the severity of your fatigue symptoms. Read each statement and <u>circle a number from 1 to 7, based on how accurately it reflects your condition during the past week and the extent to which you agree or disagree that the statement applies to you.</u>
• *A low value (e.g., 1) indicates strong disagreement with the statement, whereas a high value (e.g., 7) indicates strong agreement.*
• *It is important that you circle a number (1 to 7) for every question.*

During the past week, I have found that: **disagree <--------> Agree**

My motivation is lower when I am fatigued.   1 2 3 4 5 6 7

Exercise brings on my fatigue.   1 2 3 4 5 6 7

I am easily fatigued.   1 2 3 4 5 6 7

Fatigue interferes with my physical functioning.   1 2 3 4 5 6 7

Fatigue causes frequent problems for me.   1 2 3 4 5 6 7

My fatigue prevents sustained physical functioning.   1 2 3 4 5 6 7

Fatigue interferes with carrying out certain duties and responsibilities.   1 2 3 4 5 6 7

Fatigue is among my three most disabling symptoms.   1 2 3 4 5 6 7

Fatigue interferes with my work, family, or social life.   1 2 3 4 5 6 7

Total Score (office use only): _____

In this section we are interested in learning how your illness affects your ability to function in daily life.

For each statement, please tick <u>one box</u> that best describes your usual abilities over the <u>past week</u>.

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do

Dressing & Grooming
Are you able to:
  -Dress yourself, including tying shoelaces & doing buttons? ☐ ☐ ☐ ☐
  - Shampoo your hair? ☐ ☐ ☐ ☐

Arising
Are you able to:
  - Stand up from a straight chair? ☐ ☐ ☐ ☐
  - Get in & out of bed? ☐ ☐ ☐ ☐

Eating
Are you able to:
  - Cut your meat? ☐ ☐ ☐ ☐
  - Lift a full cup or glass to your mouth? ☐ ☐ ☐ ☐
  - Open a new milk carton? ☐ ☐ ☐ ☐

Walking
Are you able to:
  - Walk outdoors on flat ground? ☐ ☐ ☐ ☐
  - Climb up five steps? ☐ ☐ ☐ ☐

Hygiene
Are you able to:
  - Wash & dry your body? ☐ ☐ ☐ ☐
  - Take a bath? ☐ ☐ ☐ ☐
  - Get on & off the toilet? ☐ ☐ ☐ ☐

(Contd...For each statement, please tick <u>one box</u> that best describes you usual abilities over the past <u>week)</u>

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do

Reach
Are you able to:
- Reach & get down a 5 lb object from just above your head? ☐ ☐ ☐ ☐
- Bend down to pick up clothing off the floor? ☐ ☐ ☐ ☐

Grip
Are you able to:
- Open car doors? ☐ ☐ ☐ ☐
- Open jars that have been previously opened? ☐ ☐ ☐ ☐
- Turn taps on & off? ☐ ☐ ☐ ☐

Activities
Are you able to:
- Run errands & shop? ☐ ☐ ☐ ☐
- Get in & out of a car? ☐ ☐ ☐ ☐
- Do chores such as vacuuming, housework or light gardening? ☐ ☐ ☐ ☐

Please tick any aids or devices that you usually use for any of these activities:

Cane ☐   Walking frame ☐   Crutches ☐   Wheelchair ☐
Built-up or special utensils ☐

Special or built-up chair ☐   Raised toilet seat ☐   Bath seat ☐   Bath rail ☐

Long-handled appliances for bathroom ☐   Jar opener (for jars previously opened) ☐

Long-handled appliances for reach ☐   Devices used for dressing (button-hook, zipper-pull, Shoe horn) ☐

Other aid/device (please specify) _____

Please tick any categories for which you usually need help from another person:

Dressing & Grooming ☐   Eating ☐   Rising ☐   Walking ☐   Hygiene ☐   Reach ☐
Gripping & opening things ☐   Errands & housework ☐

The scales below are for you to let us know how much pain you are experiencing.

Please place an 'X' through the number that best describes how much pain you are experiencing. (1 – **no pain, 10** – **worst possible pain**):

Please rate the average level of pain you are experiencing TODAY

No pain at all

1	2	3	4	5	6	7	8	9	10

Worst possible pain

Please rate the average level of pain you have experienced during the LAST WEEK

No pain at all

1	2	3	4	5	6	7	8	9	10

Worst possible pain

<u>HADS</u>

This questionnaire is designed to help us understand how you feel. Read each item and <u>place a tick in the box opposite the reply that comes closest to how you have been feeling in the past week.</u> Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.
Tick only one box in each section

I feel tense or wound up:	I feel as if I am slowed down:
3 Most of the time 2 A lot of the time 1 Time to time 0 Not at all	3 Nearly all the time 2 Very often 1 Sometimes 0 Not at all
I still enjoy the things I used to enjoy:	I get a sort of frightened feeling like butterflies in the stomach:
0 Definitely as much 1 Not quite so much 2 Only a little 3 Hardly at all	0 Not at all 1 Occasionally 2 Quite often 3 Very often
I get a sort of frightened feeling as if something awful is about to happen: 3 Very definitely and quite badly 2 Yes, but not too badly 1 A little, but it doesn't worry me 0 Not at all	I have lost interest in my appearance: 3 Definitely 2 I don't take so much care as I should 1 I may not take quite as much care 0 I take just as much care as ever
I can laugh and see the funny side of things: 0 As much as I always could 1 Not quite as much now 2 Definitely not so much now 3 Not at all	I feel restless as if I have to be on the move: 3 Very much indeed 2 Quite a lot 1 Not very much 0 Not at all
Worrying thoughts go through my mind: 3 A great deal of the time 2 A lot of the time 1 From time to time but not too often 0 Only occasionally	I look forward with enjoyment to things: 0 As much as ever I did 1 Rather less than I used to 2 Definitely less than I used to 3 Hardly at all
I feel cheerful: 3 Not at all 2 Not often 1 Sometimes 0 Most of the time	I get sudden feelings of panic: 3 Very often indeed 2 Quite often 1 Not very often 0 Not at all
I can sit at ease and feel relaxed: 0 Definitely 1 Usually 2 Not often 3 Not at all	I can enjoy a good book or radio or TV programme: 0 Often 1 Sometimes 2 Not often 3 Very seldom

Appendix 5

Interview Schedule

Interview Schedule

1) Can you recall how you felt about a diagnosis of psoriatic arthritis?

2) Were you aware of the condition before you were diagnosed?

3) What sort of symptoms do you experience?

4) How have these impacted on aspects of your life?

5) Have you found your own way of coping with the symptoms?

6) What was/has the reaction been from your friends and family?

7) Do you feel supported by friends and family?

8) What sort of treatments do you use?

9) How have your daily activities and social life been affected?

10) How do you feel about the future?

Appendix 6

Example of theme table

Qualitative Analysis – Example of Theme Table with Quotes from interviews

FUNCTIONALITY

	Participant 1	Participant 2	Participant 3
Employment	I'd love to be going out working 15:720	can't go back to what I was doing 8:396	there's no chance..days when I can't move my hands properly 3:113
Immobility	I can't move 1:39	I couldn't walk 6:282	that stiff I could hardly move 1:17
Activity	I can't get on the floor & play with the kids 2:89	consequences of your actions is the pain..immobility 7:319	On a good day I can do a meal 2:64
Sleep	I can't sleep, you turn over, you're waking up again 1:43		I'm awake a lot through the night 4:146
Planning	I can't say I'll go out tomorrow, 'cos I don't know what it's going to be like until I get up 9:428		I have to wait for a good day, or get all kinds of equipment out to help me 10:451 just let me have one full night's sleep 10:488
Tiredness	I'm tired all the time 1:40		

LOSS

	Participant 1	Participant 2	Participant 3
Life	It's ruined my life, that's it now, that is my life 1:24	It's all about loss 7:307	
Goals Identity	I gave up on everything 7:314 It's not Sue anymore, it's Sue with arthritis 4:193	you become a different person 7:309	I'm still in there trying to get out 4:177
Body Image	Can't wear proper shoes anymore 6:257	I couldn't put a pair of shoes on 11:516	
Mobility			miss being able to get up & walk 7:329

PSYCHOLOGICAL STATES

	Participant 1	Participant 2	Participant 3
Psychopathology	Depression, that's the way it makes you feel 14:651	I'd gone into another little dark hole again 6:261 embarrassed 6:294	been on depression pills for years 4:194
Strong feelings	Angry all the time 10:452 Scared 2:60 useless 2:62		I'm so angry 4:186 useless 10:451 frustrates me 4:167
Shame	feel ashamed, probably 'cos I'm young 11:504	I was so ashamed of it 2:94	hanging my face in shame 7:296
Reflection	I can't remember not being in pain 6:262		
Pessimism	you think the worst of every-thing 11:549		
Optimism		I appreciate the small things in life 11:505	

PAIN

	Participant 1	Participant 2	Participant 3
Impact	It's too painful 2:92	somedays I can't even wipe my bottom 9:439	I've had to ask my husband to cut my food up 10:471
Measuring	how can you describe how your pain is on a ruler? 7:339 You can't put an average on pain 8:356		
Intensity	different day to day 7:345	It's there in the background 9:430	even with pain killers, I don't get relief from it 9:425
Description	It's just sharp, constant 13:644	fizzy pains..like bubbles 2:60 It's like a pair of tight shoes 9:432	it's like a nagging toothache, it's there all the time 9:434

COPING

	Participant 1	Participant 2	Participant 3
Distraction	I started getting tattoos 'cos I could contol the pain 12:580	if I zone in on it, think about it & touch it I'd go through the roof with it 9:429	have a good cry 4:183
Loss Adaption	you're concentrating on a different pain 13:615 try not to think about it 7:308 you have to learn how to move your body 2:98	don't sit down & allow myself to stiffen up again 10:448	I have a wheelchair when I go out 2:80

ISOLATION / ALIENATION

	Participant 1	Participant 2	Participant 3
Alone	feels like you're the only person with it 17:806	you're left to get on with it 13:609	
Social	you want to come out, but you can't do it 3:116	I had difficulty interacting with other people 7:328	we don't go out much anyway 3:98 I can't be bothered, any excuse 7:307
Excuses	I find I'm making excuses..to get out of it (parties) 4:180		
Friends	everyone wants to help out at first, then nothing 3:110	alienated from friends, neighbours social circle 7:327 I didn't go out 7:331	I'm more of a loner than I was 7:319
Withdrawing	I'm pushing them away 19:901	(asking for help) it gut's me, it guts me terribly 7:299	if family don't help, that's it, you either do without or do it yourself 2:51
Help	I won't ask anyone outside the house..I wouldn't lower myself 5:225		

SEARCHING FOR AN EXPLANATION

Self-blame	It's my body's fault 15:749
Doctors	I don't think it's the doctor's Fault 15:743

SEARCHING FOR AN EXPLANATION Contd

	Participant 1	Participant 2	Participant 3
Parents	mum's blaming herself 7:331	nobody in our family has it, must be your father 2:97	
Punishment	I feel like I'm being punished for something 16:751/4	I feel I've got some sort of curse 8:359	
Need	you feel angry, you need some-thing to blame 16:760		
Triggers	I can't think of anything that's triggered it 16:771	wife became extremely ill, had failure, seemed after that 1:6	

TREATMENT

	Participant 1	Participant 2	Participant 3
Regimen	don't want to take tablets no more, fed up 8:306		when I get my pills out it seems to be never-ending 5:199
Side-effects	when you've taken your tablets, You're feeling sick 8:394	I feared going on it, the side effects 8:389	
Consequences	you miss them, you know you've got to pay for it 14:694	If you don't start taking it, you're going to end up in a wheelchair 5:248	paid for it when I got out & got home (hydrotherapy) 7:344
Information	they give you a video..makes it too real 14:677/9		
Clinic	you don't get enough time 8:363	doesn't have to be a proffessional, just someone to give you the time 2:587	missed lots of my appointments ..I get fed up with them 7:313/5
Other sufferers		you get understanding there, not scared to go..in the same club 11:531	I never pay any attention to them 7:317
Staff	you feel like you're wasting her time 8:366/8	been brilliant..got me to where I am today 8:386	the people are nice 8:358
Desperation	I'll try anything 4:155		

COMPARING

	Participant 1	Participant 2	Participant 3
Old self	I used to play sport 7:325	used to be able to do joints, joinery paint & draw 10:476	I used to walk miles 4:162 I was outgoing 8:372 spend most of my time sitting 2:88
New self	it's two totally different people 7:328	inside you're head, you're the same person 7:309	
Normality	you want to be normal, 'cos you feel you're not 10:471	I just wanted to be normal 7:343	some people go in the chemist & get a small paper bag, I go & get a carrier bag 5:224

NOT BEING BELIEVED

	Participant 1	Participant 2	Participant 3
Friends	'cos they can't see it, they don't know what it's about 12:577		
Others	I'm unsteady on my feet...people think you've been drinking 19:932	no-one understands what's going on underneath 2:74	
Age	they don't think it's that bad 'cos of your age 3:108		

FUTILITY

	Participant 1	Participant 2	Participant 3
Life	It's just a life no more 6:288 Wanted to go to bed, fall asleep & not wake up 17:800/03 I couldn't cope, I'd rather not be here 17:817		
Aging	I can't see one 9:410		
Future		I was thinking I could go back to work, do retraining 8:395/7	you don't know what's going to happen in the future 1:16

Participant 1   Participant 2   Participant 3

SUGGESTIONS

Exercise   organise a venue ...so people
                                 could go & swim 8:379
Social support   we should have coffee clubs
                                 11:539
                                 a group getting people involved,
                                 need to be more active, cope with
                                 disease   13:607

Appendix 7

Example of Interview Transcript

1

2

3   I: When you think back, 11 years is quite a long time isn't it, but can you recall
4   how you felt at the time about a diagnosis of psoriatic arthritis?
5   P: *It was a surprise because it was just a pain in the knee, that's all, and I thought I*
6   *had just damaged my knee but the doctor said "oh, you've got arthritis" but he*
7   *wasn't really sure, you know, what type it was at first, when I went to the hospital*
8   *then they found out once they'd done the blood tests and that*
9   I: And were you aware of the condition at all?
10 P: *No*
11 I: Did you have the psoriasis first?
12 P: *Yeah, since I was 15*
13 I: Right, but you didn't..you weren't aware that you could get arthritis with it?
14 P: *No, they don't tell you*
15 I: So it was quite a surprise then?
16 P: *Yeah*
17 I: And did you feel it had been quite well explained once they had diagnosed it
18   and sort of told you how the condition affected people?
19 P: *Yeah, but they said to me it wouldn't spread, they said it would probably stay in my*
20   *knee...it wouldn't spread but it's in virtually every joint now*
21 I: Is it?
22 P: *Yeah*
23 I: So you're feeling quite immobolised?
24 P: *Yeah, it's ruined my life..that's it now..that is my life..really quick*
25 I: Really, it's altered you that much?
26 P: *Yeah. (Cries)*
27 I: Don't worry...OK.. and that's in the space of 11 years..and did that begin
28   fairly quickly?
29 P: *urmm.. not at first, first it was my knee..it was fine , but the last few years (cries)*
30 I: It's ok..it's to be expected..if you're happy to keep going that's fine, but if you
31   want me to stop just shout, no worries
32 P: *I just feel stupid!*
33 I: So to begin with, the first few years, you felt you were ok with it and that you
34   were coping with it and then did it..did you get a sudden flare-up or..
35 P: *The first few years it was just like my knee, that was the first to go, after that it*
36   *Started gradually going to other joints like my ankles*
37 I: And what about the impact of that on your...on your sort of day-to-day life,
38   your daily routine if you like?
39 P: *Well sometimes I get up in the morning and I can't move..it takes me hours to get*
40   *Moving, I panic about going out now, urmm, I'm tired all the time*
41 I: Are you tired because you don't sleep, has it affected your sleep pattern?
42 P: *It's both...think all the medication..I'm on quite a lot of medication and that makes*
43   *me sleepy, I can't sleep, as soon as you get to sleep and you turn over you're*
44   *waking up again*
45 I: So it's the pain that actually disturbs your sleep?
46 P: *Yeah*
47 I: OK, so that's obviously making you feel very tired, so in terms of your day-to-
48   day life, were you working when you were diagnosed?
49 P: *No, I'd been with the children, one is now 17 and one is 11.*

1

50 I: **Right, so you'd had the youngest when you were diagnosed?**
51 P: *Yeah*
52 I: **So have you not worked since?**
53 P: *No*
54 I: **And do you feel that you'll be able to work at all?**
55 P: *Not at the moment, 'cos I can't stand for long periods of time...I'm not too bad*
56   *sitting down...it's in my wrists and my hands so...mean I'd love to, it's the one*
57   *thing I'd love to do, I'd give up everything, if I could*
58 I: **How does it make you feel, the prospect of not perhaps being able to work**
59   **Again?**
60 P: *Scared*
61 I: **Scared? In what sense?**
62 P: *Useless*
63 I: **So it makes you feel useless and scared?**
64 P: *Yeah...(Cries)*
65 I: **Are you OK, sure, do you want me to stop?**
66 P: *No*
67 I: **Umm, so it's had quite a major impact do you feel on your lifestyle?**
68 P: *Yes*
69 I: **And how about aside from work, in your daily activities that you might do**
70   **with kids or whatever?**
71 P: *You can't, you know, they want to go for days out or that, you can't 'cos you can't*
72   *walk*
73 I: **So you wouldn't be able to go out and walk with them for any great distance**
74   **or...**
75 P: *No, no*
76 I: **Is that because of the pain or the tiredness?**
77 P: *It's the pain*
78 I: **So how about the treatments for pain, do you try and take something to lessen**
79   **it?**
80 P: *I'm on painkillers, strong painkillers, I'm supposed to take eight a day, but I take*
81   *More*
82 I: **Eight a day? And do they help, I mean do you get relief?**
83 P: *They take the edge of it, but it's like taking smarties, once you get used to them*
84 I: **So you're learning to live with the pain?**
85 P: *I have days when I know what to do and what not to do*
86 P: **Have you got any examples of that, of the different ways you've adapted?**
87 P: *If it's bad, then going up the stairs I go up on my bum, you find ways, of like,*
88   *coming down the stairs, I can't come down forwards, I have to come down*
89   *sideways, I can't run, I can't get on the floor, I can't get on the floor and play with*
90   *the kids and that*
91 I: **Is that because your joints won't bend?**
92 P: *It's too painful, can't get yourself back up, sometimes when I can't get myself out*
93   *of bed, 'cos you just, it's like you sieze up, you know if you're in one position too*
94   *long*
95 I: **Have you found any way of coping with that, maybe anything alternative?**
96 P: *I've got a TENS machine*
97 I: **And how's that, does that give you any sort of relief?**
98 P: *Sometimes, it depends on the pain, sometimes it will work but other times, you just*
99   *have to learn how to move your body. I think the worst of it is the way people think*

100   *about it..they think your age, you can't have arthritis it's an old people's disease,*
101   *like sometimes when I take my daughter to school they think I've been drinking, you*
102   *know because of my balance?*
103 **I: Yeah, how did that make you feel?**
104 *P: Annoyed*
105 **I: That they could actually think that?**
106 *P: Yeah, I wouldn't mind if I could drink, I can't drink (laughs)*
107 **I: Have you felt you've had quite a lot of negative reaction from other people?**
108 *P: I find that when you first tell them they don't think it's that bad because of your*
109   *age and all that, but then when you explain to them they sort of, they just get used*
110   *to it and they forget about it then, it's awful, everyone wants to help at first, then*
111   *nothing*
112 **I: So is that a sense of when you initially get told what the diagnosis is, you have**
113   **that 'honeymoon' period when people are helping and coming around and**
114   **then that stopped, and has that left you feeling isolated or..**
115 *P: Yeah, 'cos people can't understand that you are limited in what you can do and*
116   *they'll phone up and say we're having a night out, do you want to come out, but*
117   *you can't, you can't do it*
118 **I: So in terms of your social life that's...**
119 *P: I haven't got one*
120 **I: Not at all?**
121 *P: No*
122 **I: And did you before?**
123 *P: Yeah, yeah*
124 **I: I know it's difficult when you've got young kids, but you did have a social**
125   **life? Have you still got the motivation, I mean would you like to go out and**
126   **have a social life?**
127 *P: Oh yes, yes, but you feel like you're spoiling it for everyone else, you know because*
128   *you can't last*
129 **I: Have you not found a way to think about maybe going out for a couple of**
130   **Hours or..**
131 *P: Yeah, but everyone seems to make a night of it don't they? Then you've got to*
132   *say"I've got to go home", or like everyone's drinking but like you can't or they're*
133   *up dancing and you're just left, you know what I mean? (cries). I sound like a sad*
134   *case don't I ?*
135 **I: Not at all. So from your point of view, you would say the impact has been**
136   **total, both on your social life and certainly on your prospect of employment at**
137   **the moment?**
138 *P: No employer will touch you when you've got arthritis, who wants you when you've*
139   *got to go to the hospital, get your bloods done, you're going to take bad one day,*
140   *they're not going to give you a job*
141 **I: Is that sort of a regular occurrence, you having to go weekly to the hospital**
142   **for blood tests or injections or something?**
143 *P: Erm..every 4 or every 2 weeks for blood tests depending on how high my levels*
144   *are, for Dr Tompson it's usually every next available appointment every 3 or 4*
145   *months. I have to do the injections myself*
146 **I: How do you cope with that, is it quite difficult to do?**
147 *P: It's more nerve-racking than anything*
148 **I: Had you ever done anything like that before?**
149 *P: No*

150 I: So have they taught you how to do it?
151 P: *You get a nurse a nurse out for one day, I've only been on them two months*
152 I: Are you coping with that alright?
153 P: *Got to*
154 I: Is that how you feel, you've just got to get on with it?
155 P: *Got to, I'll try anything. I've tried virtually all the medications and they work for*
156   *the first three months and then stop*
157 I: So the injections that you're on, do you have the option of going into the
158   hospital to have them, or have they said you take control of it and you do
159   them?
160 P: *I can get a nurse to come out and give me them, but that means I have to sit and*
161   *wait, you know, incase something did come up and I did have to go out, it would*
162   *mean I'd be tied in*
163 I: So this way you feel you're at least slightly in control of your own medication?
164 P: *Yeah*
165 I: And do you feel immediate benefit from the injection or is there a time delay
166 P: *They said it could take up to three months*
167 I: To get any benefit?
168 P: *Yeah*
169 I: And how often do you have to inject yourself?
170 P: *At the moment it's only once every three weeks but it could go to once every week*
171 I: Right, and how about any sort of physical therapy, do you have anything like
172   massage or anything like that?
173 P: *No, I couldn't bear people touching me*
174 I: You couldn't?
175 P: *No, it's too sore*
176 I: So you're solely reliant on your injections and your painkilling tablets
177 P: *Well, how about, in terms of your children it's obviously had quite an impact, how*
178   *about with your husband, how's that sort of affected..is he still able to go out and*
179   *socialise?*
180 P: *Yeah, I make sure he does. I find I'm making excuses 'though now, you*
181   *know, like if I know there's a family party coming up I try my hardest to get*
182   *out of it, or if I know I've got to go out say to the shops the next day or go &*
183   *do something the next day, it's like I want to go out, but I'm trying to make*
184   *excuses not to go out, if I can find some way of not going out...*
185 I: What, you do what you can to avoid it?
186 P: *Yeah.*
187 I: You mention there about going out to the shops..is that like you'd avoid going
188   out to a party or something because you're trying to make sure you're fit
189   enough to be able to go & do shopping or something the day after..if you did
190   both would you not be able to do anything?
191 P: *I don't like people seeing me like this..you know, like struggling to walk or "oh Sue*
192   *why aren't you drinking" or "Sue have a drink" all of the time..it's like it's not*
193   *Sue anymore, it's Sue with arthritis. They don't say "Hiya Sue", it's "Hiya Sue,*
194   *how's your arthritis" or "what tablets are you taking now" or...you know, that's*
195   *not just Sue.*
196 I: So you feel it's not you that they're looking at? I'm getting a sense that you
197   feel your identity has gone?
198 P: *Totally (cries)*
199 I: I can see that this is obviously very upsetting for you and wonder if you've

200   spoken to your friends, good friends maybe, about..

201   P: *You can't explain it to them*

202   I: **People don't understand?**

203   P: *I think it's hard to explain how difficult it is to someone because they haven't been*

204   *through it*

205   I: **So there is a feeling of isolation & being away from your friends**

206   P: *Oh yeah*

207   I: **Well how about your husband, do you feel the same way..**

208   P: *He does understand about it, because his family, some have arthritis.., he's lived*

209   *with it 'cos his cousin had psoriasis so it's not unusual*

210   I: **So he's a bit more tuned in to it & the impact it can have**

211   P: *Yeah*

212   I: **How about everyday activities like cooking, you know sort of things we all**

213   **take for granted, everyday activities?**

214   P: *I can do like light stuff, can't lift any heavy pans & that, it's dangerous*

215   I: **What, because you haven't got the strength to..**

216   P: *I've got no strength in my wrists, not to lift heavy pans, I can do a sandwich or that*

217   I: **So if you're cooking a family meal can you cope to do..**

218   P: *I will ask my daughter or my husband, I try to do as much as I can, but I will ask*

219   *them, say will you move this for me, I can't do it or*

220   I: **How does that make you feel as, sort of, as a mum?**

221   P: *Useless...useless, you feel like you're constantly asking people to help, like a child*

222   I: **And is that quite a difficult thing to do, ask for help?**

223   P: *I've just got used to it no, but I won't ask anyone outside the house*

224   I: **So it's just your family?**

225   P: *Just my husband & daughter, I couldn't lower myself to ask anyone*

226   I: **Why would you feel it was lowering yourself to ask for help?**

227   P: *Because I shouldn't need to ask, 38, you shouldn't be asking for help should you?*

228   I: **Is that how you feel? Is it because you're 38, do you think if you were 68 you'd**

229   **think it was part & parcel of life?**

230   P: *Yeah*

231   I: **So it's kind of linked in to being a young woman?**

232   P: *I think, even when I go to the hospital I think it's mostly old people, but they look at*

233   *you as if to say " what are you doing here, you shouldn't be here, there's nothing*

234   *wrong with you", it's just the way everyone views it, I think it's drummed in to you*

235   *that it's an old person's disease.*

236   I: **And yet you know it isn't. Is there a sense that people should know more, do**

237   **you think we're lacking in perhaps making it more, sort of creating awareness**

238   **that these conditions can affect younger people?**

239   P: *Yes, 'cos everyone I've told, no-one, no-one knew it could affect someone so*

240   *young.*

241   I: **Do you feel that they're not believing you?**

242   P: *Oh, they believe me now, but I think at the beginning it was just "oh, you've got*

243   *something wrong with your knee" so it was nothing drastic, It's like my doctor,*

244   *my GP, when I went to see him I said "I've got a pain in my knee, I can't kneel*

245   *down or anything" he said, "what do you want to kneel down for, get on with it,*

246   *it's not the be all & end all "*

247   I: **So did you feel you were a bit dismissed by him?**

248   P: *It's...I'm not important. But how are you supposed to do your cleaning & that if*

249   *you can't kneel down? You don't realise how important being able to get on the*

250 *floor & that is, bending your knees & that, you seem to start understanding then,*
251 *you know how important your joints are & that, like getting in & out of the bath is*
252 *simple for anyone else, but it's a nightmare*
253 **I:** **So have you had to adapt things like that, do you walk in to a shower now as**
254 **opposed to getting a bath?**
255 *P: No, I've got a bath seat*
256 **I:** **So you've had to adapt that side of your lifestyle?**
257 *P: Mmm..extra rails on the stairs, stuff like that. Can't wear proper shoes anymore,*
258 *can't walk around without anything on my feet*
259 **I:** **Is that because of pain?**
260 *P: Yeah*
261 **I:** **So is it that constant, the pain?**
262 *P: Yeah, I can't remember not having it now, it's been that much now that I can't*
263 *remember not being in pain, I can't remember my life without it, this, this is it now*
264 **I:** **Do you feel that, sort of your life stopped with your diagnosis, is that what**
265 **your saying?**
266 *P: No, I never, I never thought of... about the diagnosis. It didn't bother me 'cos I*
267 *was told it was just in my knee I thought I'd still get around, but the more it's gone*
268 *through my joints, the more difficult it's got.*
269 **I:** **Do you feel that your life has kind of gone 'before arthritis' and 'now' because**
270 **it's altered so much**
271 *P: Yeah, I can't remember my life before, remember what it felt like to be pain-free*
272 **I:** **And do you think it's the pain that has affected the biggest aspect of how you**
273 **feel, about sort of feeling isolated & affecting your social life, do you feel that**
274 **pain is one of the major reasons why?**
275 *P: I'd say pain, tiredness & feeling nauseous all the time*
276 **I:** **Nausea is related to taking the drugs?**
277 *P: Yeah, medication & the pain-relief tablets*
278 **I:** **And you can't live without the medication because of the pain? And you have**
279 **to control the pain because it affects your sleep? So is there a sense that you're**
280 **kind of in a hamster wheel almost?**
281 *P: Yeah, it's like 'Groundhog Day', it's the same thing everyday, no difference, no*
282 *difference, it's like you think what's the point o fit, if it wasn't for the kids there's*
283 *no point, you know, just to do this every day*
284 **I:** **I sense that you are, kind of, at the end of your tether with it?**
285 *P: Mmm... (cries)...Mmm, just hope they find a cure, just want to be normal, want to*
286 *be me.*
287 **I:** **Do you view yourself as 'not normal' because of the condition?**
288 *P: It's just a life no more (cries), but then you feel guilty, you know with my husband*
289 *& the kids, because you feel like you're dragging them down. Gets to the point were*
290 *you turn into a liar because you're saying to them "I'm fine, I'm fine"*
291 **I:** **And really you'd like to be honest about it & tell them?**
292 *P: I don't want people knowing*
293 **I:** **Why, do you think they'll view you as something completely different?**
294 *P: They already do, like I said before it's "Sue with arthritis" not just Sue, It's like*
295 *the more I tell them the worse it's going to get*
296 **I:** **Do you have a special friend, like a best friend or anything?**
297 *P: I've got a few, but they've all got their own lives haven't they? Jobs, kids. I still see*
298 *them all, they still come down & I get lifts up to theirs, but it's not the same is it?*
299 **I:** **Is there a sense that you're missing out on something?**

300   P: *I'm missing out on loads, just like I'm missing out on life isn't it?*
301   **I: You feel like life is passing you by?**
302   P: *Mmm..feel like I've done nothing*
303   **I: So has it affected, kind of, what were, before you had your diagnosis, has it**
304   **affected what maybe your life goals were & what you wanted to achieve in**
305   **your life. Has all that been affected?**
306   P: *Yes, they've just gone now*
307   **I: So have you got a sense of, I don't know, loss around that, grieving almost?**
308   P: *Yeah, I've just got to try not to think about it now, the way I feel, even now if there*
309   *is a cure, it's going to take years, you're still going to be on all the medications &*
310   *to go & get a job it's going to be a big problem, like I started off doing*
311   *hairdressing & that ..can't do all that now*
312   **I: Is there something that you'd like to do, that you feel that you're never going**
313   **to be able to do?**
314   P: *No, 'cos I gave up on everything*
315   **I: But it doesn't stop you dreaming**
316   P: *It's not worth it is it? If you know you're not going to be able to do it, it's going to*
317   *make you worse dreaming about it isn't it? All I can see now, as long as I get my*
318   *youngest to 18, that's it*
319   **I: And then what?**
320   P: *I'm not bothered*
321   **I: Not bothered about anything?**
322   P: *No, my worry is looking after the kids now, as long as I can look after the kids*
323   *that's it, I don't care*
324   **I: And is that the Sue that used to be?**
325   P: *No, I used to play sport and everything, walk everywhere, always out shopping,*
326   *even used to go out with my mum, but I don't anymore*
327   **I: What do you feel you've lost from this past life?**
328   P: *It's two totally different people*
329   **I: Are you angry about it?**
330   P: *Yeah, but you don't know who to blame, there's no-one to blame is there? My*
331   *mum's blaming herself & that makes me angry 'cos she keeps buying me stuff you*
332   *know, like she's trying to compensate for everything, any new gadget or cream or*
333- *anything, she comes down "I bought you this, oh it's my fault", I've got enough to*
334   *deal with. It's just getting people to, err, even the doctors don't understand*
335   **I: You say they don't understand?**
336   P: *You go in & it's "Blah, blah, blah, how are you feeling?" It's like what really*
337   *makes me angry, honestly I feel like hitting them sometimes, they've got this, like*
338   *a ruler thing. "put the arrow on that to tell me where your pain is over the past*
339   *week", that really, really makes me angry that, it's stupid, how can you describe*
340   *how your pain is on a ruler when it's different from day to day & they say just over*
341   *the last week? Or, you get a form to fill out when you go in " what can you do,*
342   *what can't you do?"*
343   **I: So they're trying to measure what kind of, what your pain level has been & is**
344   **that quite a difficult thing for you to explain?**
345   P: *Yeah because it's different day to day, it's different morning, different to night, you*
346   *can't do it.*
347   **I: So can you think of anyway, you know, you're living with the condition, can**
348   **you think of a better way to do that, have you got any ideas of how..**
349   P: *All they'd have to do is say, to ask you, in the mornings...they just shove this thing*

7

350   *at you & say "on the level, that being the highest, that being the lowest, put the*
351   *arrow to where the pain is"*
352 **I: So they're trying to get an average for the week? So do you feel that is not the**
353   **right way to do it, you want to be able to say to them " I was screaming with**
354   **pain one day?"**
355 *P: Yeah, I want to be able to say like, in the morning it was this way or in the night,*
356   *on Tuesday I couldn't move 'cos you can't put an average on..,.how can you put an*
357   *average on pain? That means you'd have to sit & think about it constantly so...*
358   *(cries)*
359 **I: And you don't want to?**
360 *P: No*
361 **I: You don't want to be reminded of it? Have you told the doctors how you feel**
362   **about that?**
363 *P: No, No, 'cos you don't get enough time do you? You feel like Umm...they're*
364   *always saying "Oh, there's loads of people, we're so many hours behind". It's like*
365   *you go to see your rheumatology nurse, I go once every four weeks at the moment,*
366   *& you go in & she says "what's wrong?", but you don't want to tell her.*
367 **I: What stops you wanting to tell her?**
368 *P: You feel like you're wasting...wasting her time, you know she's got loads of people*
369   *sitting outside & she must hear it all the time, so what's so different about you?*
370   *Why would they want to hear about you?*
371 **I: Do you not think if you're having intense pain, or whatever, they're the**
372   **people that need to know so they can try & help?**
373 *P: Yeah, but you know it's going to be the same thing every time you go to hospital*
374 **I: So is there a sense that it's almost a waste of time for you, that even though**
375   **you go, keep your appointments & you speak to your consultant, you feel that**
376   **you're actually not going to be any better off?**
377 *P: I feel like a guinea pig, even my doctors say they're banging their heads against a*
378   *wall at the moment*
379 **I: Is that because the drugs aren't working as they should be?**
380 *P: Yeah, that's why they started me with these...he really pushed to get me...he*
381   *is..he's a good doctor, but there's only so much they can do, he really pushed to*
382   *get me on these injections hoping these would work, then if these work I'm on these*
383   *for the rest of my life*
384 **I: And does that bother you, does the treatment programme itself, is that**
385   **actually a source of concern because it's long term?**
386 *P: It just gets to the point where it does your head in & I don't want to take the tablets*
387   *no more, I'm fed up taking them, it's like, if you do go out anywhere, you've got to*
388   *take all these tablets with you, excuse yourself when you go & take the tablets,*
389   *otherwise if you don't take the tablets you're in that much pain tou're going to*
390   *have to come home anyway, can't win, might as well just stay in.*
391 **I: So the actual treatment is, kind of, part of the issue as well is it, that the**
392   **treatment itself is enough to stop you wanting to go out? Let alone the pain?**
393 *P: Yeah, 'cos you've got to think when is my tablet due? Got to make sure I take these*
394   *tablets at that time & then when you've took your tablets you're feeling sick,*
395   *you're just exhausted all day. I'll get up, get myself sorted, it's half eight I want to*
396   *go back to bed, just want to sleep.*
397 **I: Do you, do you try & have a rest during the day & catch up?**
398 *P: I could fall asleep in two minutes, but it's not fair, you know like when the kids are*
399   *off school & that, & you think, oh, it gets to the point where I panic about having*

400	*the kids in the house all day, 'cos you know you've still got to look after them, one's*
401	*only eleven, the other one can look after herself but it's still not fair is it? You still*
402	*realise you've got to do things for them even 'though they understand, but you've*
403	*got to.*
404	**I: They understand the situation that you're in?**
405	*P: Yeah, the little one's lived with it all her life, hasn't she? the older one, she was*
406	*only about six. When it first started it wasn't too bad, I could still do things, I was*
407	*only like sort of limited slightly, but now...*
408	**I: So how about your concerns for the future then? Your kids are growing up &**
409	**presumably will go off & do whatever & how about you?**
410	*P: I can't see one*
411	**I: You can't see one?**
412	*P: Same as it is now, unless all of a sudden there's some cure, if that's the case I'll*
413	*just be done some shopping won't I? (Laughing)*
414	**I: Making up for lost time?! Is there no sense of any satisfaction with your life?**
415	*P: No*
416	**I: Not in any aspect of it?**
417	*P: I'm glad I had the kids, I'm glad I had them young or I wouldn't have had any. It*
418	*takes over your life, people don't realise the pain, or how much it limits you*
419	**I: So do you feel that you're constantly preoccupied with your own illness?**
420	*P: Everything you do now you've got to think how it's going affect you, you can't just*
421	*think "oh, I'll go out, Oh, I'll do this", it's "I can do this, but...". I tidy the*
422	*bedroom & want to tidy under the bed, I can get on the floor but I'll be stuck there,*
423	*I have to get someone to lift me up. Everything you want to do you've got to think*
424	*Out.*
425	**I: So you have to pre-plan do you?**
426	*P: Yeah*
427	**I: So has your spontaneity gone completely?**
428	*P: Well, I can't say I'll go out tomorrow 'cos I don't know what it's going to be like*
429	*until I get up, so I can't just plan ahead*
430	**I: So is your situation that you wait to see each morning how you are before you**
431	**decide what you're going to do with the day?**
432	*P: Yeah, it's the only way you can do it, it's so different everyday, one day you can*
433	*feel "Oh great, I'll go & do this today" & then the next day you'll pay for it, if*
434	*you've overstretched what you normally do, you will pay for it the next day 'cos*
435	*you're totally seized up*
436	**I: Is it worth it? Do you feel that...there's always a cost in everything we do isn't**
437	**there? But do you feel that if you can go out & have a good day it's worth the**
438	**pain & the discomfort the following day or the following week?**
439	*P: You get used to it, you get used to accepting it so..I'd do anything to get out & just*
440	*live a normal life. I've told the doctors that, I'd give up every penny I had,*
441	*everything I had just to be back the way I was.*
442	**I: Is that a sense of desperation?**
443	*P: I suppose it's just the way you get to thinking, I mean, you heard the word, I*
444	*remember when before I had arthritis, arthritis meant nothing to me, I just thought*
445	*you got a pain like people get in some of your joints, that was it, it was nothing,*
446	*you don't realise how...how much it changes someone's life*
447	**I: And apart from their lives, you've quite clearly put across that it changes the**
448	**Person**
449	*P: Yeah, it takes you over, it's got to the point now I've started to think of myself as*

450 'Sue with arthritis', it's not me no more. I actually feel angry with everyone, don't
451 know why, it's like you're not getting heard, you feel like shouting. I lose my
452 temper very quickly, not with the kids or anything, just angry all the time
453 I: **And do you think that's because of the condition that you're living with?**
454 P: *Yeah*
455 I: **You didn't used to be angry?**
456 P: *No, No I was always shy & quiet. People come up to me & they moan about stupid*
457 *Things 7 you feel like saying, you know, "get a grip, I wish that's all I had to moan*
458 *over", but they don't get it. If you went up to someone in the street who hasn't got*
459 *arthritis...it's nothing, it's just another condition*
460 I: **And that's what makes you angry, the fact that there isn't the recognition?**
461 P: *Yeah, people don't...they don't get it. They can't understand it until it happens to*
462 *You, I don't think there's any way to explain, they..I think people need to know*
463 *that's it's not just an old persons disease*
464 I: **Have you considered making, as some of your goals in life you feel got taken**
465 **Away, have you considered making that a goal..to try & make the condition**
466 **more high profile & educate the person in the street?**
467 P: *I don't see the point, people don't want to 'cos it reminds you too much, it makes*
468 *you realise that you've sort of pushed it to the back of your mind & you've just got*
469 *to get on with it*
470 I: **so you'd quite like to forget that you're living with the disease?**
471 P: *I think everything is a constant reminder but you just want to...you just want to be*
472 *normal 'cos you feel you're not normal*
473 I: **What was being 'normal' before?**
474 P: *Stupid things. Walking down the street without having to walk next to a wall, you*
475 *know, so you've got something to hold on grab on to , being able to carry shopping*
476 *bags without worrying "Oh, I can't buy that because it's too heavy, I won't be able*
477 *to carry it"*
478 I: **Pretty much everyday tasks?**
479 P: *Opening a tin, turning over in bed without waking up in pain, stupid things.*
480 I: **It's very much things that probably we all take for granted when we're in**
481 **good health?**
482 P: *Yeah, it's like going on holiday, we go to America but everyone goes around th e*
483 - *theme parks, where I'll just sort of sit,I can't go on any of the rides or anything,*
484 *I've just got to sort of sit, ill say "Oh, just leave me here, you go off & do what*
485 *you've got to do", It's daft because you become a person-watcher, like a people-*
486 *watcher, makes you more aware of what's going around*
487 I: **Has the condition done that to you? Do you find that you think more about**
488 **maybe other people with other conditions & how they must be feeling & what**
489 **they're thinking?**
490 P: *I think constantly. I find my mind, it doesn't sleep...something is going on all th e*
491 *time. It's like stupid problems, you can't let them rest because you're thinking*
492 *about them, you're thinking the worst of everything...like you can't help..you feel*
493 *like nothing good happens anymore. It's like in the summer, some mums, you know*
494 *they get out in the street & play rounders with the kids & you've just got tio sit up 7*
495 *watch, wish I could, I'd get out there with them, but you feel like they don't*
496 *understand, they're like "Oh, come on" & you say "oh, I can't I'm doing*
497 *something or.."*
498 I: **so you're aware of making lots of excuses?**
499 P: *Yeah, got an excuse for everything me. I don't need changing into a liar, because*

500 *you don't want...you want to say " I can't cope with that, I've got arthritis", it's*
501 *not what you want to do so you make an excuse.*
502 I: **Don't you think it's OK to say "I can't do it because I've got arthritis"? Is**
503 **that not OK to be able to say that to them?**
504 P: *I wouldn't want to...I juat feel ashamed, probably because I'm young, because it's*
505 *an old persons disease & you don't hear other people in the street "I've gotthis*
506 *wrong with me, I can't do that"*
507 I: **Do you think maybe other people are sitting at home as well & they've got**
508 **something wrong & they want to come out & say "I can't do it because.."?**
509 P: *Probably, but you don't see it, do you? Like you hear of children with arthritis, but*
510 *how many of them do you see in the street? Can't say I've ever seen them.*
511 I: **Do you think there would be any benefit in something like a support group?**
512 **You know, where a group of people with the same condition, like psoriatic**
513 **arthritis, get together & relate their own experiences & things, do you think**
514 **something like that would be useful?**
515 P: *I think a lot of people would. I'm shy, I'd find it difficult myself, but I suppose once*
516 *I'd got into it...it's something you just don't hear of it. If there is something it's got*
517 *to be close*
518 I: **Yes, because presumably mobility is an issue, if getting to hospitals or places**
519 **where they could hold a group?**
520 P: *Yeah*
521 I: **You've mentioned a couple of times that you wouldn't do something because**
522 **you're shy, do you just feel that you're shy now or...**
523 P: *I've always been shy, I've always had, sort of the back seat*
524 I: **So it's not something that's happened as a result of your condition?**
525 P: *No, it's like if there's an argument in the family, they all say " We'll go to Sue, 'cos*
526 *Sue doesn't drink, Sue's the shy one, she'll sort everythying out"*
527 I: **So your condition hasn't made you shy particularly, even though you feel like**
528 **you've withdrawn a bit from life...the shyness isn't a result?**
529 P: *No, the shyness has always been there. Then you wonder if it's going to pass on*
530 *to the kids or not...every little twinge...*
531 I: **Is that a worry for you, about their future health? Is that something you've**
532 **discussed with the consultant?**
533 P: *They reckon it won't, but you can't be sure about some things, I didn't think I*
534 *Would end up with it. I think that scares me because I can't do anything to control*
535 *It, there's no cure, once you've got it, you've got it.*
536 I: **Well how about the focus on your psoriasis, is that just an added burden to**
537 **the whole thing?**
538 P: *Sometimes it clears up totally, but then just as you're getting used to not having it,*
539 *it just really flares up again & then you need help with the creams because you*
540 *can't twist around to put your creams on. I'm always saying to the kids, because I*
541 *got it through exams worrying, "don't worry, don't get stressed out"*
542 I: **That's when it first started, was it?**
543 P: *Yeah, when I was doing my last lot of exams at senior school. I'm one of those*
544 *people who worry about anything, a knock on the door, I worry who it is, it's just*
545 *the way it goes, it just gets worse & worse, you know because you're not really*
546 *getting out & that, you just think it's got to be something bad*
547 I: **Do you never expect anything good to happen or anything good to knock at**
548 **your door?**
549 P: *No, what is there? What is there that's going to be good?*

550 I: **What would you like there to be good?**
551 P: *You just do don't you? If someone came knocking on my door to say, " Sue, we've*
552 *got a trip organised or we've got this organised"...what's the point?*
553 I: **So even if somebody made the effort to organise something it wouldn't**
554 **particularly motivate you to want to go & take part?**
555 P: *I'd try, but all you're thinking of is at the end of it, you know, what's going to be at*
556 *the end or halfway through it or, you know, it's just going to be the pain, or you're*
557 *too tired & just think "oh, I can't be bothered"*
558 I: **So is you expectation that you go & do something, if you go & do something,**
559 **you know it's going to end up in a lot of pain?**
560 P: *Yeah, if you know it's there, you know it's going to be that way, you know whatever*
561 *you do you're going to suffer for it*
562 I: **So that would prevent you, I assume, from enjoying anything, whether it be**
563 **from saying "let's go to the pictures or..?"**
564 P: *Especially the pictures, you're stuck in those little seats for ages & you fidget &*
565 *people don't understand why you're moving around*
566 I: **Do you think there is something to be said for your condition being more**
567 **Visible, as it were, for example if you are in a wheelchair were there is an**
568 **obvious disability?**
569 P: *Yeah because when people can't see it, they don't understand it*
570 I: **So do you feel you would get a better reaction if you were on crutches or in a**
571 **wheelchair?**
572 P: *People would sort of know to..like when you've got kids around you, you're*
573 *constantly standing back incase they knock you or anything...it's really painful,*
574 *but whereas if you're on crutches or anything, they know to be careful*
575 I: **Do you feel that people would react more positively to you?**
576 P: *Yeah, but...it's hard to say because I wouldn't want to be on crutches or in a*
577 *wheelchair , I wouldn't wish that on anyone. It's just so hard because they can't*
578 *see it, they don't know what it's about, so they don't know, you can't until you've*
579 *got it, until it's happened to you, even someone who lives with you, they can't fully*
580 *understand it, that's the point. This is going to sound stupid (laughs), I started*
581 *getting tattooes because I could control the pain*
582 I: **because you could?**
583 P: *It's like...this sounds really weird, you're getting pain but you know it's going to*
584 *stop, it's like harming yourself but not going that far because you know that pain is*
585 *there, but that pain is going to stop. It sounds stupid doesn't it?*
586 I: **No, it's very interesting**
587 P: *'cos the doctors...the nurses used to say to me," wait until the doctor sees them",*
588 *but I couldn't explaint to them, why I'd had it done. It made me sort of different, I*
589 *was getting something for myself, even though it was causing pain I knew the pain*
590 *would stop*
591 I: **Was it because you were in control?**
592 P: *Yeah, I was in control of all that pain*
593 I: **So did you have one done first just because it was the 'in-thing' to have done**
594 **& then because of how it felt..**
595 P: *Yeah, because I'd put it off for years, 'cos I'd always liked them, I had one done*
596 *last year, "God that hurt" but it stopped & then I got to the point where I wanted*
597 *that pain because I knew it was going to stopa couple of hours later. It sounds*
598 *strange.*
599 I: **So how may did you have done?**

600   P: *Three*

601   **I: And would you consider having another one done?**

602   P: *Yeah, with all I'm going through I'm trying to stop myself getting another one. The*

603   *only way I can see it, it's like hurting yourself but...because you know you can*

604   *control the pain...*

605   **I: Did you feel quite elated when the pain stopped?**

606   P: *Yeah, yeah*

607   **I: Is it a nice sensation? You'd have the pain & then it's gone?**

608   P: *Yeah, then it had gone*

609   **I: So you get a buzz from it?**

610   *Yeah*

611   **And is that the first time you've had a 'high', if you like, for a long time?**

612   P: *Yeah, it made me happy, I thought "Oh God, I'm not in pain". I know it sounds*

613   *weird, but like, that really hurts but, god the pain had gone*

614   **I: Does it distract you from the pain of your arthritis? Is the pain..**

615   P: *Yeah, 'cos you're concentrating on a different pain*

616   **I: So you were distracted from the pain in your joints, so you weren't aware of**

617   **the joint pain?**

618   P: *No, 'cos the pain was there, at the tattoo (touches tattoo). You're saying "she's*

619   *mad!"*

620   **I: Do you not think it sounds like it makes sense?**

621   P: *It does to me. But then like every time we go on holiday I think "Oh, I'll get a*

622   *another tattoo & I'll get it in a different place & see if...what it hurts". It wasn't*

623   *"oh, look at the pictures" It was " I wonder how much it's going to hurt?"*

624   *because I knew at the end of the day "God, the pain's gone, look I had pain there,*

625   *but it's gone"*

626   **I: And then did you become aware of your joint pain again?**

627   P: *Yeah*

628   **I: So you have distraction for what, a few hours?**

629   P: *Yeah, because, like, when it's done it really hurts, or when he's doing it, it really*

630   *hurts, you know, it's like lots of needles, but it's a different pain, it's a pain you*

631   *know that's going to go*

632   **I: So it's worth putting up with that pain so you don't feel the joint pain for even**

633   **just a short period?**

634   P: *Yeah, so it...it takes your mind of it, 'cos you're hurting somewhere else*

635   **I: How did you feel when you became aware again of your joint pain?**

636   P: *It didn't bother me, it didn't bother me for the next couple of days, 'cos you know*

637   *you've got different pain, 'cos all the pains in your joints feel like the same pain &*

638   *you know it's arthritis pain & you think "Oh, I've got something different". Feels*

639   *like a different pain, that's not arthritis pain, I know that's going to go away.*

640   **I: So did that feel quite strange – having a different sensation after so many**

641   **years of constant pain?**

642   P: *Yeah, arthritis pain is just one type of pain*

643   **I: Can you describe it?**

644   P: *It's just sharp, constant. It's like stupid leaflets, you know like you get those*

645   *leaflets you get at the doctors & they say "how does the pain start/" & "when*

646   *does the pain stop?" Stupid questions, you know, who's making them up?*

647   **I: So people don't understand?**

648   P: *No, they haven't got a clue. They don't know, they don't know. It feels, that thing*

649   *with the questions, like, if we ask enough questions we'll understand how the'rey*

| 650 | *feeling. I think...I think what it boils down to, is just depression, that's the way it* |
| 651 | *makes you feel. I just feel down all the time.* |

I: **Do you feel depressed?**

P: Yeah

I: **Have you had a diagnosis of depression?**

P: My GP reckons, but I'm not going to take anything for it, I won't, I take enough
tablets, I don't want to take anymore, I don't want to go down that road.

I: **So how do you try & cope with it then? Do you have your own sort of strategy**
for dealing with it?

P: Things like books, reading, likes of them, puzzles, I constantly try & take my mind
off it & think of something else, everybody else's problems, everything is a
problem that has got to be worked out, something that will keep my mind ticking
over, my mind is just constantly on the go, something that's not quite physical,
more mental than physical which I know I can do

I: **So is that how you occupy quite a lot of your time? You mentioned your**
puzzles and..

P: Yeah

I: **and games & stuff, is that how you get through your day?**

P: Yeah

I: **You mentioned reading, is that one of your main pass-times?**

P: If I pick a book up, I can't put it down (laughs)

I: **Does that give you a lot of pleasure? I mean is reading a source of pleasure or**
is it just because you feel that you can't do something else?

P: I enjoy reading

I: **If you read a lot, have you spent time trying to read up about your condition?**
Are you one of these people that's gone out & tried to get information?

P: Yeah a little. I find it helps. It's like when I started my injections they give you a
video to watch, but I don't think they should give you that

I: **Why was that?**

P: Just ...they show you everything, it makes it too real

I: **Is it a case of you don't want to know that much? Being told you need the**
injection & the possible side-effects, that's all you need to know?

P: Yeah, you don't need to know

I: **Did it almost put you off wanting to take your injections?**

P: I was ready to say "No" to the nurse when she turned up, but she sits there
watching & makes you do it, so it's easier to do it & get it over with, but then
that's another thing I've got to worry about now. It's like the nurses, they say "Oh,
it's no problem, just poke it in, put the stuff in, take it out, end of story. it's not that
big a needle" It is when you've got to do it yourself. Then you know you've got
them in the house (the needles) with the kids. Everything just seems to turn into a
worry.

I: **The treatment regime sounds, from what you've said, that it does throw up**
quite a lot of concerns for you, both in having to actually inject, taking the
tablets & the long-term prospects of all the drugs?

P: It's having to take them all the time. It's a case of if you miss them, you know
you've got to pay for it

I: **How about the economic cost of having a long-term condition like this? In**
terms of, you know, prescriptions, & constant visits to the hospital, not being
able to work, I mean has that been a major impact on your life?

P: You have to make do

I: Is it something you worry about, or because you were off having the kids at the time was it not such a big issue?

P: *No, because it's something you get used to, but there's never like spare money in case you think "what if I go really bad" I can't go & spend this amount of money because I've got to go to hospital next week, or what if they take me into hospital, because a few months ago it got really bad & he wanted to take me in for two weeks & I turned around & said "No, I've got kids, it's not an option"*

I: Do you feel that having a family actually impacts on how you deal with your treatment? I mean, if you hadn't have had kids, would you have gone into hospital?

P: *Yeah*

I: And you felt that you needed to be there, in hospital?

P: *It's got to the point now where the doctor says "we want to do this, we want to do that", I'll go "just do it, if it's going to work, do it", "take these tablets", I say "if they're going to work, do it, do it, if you've got a miracle cure give me it". It's like they were doing a drugs test & I said "I'll do it, I don't want to know the side-effects are or that, I'll just do it"*

I: You'll do anything to get some relief?

P: *Yeah, if they could, say to me you can start again, get a job...*

I: is that a chance to be back to what you consider 'normal'?

P: *I'd love to be going out working, I know they say some people play on it & all that, like, get to sit in the house all day & that it's better than going to work it's daft, but I'd love to go to work.*

I: Is part of that because of the social contact, you know, you've got people around you?

P: *Yeah, it's just, I think that's what my husband can't understand, like his work, he's meeting different people all the time, even though he says "My work is boring, you don't understand", I say "No, it's a different face all the time". People see him for him, like he's the happy-go-lucky one, no problems, no ...but I think that bit of it he doesn't get*

I: So that's how you want to be looked at?

P: *No, I just want to be me. I don't want to be, like, "are you alright to do this, Sue? Are you alright to do that? Or you find people will ask someone else because they know you can't.*

I: Do you feel that you won't ever be you whilst you've got this condition?

P: *Mmm, yeah, it's not going to happen is it? Unless I can control it, mind you I've forgotten what that means, it's been that long*

I: Do you feel that even though you're doing your drug treatments, that you still can't control it & that you're administering to it rather than controlling it?

P: *Yeah, even the doctors have said..they reckon like the level in your blood is supposed to be about 5, mine was reaching about 188, they've got it down to 90. That's like proving to the doctor that I am in pain, but he's trying everything he can, he's tried me on everything. I'm just awkward. I mean I don't think it's like the doctor's fault or anything, but I still think, even though, like if...they don't understand it*

I: You say you don't think it's the doctor's fault?

P: *They've tried everything they can try.*

I: You don't feel they're letting you down?

P: *No, no, Dr T is a brilliant doctor, he's done everything for me, but there's only so much they can do isn't there? It's my body's fault, if my body is not taking to the*

15

750	*drugs it's not their fault is it? I think that's what makes me angry as well, my*
751	*mum's blaming herself, but I'm blaming me. I keep thinking I must have done*
752	*something or, but I can't think what*
753	**I: Why, because you've got this arthritis?**
754	*P: Yes, I feel like I'm being punished for something, I don't even know what, I don't*
755	*do drugs, I don't drink, don't smoke, you know I do everything right & yet I'm still*
756	*being punished when there's all these people walking around, drug dealers, people*
757	*taking drugs & that. They don't know they're born. I feel like I'm being punished.*
758	**I: You mention the need to blame there a couple of times, do you really think**
759	**you have to blame somebody for this? Does it not just happen?**
760	*P: I know it just happens but you fee that angry that you want to...you need something*
761	*to blame, there's got to be a reason for it, there must be. Like, I'm angry that when*
762	*I got the psoriasis the hospital never mentioned it, that this could happen. I think to*
763	*myself, "well, I could have taken cod-liver oil & maybe helped this for 12 years".*
764	*Maybe they should warn people, because I was never told nothing.*
765	**I: Have you since asked why you weren't told?**
766	*P: O, I asked once & they just said "Oh, we don't, we just don't mention it"*
767	**I: So does your psoriasis tend to flare at the same time as your arthritis? Do the**
768	**two go together?**
769	*P: I had psoriasis for years before they even said I had arthriris, I had psoriasis from*
770	*when I was was 15. I never had any problems up until I was about 27 & then my*
771	*knee started, I don't even know what triggered it off. I can't think of anything*
772	*that's triggered it off.*
773	**I: But now if you get a flare up of psoriasis, does your arthritis kick-in as well?**
774	*P: No, because that's just constant anyway*
775	**I: So the two don't tend to flare together?**
776	*P: No*
777	**I: And is the psoriasis, when it flares, visible?**
778	*P: It's on my knee (rolls up trousers to show me)*
779	**P: Do you get affected on your face?**
780	*P: Only over the last month or so I've been getting it under my nose. I've never, ever*
781	*suffered with it on my face, it's always been..I've been able to cover it ip. You*
782	*never, ever see me in a skirt, never, it's always trousers*
783	**I: Is that because you don't want it visible?**
784	*P: Yeah, plus all my knees are always swollen, you know, with the arthritis.*
785	**I: Are you quite conscious about your image?**
786	*P: Yeah, like about three months ago I started losing my hair, you can see my fringe*
787	*is just growing back, so that was another thing to worry about, losing my hair, but*
788	*the doctors just said that's because I wasn't well & it came out as hair loss. Every*
789	*corner you turn there's something else waiting for you, around the corner.*
790	**I: You've had a lot to contend with**
791	*P: When it happens you think "what's going on", you try & cope because you know*
792	*there is nothing they can do*
793	**I: Is there a sense that you... because you learn & have adapted to changes in**
794	**your lifestyle because of the condition, do you feel that that you can cope with**
795	**things that are being thrown at you, like your hair dropping out?**
796	*P: You've got to, you've got no choice, you've got to teach yourself to do it or you're*
797	*just going to get yourself more & more worked up to the point where you're going*
798	*to snap & it's happened*
799	**I: What, that you snapped?**

800   *P: Yeah, I just got to the point where I felt as though I wanted to go to bed, fall asleep*
801   *& not wake up (cries) so you can't let yourself get that far, but then when you go*
802   *into hospital you can't explain this to the doctors. It's like, you think if you tell*
803   *them they're not going to believe you*

804   **I: Do you not think there must be other people that feel the same way & that**
805   **Maybe they have heard that before?**

806   *P: You don't tend to think of other people when you go there, it feels like you're the*
807   *only person with it*

808   **I: Feel like you're alone?**

809   *P: When I go to the hospital it's all old people, you're sitting there & you're watching*
810   *them & you can see the way their fingers have bent & all that, & it's starting to*
811   *happen to my toes & you think "I don't want to be like that when I'm older".*
812   *That's what you start thinking, that's why I don't want to be old, old people scare*
813   *me now. You think "if I'm struggling now, what am I going to be like when I'm*
814   *old?"*

815   **I: Growing old frightens you, the prospect of it?**

816   *P: Yeah, I don't like being around old people, you know like pensioners who are*
817   *struggling anyway. You see them at hospital & all their hands are twisted with the*
818   *arthritis. I couldn't cope, I'd rather not be here.*

819   **I: You've mentioned that a few times, is it something that has gone through your**
820   **mind?**

821   *P: Yeah, it's 'cos I've got the kids, there's no point really is there?*

822   **I: What about your husband?**

823   *P: He knows my life..you want a life, you want a proper life don't you?, not just*
824   *Same everyday then worrying about what you're going to do & then if you feel*
825   *alright, going out & then halfway through the day you think "I'm in agony, I'll*
826   *have to go home", go home & take my tablets, go home & do my injection*

827   **I: Do family life & your marriage not give you some sense that life is worth**
828   **living?**

829   *P: I feel like I'm letting the kids down, but I don't want them having someone in my*
830   *place, I always think they're never going to call someone-else' mum' or that. You*
831   *feel like they're missing out, even though they say they're not, you feel like they*
832   *must be missing out on something. It's like the youngest will say can we go out &*
833   *I'll say "sorry babe we can't, I'm too sore today, you'll have to wait for another*
834   *day" & she'll just go "OK".*

835   **I: Have they learnt to cope with it, I mean something like that if they want to go**
836   **somewhere do they say they'll organise to go with a friend?**

837   *P: It doesn't bother them, if I say I can't they say "OK, don't worry about it", but*
838   *then I feel like I'm letting them down, I can't do it. But then when they're 18, or*
839   *left home, they're sorted then...you know while I've got them here I've got*
840   *something, I've got to get up & do things. It's like, I don't force myself, but you*
841   *know you've got to get up & you've got to do them & you've got to look after them*
842   *so you've got a purpose*

843   **I: So you feel that your purpose in life at the minute is...**

844   *P: Looking after the kids*

845   **I: That's your reason to get up in the morning?**

846   *P: Yeah, so what's going to happen when they...*

847   **I: Is that a source of worry to you, about how, if you think further ahead, how**
848   **you might actually feel when they're not here, when they're away or married?**

849   *P: It's like my eldest daughter now, she's got her first boyfriend & I can't let go. He*

Appendix 8

Ethics and R&D Approval

Ref.: **7.02**

liverpool
JMU

Catherine Aitken
1 Berwick Drive
Blundellsands
Liverpool
L23 7UH

Thursday 13th September, 2007

Dear **Catherine,**

With reference to your application for Ethical approval titled:

Psoriasis Arthritis and Psoriasis: The role and implications of psychosocial factors.

Thank you for correspondence responding to the proviso and I am happy to confirm your application is fully approved.

The Ethics Committee approval is given on the understanding that:

(i)   any adverse reactions/events which take place during the course of the project will be reported to the Committee immediately;
(ii)   any unforeseen ethical issues arising during the course of the project will be reported to the Committee immediately;
(iii)   any change in the protocol will be reported to the Committee immediately.

Please note that ethical approval is given for a period of five years from the date granted and therefore the expiry date for this project will be **February 2012**. An application for extension of approval must be submitted if the project continues after this date.

I am enclosing form EC5 and would be grateful if you could spare the time to complete the questionnaire and return it to me.

Yours sincerely

Jo McWatt
Graduate Research Administrator
Tel: 0151 231 3119
E-mail: j.m.mcwatt@ljmu.ac.uk

CC: Supervisor – **Dr Helen Poole**

Research & Development Directorate
Room 2.05/2.06
Clinical Science Centre for Research & Education

R&D Director- Professor R J Moots
R&D Manager- Mr. Neil Whalley
R&D Co-ordinator – Ms Lorraine Broadfoot

Tel: 0151 529 5871; Fax: 0151 529 5875
Email: neil.whalley@aintree.nhs.uk

University Hospital Aintree
Lower Lane
Liverpool
L9 7AL

TO: Cathy Aitken – Liverpool John Moores University

FROM: Mr. Neil Whalley – R&D Manager

DATE: 12th June 2007

Re: **R&D Management Approval: Study Title: PSA Psoriasis – Quality of Life Issues**
R&D Ref: 06RM009
Ethics Ref: 06/Q1501/198

I am writing to acknowledge receipt of the fully completed Registration Documents for the above project.

I am pleased to inform you that the R&D Committee has now granted management approval and the project has been entered into the Trust's R&D Project Database. Aintree Trust's indemnity is in place for staff working on the project.

For this project you have personally undertaken to ensure that all work carried out within the Trust will at all times comply with the Medicines for Human Use (Clinical Trials) Regulations 2004 and standards defined within the ICH-GCP guidelines.
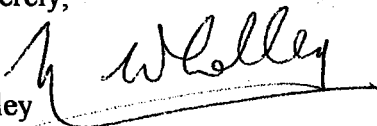
Additionally, in accordance with the NHS Research Governance Framework requirements, you must simultaneously send the R&D Directorate copies of all correspondence you send or receive in connection with this study, that concerns the reporting of any:-
   a) **Serious Adverse Events (SAE's), as defined by the study Protocol**
   b) **Suspected, Unexpected, Serious Adverse Reactions (SUSAR's)**
   c) **Safety Reports**

Please also note that Research Governance stipulates that we will require a copy of your project outcome report as soon as this becomes available.

Yours sincerely,

Neil Whalley

Cc   Dr Marina Anderson – Rheumatology Research, AHT